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Enacting Occupation and Identity: Perspectives of Children and Their Parents

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Graduate Program in Health and Rehabilitation Sciences
A thesis submitted in partial fulfillment of the requirements for the degree in Doctor of Philosophy
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Enacting Occupation and Identity: Perspectives of Children and Their Parents

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by

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Graduate Program in Health & Rehabilitation Sciences

A thesis submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy

The School of Graduate and Postdoctoral Studies
The University of Western Ontario
London, Ontario, Canada

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Abstract

Children with disabilities are at risk for limited opportunities to engage in childhood occupations. Occupation is defined broadly as everything people need, want, or are obliged to do, and as understanding how social dimensions shape occupations and opportunities for participation. Emergent literature suggests that identities are shaped by what we *do*. This research examines how occupation is implicated in the shaping of identities for school-aged children with physical disabilities in light of the socio-cultural dimensions that shape opportunities for children to participate in childhood occupations.

This work is comprised of five integrated manuscripts, in addition to introduction, methodology, and discussion chapters. The first manuscript contributes to disciplinary discussions about occupational identity as an emerging construct and calls for a socio-cultural theoretical perspective to considerations of occupational identity. The second manuscript examines a disability studies perspective, and introduces the concept of reflexivity as important for professional practice in occupational therapy. The third manuscript discusses photoelicitation as a promising method for eliciting children's perspectives in research. In addition philosophical underpinnings, practical considerations, ethical considerations, and examples from this research are discussed. The fourth manuscript reports on the empirical work, examining how occupation is implicated in the shaping of identity for children with physical disabilities. In depth case studies were used to investigate participation in occupations and perceptions of identity with six children and their parents. Each case was analyzed using concept maps and coded for conceptual categories. Six categories are presented: Perceptions of Self and

Other: Living with Disability; Family Identity, Tradition and Culture; Relational Identity: A Sense of Belonging; Pride, Success, and Seeing things through...; Growing up and Keeping Up; and Identity as Dynamic. Finally, the fifth manuscript revisits the topic of reflexivity, and discusses its merit in ethical research with children.

This thesis contributes to knowledge pertaining to socio-cultural factors that shape opportunities for children to participate in occupations, and the relationship between occupation and identity for children with physical disabilities. In addition this work contributes to methodological and ethical discussions about conducting research with children. This work has implications for occupational science, health care professionals, policy, children and parents.

Key Words: Childhood, Identity, Disability, Occupation, Participation, Occupational Science, Occupational Therapy

Co-Authorship Statement

I, Shanon Kathleen Phelan, acknowledge that this thesis includes four integrated manuscripts that evolved as a result of collaborative endeavors. In the four manuscripts, the primary intellectual contributions were made by the first author who: researched the methodology, designed the research, developed the ethics application, conducted the literature reviews, established relationships with gatekeepers, undertook the data collection, transcribed and coded the data, led the data analysis and led the writing of the manuscripts. The contribution of the co-author, Dr. Elizabeth Anne Kinsella, was primarily through the supervision of the research, theoretical and methodological guidance, reflexive dialogue, and intellectual and editorial support in crafting the work for publication.

Dedication

This work is dedicated to my parents, Paul and Marylou Phelan. You taught me to love, to persevere, to dream, and to believe in myself. Without you, I would not be who I am today.

This work is also dedicated to my husband, Dan Spears. You have been my rock in so many ways—always reminding me “you got it”. I thank you for living this dream with me. For so many reasons I could not have done this without you.

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Where do I begin...these last five years have been a culmination of shared experiences, all of which have in some way contributed to this work directly or indirectly. I have appreciated the opportunity to engage in critical conversations, both in and out of the classroom, as these conversations have forever changed my view of the world as I know it in this moment.

To begin, I must express my sincere gratitude to my supervisor Dr. Anne Kinsella. No words can describe how much you have given to me throughout this journey, and I am indebted to your generosity. You have taught me how to conduct research with integrity, how to write with intention, and how to teach from the heart, all through example. Not only have you been my mentor, but you have been my shoulder to lean on whenever I needed one, and I can not tell you how much that has meant to me. When beginning this journey I could have never expected to have the privilege of gaining the gift of such a friendship along the way.

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List of Abbreviations

EA: Educational Assistant

IRB: Institutional Review Board

MSc: Master of Science

OI: Occupational Identity

OS: Occupational Science

OT: Occupational Therapy

PACS: Pediatric Activity Card Sort Assessment

PEI: Photoelicitation Interview(s)

PhD: Doctor of Philosophy

1. Introduction

When I talk about occupation, I am drawing upon occupational science and occupational therapy literature, where occupation is defined very broadly as "all that people need, want, or are obliged to do" (Wilcock, 2006, p.9), and as understanding how social dimensions and contextual features shape occupations and opportunities for participation. Townsend and Polatajko (2007), for instance, define *occupations* as "groups of activities and tasks of everyday life, named, organized, and given value and meaning by individuals and a culture" (p. 369). Occupational identity is an emerging construct in both occupational science (OS) and occupational therapy (OT) literature. This construct is in its early stages of conceptualization, and presents itself with an array of underlying assumptions. In order to enrich future efforts to conceptualize this construct, I suggest that it may be necessary to draw upon existing literature within various complimentary disciplines. In light of my doctoral research, it is my intention to contribute to the exploration of occupation and its connection to identity, drawing upon a socio-cultural perspective.

1.1 Situating the Researcher: A Reflection on Personal Experiences and Pre-understandings

Prior to beginning doctoral school, I worked for two years as an occupational therapist working primarily with children with disabilities in the school system. Many of the questions that emerged for me during that time drive the work that is presented in the pages that follow.

My clinical experience working in pediatrics has allowed me to begin to understand the importance of meaningful occupations for children with disabilities, and how opportunities to participate in occupation can potentially shape and reshape a child's (occupational) identity. Social issues related to occupation, participation, choice, and identity emerged as prevalent concerns in my practice. With these experiences, I began to question how children with disabilities construct their identities through occupation, and what social implications arise during this process. Initially, I had planned to work as an occupational therapist for five years before pursuing a doctoral degree. However, these questions, along side the many tensions I experienced in practice (elaborated in chapter three), were quite persistent in my thoughts and it seemed like the time had come to explore them.

As a therapist working in the schools, I noted that for some children with disabilities, the academic, social, and developmental gap grows exponentially as they progress through school. Eventually children start to become aware of such gaps, which may potentially play a role in shaping their identities and occupations (chosen or ascribed). Similar ideas were depicted in the study conducted by Heah, Case, McGuire, and Law (2007) when presenting parents' perspectives of their children with disabilities' successful participation. One parent described electing to switch the child from an integrated school, to a segregated school: "She was starting to really compare herself last year. Not so much in appearance, but definitely intellectually. She was noticing a big gap" (Heah et al., p. 44). In my experience as an occupational therapist, I noticed that as some children become aware of their limitations (whether it be due to their impairments, their social environments, or a combination of both), they often disengaged from

activities, which at times lead to isolation and withdrawal. I questioned my role in this awareness and disengagement, as I came to the classroom to re-assess or offer intervention strategies. I often felt like I was a constant reminder of what children could not do, and it did not sit well with me.

In practice I have witnessed both “positive” constructions of identity and “damage” to identity, as children transition through the school system. This ultimately appears to impact their success with respect to school-related activities, their sense of self and their well-being. Coming from my background as a therapist, it seems evident that occupational therapists working in the school health sector could potentially play a role in facilitating the positive construction and reconstruction of children’s occupational identities by assisting children in navigating occupational transitions and discovering and maintaining meaningful occupation. What I did not initially consider was how significant socio-cultural factors were in shaping opportunities to participate, and thus shaping identities. When looking outside of the individual dimension, I realized there were so many factors influencing occupation and identity that were beyond anyone’s conscious control. It was this social dimension that really intrigued me and brought me to this work.

1.2 Occupation, Identity, Occupational Identity:

An Evolution of Terms

I have always been interested in the relationship between occupation and identity, since introduced to the concept in my occupational therapy masters program in 2003. I can remember the first time I really thought about occupation and identity, for my first MSc assignment on occupation and choice. Dr. Thelma Sumsion was our professor. I was

nervous to write my very first master's level paper. I read Michael J. Fox's biography, *Lucky*, and was to analyze it from an occupational perspective using a specific construct (I chose *choice*). I dug up this paper out of personal interest at the start of my PhD, as I began to feel that same fear of *writing my first PhD-level paper*. Looking over the paper I saw a recurring theme: *the self*. I saw terms and phrases like: sense of self; self-worth; self-efficacy; self-determination; self-perceived health and well-being; self-confidence and perception of self. Looking back, I can see I was already considering a relationship between occupation and "self".

To be honest, upon commencing this research, I could not align my self with one single school of thought pertaining to occupation and identity. At times I felt aligned with the term "occupational identity" and felt a strong desire to design a research project that may help further conceptualize this construct. At times I felt aligned with the idea that occupation and identity were separate (but related) entities, and in order to commit to occupational identity as a construct on its own, I would like to see it grounded in theory and research. After completing this work, I believe I have generated more questions than answers, however I also believe that this is a good thing. More questions are necessary to advance these ideas and push the boundaries on static constructs and theories.

I do not feel comfortable assigning one definition of occupation and identity, or occupational identity, to this work for the reasons previously stated. In the interest of avoiding repetition, the following provides a brief overview of key constructs contributing to the understanding of occupation, identity, and occupational identity. These constructs are revisited and elaborated in chapter two (integrated manuscript entitled, *Occupational identity: Engaging socio-cultural perspectives*) and chapter six

(integrated manuscript entitled, *Childhood, identity, and occupation: Perspectives of children with disabilities and their parents*). Some repetition is unavoidable in setting up the manuscripts, however it is necessary to introduce constructs at this point to understand the evolution of this research.

1.2.1 Occupation “AS” Identity

Christiansen (1999, 2004) was one of the first scholars to draw our attention to the connection between occupation and individuals’ personal and social identity in occupational therapy literature. He suggested that participation in occupation contributes to one’s construction of identity, and that one’s daily occupations are the primary means to communicate her/his identity (Christiansen, 1999). He stated that “when we build our identities through occupations, we provide ourselves with the contexts necessary for creating meaningful lives, and life meaning helps us to be well” (Christiansen, 1999, p. 547), making the link between well-being and occupation, under the assumption that we build identities through occupations that are meaningful to us. Christiansen (1999) proposes that identity is comprised of self-esteem and self-concept, which reflects and is influenced by the larger social world. These early ideas have become the foundation for the conceptualization of occupational identity (OI) as a construct.

1.2.2 Occupational Identity

Gary Kielhofner proceeded to link occupation and identity, coining the term *occupational identity*. Kielhofner (2008) defines OI as “a composite sense of who one is and wishes to become as an occupational being generated from one’s history of

occupational participation. One's volition, habituation, and experience as a lived body are all integrated into occupational identity" (p. 106). Kielhofner (2008) has developed a model where OI and occupational competence co-develop, which in turn, determines the success of occupational adaptation. In this sense, occupational competence is defined as "the degree to which one sustains a pattern of occupational participation that reflects one's occupational identity" and occupational adaptation is defined as "the construction of a positive occupational identity and achieving occupational competence over time in the context of one's environment" (Kielhofner, 2008, p. 107).

Anita Unruh is another scholar who has contributed to the conceptualization of OI, suggesting that:

occupational identity could be conceptualized as the expression of the physical, affective, cognitive, and spiritual aspects of human nature, in an interaction with the institutional, social, cultural and political dimensions of the environment, across the time and space of a person's lifespan, through the occupations of self-care, productivity and leisure (Unruh, Versnel, & Kerr, 2002, p. 12).

Unruh (2004) draws attention to the fact that socially, people are defined by what they do, illustrating this by using an example of a common question asked in social venues, "so...what do you do?" (Unruh, 2004, p. 290). She also speaks of peoples' public identities (based on work, productive occupations, and acknowledging the social value attached to work) and private identities (based on solitary, creative, and leisure occupations, acknowledging the personal investment attached to such occupations) (Unruh, 2004). Unique to Unruh and her colleagues, is the emphasis on spirituality and its potential to influence OI (Unruh, 2004; Unruh et al., 2002).

1.3 Occupational Identity:

Common Attributes and Unique Contributions

1.3.1 Competence

Christiansen (1999, 2004), Kielhofner (2008), and Unruh (2004) speak of competence as a necessity for the development and construction of OI. Christiansen (1999) relates competence to experiences of success and social approval. He suggests that as one experiences success, one enhances one's view of self. Christiansen (1999) also contends that "social approval and competent performance are instrumental to our thoughts of actions that will help us avoid or realize possible selves" (p. 553). Kielhofner (2008) elaborates on the need for competence in order for one to develop OI and essentially reach successful occupational adaptation. He also suggests that although you can have some degree of OI without occupational competence, you can not have occupational competence without OI. In addition, Unruh (2004) suggests there is a relationship between competence and adaptation (along with life experiences, choice, and environmental factors) that works to shape one's OI, likely drawn from Kielhofner's theory.

In the literature, threats to participation in occupations are seen as threats to occupational competence and to the development of OI (Christiansen, 1999; Kielhofner, 2008; Unruh, 2004; Unruh et al., 2002). These *threats* include the onset of disability, impairment, and/or illness. Christiansen (1999) advocates that it is at this point in time where intervention is necessary, suggesting a role for occupation. Unruh et al. (2002)

suggested that threats to occupational identity may result in losses that may require resolution in order to enable reshaping of one's occupational identity. In addition, Kielhofner (2008) also suggested that threats to occupational adaptation may require the rebuilding of OI and occupational competence. I suggest that this notion of needing to repair threatened identities may be seen as operating under the assumption that individuals need be autonomous and that intervention needs be focused at the level of the individual. There also appears to be an assumption that there is "one" occupational identity to be repaired, versus thinking about identities as multiple or dynamic.

1.3.2 Choice and Control

Christiansen (1999, 2004), Kielhofner (2008), and Unruh (2004) all contend that occupations contributing to identity are chosen, controlled, and goal-directed. Important to keep in mind here, there is a broad assumption that we all have the opportunity to "choose freely", which is a Western ideal. However, this ideal is challenged by many socio-cultural thinkers; this is further discussed in chapter two.

1.3.3 Motivation

Christiansen (2004) assumes that identity is based on the development of the self, *self* being a product of motivated acts. He asserts that "motivation explains how people gain an identity that is associated with their participation in particular occupations" (Christiansen, 2004, p. 123). He suggests that our acts are influenced by regulatory motivators (those which are physiological in nature such as hunger, fatigue, pain etc.) and purposeful motivators (those which are intentional). In this light, Christiansen (2004)

suggests that occupation could also be shaped by one's identity, but more in reference to regulatory motivators, for example if one is hungry, he or she will make food.

1.3.4 Social Acceptance

Expectations of success or failure are also thought to play a role in influencing participation in selected occupations (Christiansen, 2004; Kielhofner 2008). Such expectations are thought to stem from what society demands and accepts. Christiansen (2004) suggests that positive identities are fostered when individuals perceive approval from greater society with respect to their *chosen* occupations. In addition, Unruh (2004) suggests that the temptation by society is to define ourselves by our productive occupations based on the social value that is attributed to work in our culture. In some Western societies there is a great emphasis on the social, economical, and political value attributed to work, whereby participation in productive occupations during pre-retirement years are considered social norms. Individuals then need to either conform to or reject social norms and expectations when constructing their OI (Unruh, 2004). Both social dimensions and the reliance on productivity are discussed further in chapter two.

1.3.5 Future Possibilities

Common throughout the OI literature is the idea that OI is influenced by the notion of possible selves and future possibilities (Christiansen 1999, 2004; Kielhofner, 2008). Kielhofner (2008) goes as far as suggesting that OI serves "both as a means of self-definition and as a blueprint for upcoming action" (p. 106). Unruh (2004) envisions OI slightly different in this respect, more along the lines of articulating a need for

continuity, seeking a balance of meaningful occupations within OI. Ultimately, both concepts perceive OI to be a process or a continuum that carries one forward.

1.3.6 Development of OI through Childhood

With respect to identity development in childhood, Christiansen (1999) suggests that as children, we learn that we are members of a family, are male or female, have characteristics that are in common or contrast with others, and that our identity development continues to be influenced by social relationships. Unruh (2004) adds that in childhood, a significant part of development and construction of OI is centered on mastery of self-care occupations. She also claims that preferred leisure occupations may convey something about who a child is becoming and provide some indication of the development of personality characteristics (Unruh, 2004). Although Christiansen and Unruh both speak of OI as developing throughout the lifespan, they do not expand on development through childhood. Kielhofner (2008) on the other hand, engages in this discussion to a greater extent.

Kielhofner (2008) also refers to the development of OI in childhood, claiming that “occupational identity emerges in childhood...by late childhood, children have a fairly well developed sense of who they are” (p. 131). He suggests that children begin to explore unique interests that individualize identity and assist in developing occupational competence. This occurs secondary to an extensive transformation of volition, habituation, and performance capacity (Kielhofner, 2008). From their perspectives, as children experience themselves doing things, their sense of personal causation, interests, and values begin to emerge. Such changes allow the child to emerge as an occupational

being as they develop their own ways of thinking, feeling and doing. In early childhood, children begin to take initiative in making their own activity choices. Advancing through later childhood, children begin to select their own personal projects, such as learning to play a musical instrument or joining a team, which contributes significantly to the construction of their OI (Kielhofner, 2008). Throughout the childhood experience, occupational choices may at first be assisted by parents, using the parents to provide a rationale for participation in select occupations (Kielhofner, 2008).

Kielhofner (2008) claims that through children's experiences of failure and success, they acquire knowledge, capacity, and feelings of self-efficacy. These newly acquired attributes then become more accurate and complex. Cultural messages pertaining to values and awareness of adult approval/disapproval of actions and corresponding social value of doing things begin to influence their occupational choices. Kielhofner (2008) suggests that during this time children begin to value productive roles and activities, and begin to take initiative in participation in occupations such as household chores and schoolwork activities. OI is further developed as children take on different roles, beginning as a player, family member, and progressing to a student, friend, and/or group member (Kielhofner, 2008).

1.4 Analyzing Current Research Trends

Table 1 offers a detailed overview of recent studies directly or indirectly related to occupational identity. Strengths and drawbacks of current research trends will be discussed in reference to this overview.

Table 1: Review of Current Occupational Identity Literature

Authors	Title	Methodology/ Method	Participant Group	Key Contributions
Asaba & Jackson (2011)	Social ideologies embedded in everyday life: A narrative analysis about disability, identities, and occupation	Ethnographic and narrative approach	Adult (age not disclosed) -1 male, Disability	<ul style="list-style-type: none"> • Examples of how social ideologies influence choices, occupations and identities. • Discussion of how social ideologies are embedded within daily occupations and environments. • Suggest more consideration to policies that enable or hinder opportunities to try out alternative identities.
Braveman & Helfrich (2001)	Occupational identity: Exploring the narratives of three men living with AIDS	Narrative	Adult, 41-47 yrs -3 males, AIDS	<ul style="list-style-type: none"> • Example of a stable, progressive, and regressive narrative slope. • OI used to understand the narratives. • OI may be useful in understanding work history/functional capacity for return to work.
Braveman, Kielhofner, Albrecht & Helfrich, (2006)	Occupational identity, occupational competence and occupational settings (environment): Influences on return to work in men living with HIV/AIDS	In-depth Interviews	Adult, 32-52 yrs -16 males, HIV/AIDS	<ul style="list-style-type: none"> • Constructs of OI, occupational competence and occupational settings (environment) aid in understanding the experiences and narratives of people attempting to reenter life roles. • Participants whose health was severely impacted, who experienced difficulty with multiple roles, and who had limited interaction outside the home reported a lower sense of OI.

Authors	Title	Methodology/ Method	Participant Group	Key Contributions
Christiansen (2000)	Identity, personal projects and happiness: Self construction in everyday action	Review of archival data, battery of assessments	Adults, 19-79 yrs -78 females, 42 males (Students, Workers, Retirees)	<ul style="list-style-type: none"> • Goal-directed occupations contribute to identity development. • Self-expression influences satisfaction and well-being. • Supports a constructionist view that goal directed projects provide important opportunities for shaping identity.
Finlay (2004)	From ‘Gibbering Idiot’ to ‘Iceman’, Kenny’s story: A critical analysis of an occupational narrative	Narrative	Adult (age not disclosed) -1 male, Mental Illness	<ul style="list-style-type: none"> • Position: sees the self as multiple, variable and emerging through social interactions. • Complex layers of meaning, experience and identity emerged from the participant’s narrative.
Goldstein, Kielhofner, & Paul-Ward (2004)	Occupational narratives and the therapeutic process	Narrative	Adult, 26-37 yrs -2 males, AIDS	<ul style="list-style-type: none"> • OI → agentic plot vs. victimic plot (Polkinhorne) • Narrative reveals OI, life experiences and environmental influences. • Differences in narratives accounted for differences in treatment outcomes. • Important to consider OI when approaching intervention strategies.

Authors	Title	Methodology/ Method	Participant Group	Key Contributions
Haines, Smith, & Baxter (2010)	Participation in the risk-taking occupation of skateboarding	Ethnography	Adult, 18-35 yrs -7 males	<ul style="list-style-type: none"> Skateboarders in the study expressed cultural identity through clothing, hairstyles, accessories, as well as symbols directly associated with the skateboarding subculture.
Haltiwanger, Rojo, & Funk (2011)	Living with cancer: Impact of expressive arts	Case Study	Adult, 57 yrs -1 female, Illness	<ul style="list-style-type: none"> Four major themes emerged reflecting the impact of the support group on the reshaping of the OI of the participant: life interrupted, brave hearts, immoral beloved, and life redefined. Participation in the support group intervention helped to uncover suppressed feelings about interrupted occupational identity—allowing the participant to rediscover herself. Supports OT interventions in oncology to re-establish habits, roles, and routines to achieve a positive occupational identity.
Hasselkus & Murray (2007)	Everyday occupation, well-being, and identity: The experience of caregivers in families with Dementia	Narrative	Adults, 33-82 yrs -27 females, 6 males, Caregivers	<ul style="list-style-type: none"> Importance of everyday occupation for caregivers was emphasized. Seeking to maintain well-being for themselves and those they cared for, struggling to negotiate changing relationships and establish new ones, and responding to

Authors	Title	Methodology/ Method	Participant Group	Key Contributions
				the demand in changes to their own identities, were reported.
Horne, Corr, & Earle (2005)	Becoming a mother: Occupational change in first time motherhood	Exploratory Study -semi-structured interviews -questionnaires	Adults, 28-42 yrs -6 females, Mothers	<ul style="list-style-type: none"> • New mothers establish new occupational patterns. • Role of a mother becomes part of self-identity; occupations performed within this role become meaningful and routine.
Howie (2003)	Ritualising in book clubs: Implications for evolving occupational identities	Multi-strategy sequential design (interviews, survey, factor analysis)	Adults/Older Adults, 27-88 yrs -705 females, 16 males	<ul style="list-style-type: none"> • Ritualising facilitates specific customs, experiences and community that lend to heightened self-concept. • Suggests further research is needed to examine occupation-based community groups and how the role of ritualizing facilitates the development of occupational identities.
Howie, Coulter, & Feldman (2004)	Crafting the self: Older persons' narratives of occupational identity	Narrative	Older Adults, 78-87 yrs -4 females, 2 males, Retirees	<ul style="list-style-type: none"> • Leisure/creative occupations maintained across the life cycle contribute to the building of OI. • Link to OT, supporting clients to plan for and build OI's in later life.

Authors	Title	Methodology/ Method	Participant Group	Key Contributions
Isaksson, Josephsson, Lexell, & Skär (2007)	To regain participation in occupations through human encounters—narratives from women with spinal cord injury	Narrative	Adults, 25-61 yrs -13 females, Disability	<ul style="list-style-type: none"> • Complex changes after spinal cord injury altered women's sense of identity and influenced how others in their social network perceived them. • Human encounters are important for persons with spinal cord injury in restructuring their occupational identity and needs for participation in occupations.
Johansson & Isaksson (2011)	Experiences of participation in occupations of women on long-term sick leave	Grounded Theory	Adults, 44-58 yrs -8 females, Illness	<ul style="list-style-type: none"> • Long-term sick leave changed women's roles, habits, routines and negatively affected participation in occupation and social relationships. • Over time, women found strategies to rebuild OI, regain occupational competence and increase participation in occupation.
Klinger (2005)	Occupational adaptation: Perspectives of people with traumatic brain injury	Interviews	Adults, 29-45 yrs -6 males, 1 female, ABI	<ul style="list-style-type: none"> • Participants described a change in self-identity following injury. • Self-identity and engagement in occupation were closely related. • Reframing self-identity and acceptance of a new self was essential for successful occupational adaptation and rehabilitation.

Authors	Title	Methodology/ Method	Participant Group	Key Contributions
Laliberte- Rudman (2002)	Linking occupation and identity: Lessons learned through qualitative exploration	Secondary analysis drawn from 3 qualitative studies	Adults/ Older Adults -Retirement, Disability, Mental Illness	<ul style="list-style-type: none"> • Suggest a dialectic relationship between occupation and identity. • Occupations influence personal and social identity, and personal/social identity influence occupations. • Identity is an active process (P-E interaction).
Lysack & Seipke (2002)	Communicating the occupational self: A qualitative study of oldest-old American women	Ethnographic interviews	Older Adults, 85+ yrs -23 females, Illness, Disability	<ul style="list-style-type: none"> • “Occupational self”, self-concept • Importance of fulfilling roles as part of a sense of self. • Illness/disability can lead to disrupted identity. • Relationship between occupational performance and well-being. • Important to present as occupationally competent to self and others.
Magnus (2001)	Everyday occupations and the process of redefinition: A study of how meaning in occupation influences redefinition of identity in women with a disability	Interview/phenomenology-hermeneutic approach	Adults, 20-60 yrs -10 females, Disability	<ul style="list-style-type: none"> • Redefinition of identity when faced with a disability begins with strategies to avoid defining identity with disability. • Over time, strategies changed, organizing occupations in new ways and take on meaningful occupations. • Meaning of preferred occupations is associated with identity. Identity is redefined through occupational choices and environmental influences.

Authors	Title	Methodology/ Method	Participant Group	Key Contributions
Martin, Smith, Rogers, Wallen, & Boisvert (2011)	Mothers in recovery: An occupational perspective	Narrative	Adults 18-47 yrs -10 females, Addiction	<ul style="list-style-type: none"> • OTs can contribute to treatment by helping clients rebuild their OI through meaningful occupations. • Treatment must focus on reconstructing a healthy OI based on client's pre-addiction strengths and occupational interests.
Phillips, Kelk & Fitzgerald (2007)	Object or person: The difference lies in the constructed identity	Ethnography	Adults - Experts, locals, people living in Scotland	<ul style="list-style-type: none"> • Constructed identity is a dynamic process involving agency in power relationships with other people. • If self-agency is denied, then one creates a construction of truth rather than constructing identity. • Advocates for the use of the theory of constructed identity (Unified Theory of Self).
Reynolds (2003)	Reclaiming a positive identity in chronic illness through artistic occupation	Interviews	Adults, 30-69 yrs -10 females, Chronic Illness	<ul style="list-style-type: none"> • Participant's engagement in artistic occupation during illness contributed to a positive identity as a textile artist over time. • Artist identity enabled participants to continue to express pre-illness self and values.
Segal (2005)	Occupations and identity in the life of a primary care giving father	Narrative	Adult, early 40's -1 male	<ul style="list-style-type: none"> • Idea that there is a link between occupation and identity. • Threads of continuity help maintain a coherent identity when perceived identities are challenged.

Authors	Title	Methodology/ Method	Participant Group	Key Contributions
Smith, Suto, Chalmers, & Backman (2011)	Belief in doing and knowledge in being mothers with arthritis	Narrative	Adults, +19 years -8 females, Disability	<ul style="list-style-type: none"> • “Just because I can’t do, doesn’t mean I’m not a mom”—main storyline. • Despite disruptions in motherhood tasks, participants described strong identities as mothers.
Unruh (2004)	“So...what do you do?” Occupation and the construction of identity	Interviews	Adult (age not disclosed) -1 male	<ul style="list-style-type: none"> • 3 themes: occupation and continuity of OI; contributions of productivity, leisure, and self-care to OI; public and private aspects of OI. • Meaningful occupations are related to OI. • Understanding OI may be necessary for developing a collaborative approach to OT intervention.
Vrkljan & Miller Polgar (2007)	Linking occupational participation and occupational identity: An exploratory study of the transition from driving to driving cessation in older adulthood	Semi-structured interviews	Older Adults, 74-80 yrs -1 female, 1 male	<ul style="list-style-type: none"> • Interdependent relationship exists between occupational participation and OI. • Potential consequences on identity when meaningful occupations are disrupted. • Link between meaningful occupations & identity.

Authors	Title	Methodology/ Method	Participant Group	Key Contributions
Wilson (2010)	Occupational consequences of weight loss surgery: A personal reflection	Autoethnography	Adult, 50+ yrs -1 female	<ul style="list-style-type: none"> Capacity for participation in occupations, changes in patterns and routines, interactions with others, losses and gains, and occupational choices contribute to changes in occupational identity. Suggests more focus on how participation in occupation is shaped by identity, especially for those who actively choose life changes that have consequences for participation.
Wiseman & Whiteford (2007)	Life history as a tool for understanding occupation, identity and context	Life history methodology	Adults, 65+ yrs -8 males, Retirees	<ul style="list-style-type: none"> Methodology revealed the complexities and strategies used to reconstruct identity after retirement. Provided insights re: meaning, patterns, social/environmental contexts, coherence of identity and lifespan development of identity.

1.4.1 Strengths

There has been limited research in OS and OT literature, linking occupation to identity, although more research studies are beginning to emerge. Existing research studies exploring OI (see Table 1) have primarily used qualitative methods, mainly generic qualitative interviews, narrative methodology, and life history methodology. Other research studies in the field have made reference to identity in their findings, however it has not been a primary focus of attention.

Relevant research appears to be what funding agencies and greater political and societal discourses demand, and is often associated with notions of action, application, and advocacy (Rylko-Bauer, Singer, & Van Willigen, 2006). Research studies have begun to articulate the relevance of OI research by highlighting implications with respect to OT practice (Christiansen, 1999; Collins, 2007; Howie, Coulter, & Feldman, 2004; Lysack & Seipke, 2002; Unruh, 2004), which may be considered a strength regarding its conceptualization. Researchers are beginning to link OI with constructs such as occupational participation (Vrkljan & Miller Polgar, 2007) and spirituality (Collins, 2007; Unruh, Versnel, & Kerr, 2002), which I contend is just the beginning of an important line of scholarship.

1.4.2 Drawbacks

Historically, identity has been a highly researched concept in sociology, psychology, philosophy, and anthropology literature. There are many existing theories that have not been explored utilizing an occupational perspective. As a result, I have discovered that OI is lacking a solid philosophical and theoretical foundation, and

contend that it would benefit from exploring and importing contemporary theories from other disciplines to inform OI theory. Christiansen (1999, 2004) makes some brief references to theorists such as Maslow, Deci, Ryan, Piaget, and Mead, however the connection between their work and further conceptualizations of OI is unclear. These theories are also highly individualistic in nature, and do not necessarily address issues beyond the person which may also be implicated in identity.

The majority of existing research has focused on occupational identities for adults and older adults (Howie, Coulter, & Feldman, 2004; Laliberte-Rudman 2002; Lysack & Seipke, 2002; Magnus, 2001; Reynolds, 2003). This intense focus has left a significant gap in knowledge with respect to children with or without disabilities and the construction of OI. No research to date has approached the issue of occupation and identity from a child's perspective. Furthermore, a comprehensive understanding of occupation and identity throughout childhood and adolescence is essential to advancing this construct.

Conceptualizations to date operate under assumptions that have not been thoroughly unpacked and challenged. It has been assumed that occupations contributing to OI are freely chosen. What has not been addressed or problematized are the conditions that allow for "free choice". I question the true level of consciousness available in decision-making in light of social and political parameters, demands, norms, and expectations. I also question whether choice is perceived by the individual or by the broader social world. Granted, Christiansen (2004) admits that not all activities are freely chosen, as we are influenced by habits, routines, physiological factors, and environmental factors. However, in-depth discussions regarding social and political factors and the

implications for free choice have started to take place in the occupational science field (Whiteford & Hocking, 2012).

The notion that occupations contributing to OI are individualistic, goal-directed, and lead to future possibilities is largely based on Western cultural assumptions. A dominant discourse exists within this domain, focusing on self-efficacy, self-confidence, self-esteem, personal success, personal motivators, personal goals/achievements, and personality traits with respect to how they contribute to OI. What is not addressed is the notion of collective occupations, and collective identities. Dickie, Cutchin, and Humphry (2006) advocate for the need for a collective understanding of occupation, as “occupation is rarely, if ever individual in nature” (p. 83). There is also a great focus on the *future* and *possible selves*, which is not necessarily a focus of cultures outside of the Western view. This leads to barriers in utilizing this construct in cross-cultural contexts, as not all cultures value the individual in the same way as North American cultures.

As we continue to conceptualize constructs such as OI, it is important to consider that in general, occupational science research focuses more meticulously on the individual determinants of occupation (Dickie, Cutchin, & Humphry, 2006; Hocking, 2012; Molineux & Whiteford, 2006). Molineux and Whiteford (2006) suggest that this may be attributed to the history of occupational therapy and dominant Western values concerning the individual versus the collective. This perspective has been criticized for its limited forms of knowing and alienation of diverse cultures (Molineux & Whiteford, 2006). As a result, the knowledge privileged within occupational science, in this case with respect to OI, may have limited cultural transferability. This is not to imply that this research is not useful and necessary, but that in order for constructs to be conceptualized

and to make sense to other epistemic cultures, we as occupational scientists need to consider ways of knowing beyond the individualistic view. In addition, Hocking (2012) contends “it seems clear that occupational scientists need to move beyond (often romanticized) accounts of individualized experiences if the discipline is to make any contribution to understanding and responding to the occupational issues of people who experience systematic disadvantages and marginalization” (p. 59). This would include children with disabilities.

1.5 Rationale

Children with disabilities are at risk for limited opportunities to engage in childhood occupations (Heah, Case, McGuire, & Law, 2007). Considering identities are shaped and reshaped by what we *do*, limited opportunities to engage in occupations inherently threaten the construction of identity (Christiansen, 1999). Parents’ values and preferences, particularly their personal sense of enjoyment and opinions pertaining to the child’s best interest, play a dominant role in what occupations children with disabilities are able to participate in (Heah et al., 2007). Vigilance also plays a role in opportunities to engage in occupations, as parents may feel the need to be more guarded about the occupations their children engage in because of the nature of their disabilities, potential safety risks, lack of supportive social structures, potential for inappropriate interactions with other children, and a history of unaccommodating and discriminatory experiences (Baker & Donnelly, 2001; Heah et al., 2007). These factors are likely to shape occupations and identities of children with disabilities.

The majority of existing OI research has focused on the occupational identities of adults and older adults transitioning through illness and post-retirement years (Howie, Coulter, & Feldman, 2004; Laliberte-Rudman 2002; Lysack & Seipke, 2002; Magnus, 2001; Reynolds, 2003). This intense focus has left a significant gap in terms of advancing knowledge with respect to children and the construction of identity through occupation. Although scholars have suggested that OI develops throughout the lifespan (Christiansen, 1999; Kielhofner, 2008; Unruh, 2004) and some early conceptual work has emerged, no research to date in the occupational science or occupational therapy fields have systematically studied how occupation is implicated in the shaping of identity for children.

Traditionally, there has been an emphasis on researching occupational constructs using individualistic frameworks (Hammell, 2009; Hocking, 2012; Molineux & Whiteford, 2006, Phelan & Kinsella, 2009). Similarly, traditional identity theory work maintains a strong focus on individualistic perspectives. Yet, those who draw on socio-cultural perspectives call for increased attention to socially oriented perspectives in order to study how identities are formed, shaped and reshaped through social and cultural experiences (Gergen 1994, 2000; Taylor, 1992). I contend that this perspective has much potential for advancing knowledge in occupation-based literature, and for potentially contributing to ideas that may be applicable in different cultures, societies and epistemic communities.

In summary three problems provide a rationale for this research:

- 1) There is little research on how occupations are implicated in the shaping of identity in children.
- 2) Children with disabilities appear to be particularly at risk for restricted opportunities to engage in occupations due to socio-cultural factors.
- 3) There is little research on OI from a socio-cultural perspective.

1.6 Purpose of the Research

Given the above discussion, and identification of problems requiring attention, the purpose of this research is to examine how occupation is implicated in the shaping of identities for school-aged children with physical disabilities in light of the socio-cultural dimensions that shape opportunities for children to participate in childhood occupations.

Three research questions inform this work:

- 1) How is identity shaped through participation in everyday occupations in the lives of children with disabilities?
- 2) How are socio-cultural factors implicated in children with disabilities' opportunities to participate in childhood occupations?
- 3) How might a socio-cultural perspective reveal aspects of occupation and identity that are shaped by the dialectic between individual and social dimensions?

1.7 Situating Myself within this Work:

A Reflection on Epistemological Underpinnings

Originally, beginning my doctoral course work I identified myself as working within the constructivist paradigm, whose aim of inquiry is the understanding and reconstruction of the constructions held by both the researcher and the researched (Guba & Lincoln, 2004). Ontologically, I recognize that there are multiple meanings and subjective realities (Finlay, 2006). Constructivists take a “transactional and subjectivist stance that maintains that reality is socially constructed”, and therefore the dynamic interaction between researcher and participant is central to capturing and describing participants’ experiences” (Ponterotto, 2005, p. 131). It follows that through the interaction of the researcher and the participant, deeper meanings can be uncovered. Findings are then constructed between researcher and participant through dialogue and interpretation (Ponterotto, 2005).

As I progressed through the program, I began to notice a shift in my thinking. With exposure to different theories, perspectives, literature, and generative dialogue with professors and peers, I began to explore notions of social constructionism. Stanley Fish (as cited in Crotty, 2007, p.52) once said “all objects are made not found” however “the means by which they are made are social and conventional”. Social constructionism seeks to illuminate how people see and understand the world in which they live (Gergen, 2003). Social constructionists do so under certain assumptions unique to their beliefs. Within this view, it is assumed that knowledge is constructed through relationships between individuals and the world around them. This knowledge is also culturally and historically situated, both of which influence perceptions of reality beyond what is often

at a conscious level (Gergen, 2003; Mallon, 2007). Social constructions can be seen as ways to exert control over individuals within a society, “it is in its power over life and death that it manifests its ultimate control over the individual” (Berger & Luckman, 1966, p. 181). Berger and Luckman (1966) suggest that “the social channeling of activity is the essence of institutionalization, which is the foundation for the social construction of reality” (p. 182).

Although aligning myself in the social constructionist tradition felt more fitting, in that I believe that the power of discourse and relationships shape knowledge and meanings often beyond consciousness, I could not resign myself to the idea that human agency was a myth within the socially constructed world. Here, is where I found distinguishing between constructivism and social constructionism to be helpful. Crotty (2007) contends that *constructivism* “points up the unique experience of each of us. It suggests that each one’s way of making sense of the world is as valid and worthy of respect as any other, thereby tending to scotch any hint of a critical spirit” (p. 58). On the other hand, Crotty points out that *social constructionism* “emphasizes the hold our culture has on us: it shapes the way in which we see things (even the way in which we feel things!) and gives us a quite definite view of the world” (p. 58). Crotty goes on to recognize “that it is limiting as well as liberating and warns that, while welcome, it must also be called into question. On these terms, it can be said that constructivism tends to resist the critical spirit, while constructionism tends to foster it” (p. 58). In distinguishing between both epistemologies, I see them as part of a continuum, where constructivism appears to be on the far left, focusing “exclusively on the meaning-making activity of the individual mind” (Crotty, 2007, p. 58), and social constructionism on the far right,

focusing on the collective creation of meaning through language and social processes. While I situate myself closer to the far right on the continuum, I can not leave my tendencies to recognize the role the individual might potentially play in a dialectic relationship with the social dimensions and discourses available. I also recognize my desire to think critically and put everyday knowledge up for question, which aligns well with this perspective.

Finally, as I progressed even further in my doctoral work, discovering critical disability studies and feminist literature, I opened a door from which I cannot return. Critical perspectives have the potential to create new ways of seeing everyday phenomena, allowing one to gain awareness of power relationships within society and recognize the forces of hegemony and injustice (Crotty, 2007; Simon, 1992). To be critical is to begin to question ideology, common values and assumptions, and to challenge conventional social structures in attempts to initiate social action and change (Crotty, 2007). When I stumbled upon and began to read about critical and feminist perspectives on disability, I felt as if I could finally name some of the tensions I felt as an occupational therapist in practice (further discussed in chapter three). I must recognize and be up front with this perspective, because this lens will now be forever with me—through design, data collection, data analysis, and dissemination.

As difficult as it is to articulate my standpoint as a researcher, or choose a paradigm that I feel best describes who I am and where I have come from, I take this stand acknowledging that I see my position as dynamic, changing day-to-day with every new experience, and in the process of growth and development. As a constructionist-constructivist developing a critical perspective, I believe that identity is shaped through a

dialectic between personal and social narratives. The social world has an impact on how children negotiate their identities and also on the opportunities afforded to children to participate in meaningful occupations. Meanings attributed to experiences have an impact on identity construction and re-construction. As a result, I believe occupation and identity (or occupational identity) to be dynamic and plural, however I suspect that some common threads may exist throughout transitions and transformations over the life span. Like Burr (2003) I see identity as socially constructed, but I also believe that human agency is possible even if only to choose or resist available discourses situated in time, history, place, and culture.

1.8 Social Construction of Knowledge

It is also important for me to make explicit my assumptions about knowledge, and how knowledge is constructed, as it is with such knowledge that we make decisions and act. These assumptions inform the design and interpretation of my research. Social constructionists believe that theories are constructed based on human culture and decisions, such that such theories may have been different given different cultures or decisions of that time (Mallon, 2007). Social constructionists also look at the reasons why certain theories are accepted in context, and perhaps more closely at the “wrong reasons” that seem to justify theories accepted into mainstream culture (Mallon, 2007).

Language is thought to play a dominant role in the construction of knowledge, taking on the forms of texts, documents, journals, lectures, and discussions to name a few (Gergen, 1995). However, this notion is more complex than it appears. It is the interplay

of language, society, and its context that creates meaning, and contributes to knowledge (Gergen, 1995).

Mallon (2007) suggests social constructionist critiques are “driven by the hope of showing that accepted theories do not simply depict natural facts, but rather were chosen because they rationalize injustice” (p. 96). Although this quote appears to be alarming and perhaps a little extreme, it is one that has got me thinking about the status quo and provoked many questions coming from this work. It is this perspective that I am particularly interested in, as it is through my experience as an occupational therapist in school health that I have come to question how society has constructed the notion of children’s identities, disabilities, and *normal* childhood development and experience.

1.9 Plan of Presentation

This doctoral dissertation is presented in an integrated manuscript format. The manuscripts that have been included in this work are varied in their orientation encompassing theoretical, conceptual, practical, reflexive, and empirical work. This work contributes to the conceptualization and study of occupation and identity with children, to a call for reflexive practices with children, and to methodological considerations such as the use of photo-elicitation methods and approaches to ethical research with children.

In chapter one, I have introduced the emerging construct of occupational identity, situated this construct within current literature trends, and situated myself as a researcher. I have also introduced a rationale for this work, the purpose of the research and the three main research questions.

Chapter two introduces the first of five integrated manuscripts, entitled *Occupational identity: Engaging socio-cultural perspectives*. This manuscript has been published in the *Journal of Occupational Science*, 2009, and contributes to disciplinary discussions about occupational identity as an emerging construct. This manuscript reflects my socio-cultural theoretical perspective, a perspective that attends to socially, relationally, discursively, and culturally oriented dimensions of identity formation. In addition, it proposes a socio-cultural approach to occupational identity, thus making a contribution to conceptualizations of occupational identity in the field of occupational science. The ideas in this manuscript informed the design, data collection, data analysis, and discussions of this research.

Chapter three, an integrated manuscript entitled *Constructions of disability: A call for critical reflexivity in occupational therapy*, serves multiple purposes in this dissertation. This manuscript was published in the *Canadian Journal of Occupational Therapy*, 2011. First, it paints a picture of my theoretical lens (disability studies perspective), from which I interpret the findings of the case study research. It also paints a picture of who I am as a researcher and an occupational therapist, and how I have come to this work, including some of my assumptions and pre-understandings. Finally, it introduces the concept of reflexivity, which is a common thread throughout this dissertation.

Chapter four describes the methodology, methods, and methodological decisions made in this research. This chapter discusses case study as an overarching methodology, presenting a background, rationale, strengths and limitations of its use. It also details the methods used to conduct this research including: participant recruitment, data collection,

and data analysis. This chapter works in tandem with chapter five, entitled *Photoelicitation interview methods and research with children: Possibilities, pitfalls, and ethical considerations*. Chapter five has been published in a book: *Creative spaces for qualitative researching...Living research*, edited by J. Higgs, A., Titchen, D. Horsfall and D. Bridges, 2011. Photoelicitation interviews are discussed in-depth as a promising method for eliciting children's perspectives in research. In addition philosophical underpinnings, practical considerations, ethical considerations, and examples from this research are discussed.

Chapter six is comprised of the fourth integrated manuscript entitled, *Childhood, identity, and occupation: Perspectives of children with disabilities and their parents*. This manuscript presents the empirical work garnered from this research, and has been submitted to the Journal of Occupational Science. The major findings of this work are presented here. This manuscript examines how occupation is implicated in the shaping of identity for children with physical disabilities, and discusses how a socio-cultural perspective reveal aspects of occupation and identity that are shaped by the dialectic between individual and social dimensions. Six categories are presented: Perceptions of self and other: Living with disability; Family identity, tradition and culture; Relational identity: A sense of belonging; Pride, success, and seeing things through...; Growing up and Keeping Up; and Identity as dynamic.

Chapter seven presents the fifth integrated manuscript, entitled *Picture this...Safety, dignity, and voice, Ethical research with children: Practical considerations for the reflexive researcher*. This manuscript is in press with the journal of Qualitative Inquiry, and scheduled for publication in fall 2012, volume 18, issue 9. This manuscript revisits the topic of reflexivity, and discusses its merit in ethical research with children.

Examples and excerpts from the findings of this study are used to illustrate reflexive research in procedural ethics and ethics “in the moment”. Guiding reflexive questions are presented for researchers to consider as a practical guide when conducting research with children.

Chapter eight discusses and concludes the dissertation. Emerging insights from this research and implications for occupational science and occupational therapy are discussed, and a proposal for a future research agenda is presented. Reflexivity is revisited once again reflecting on the research as a whole, methodological decisions made in the process, and my own personal growth as a researcher throughout this process. Finally, quality criteria used to assess the empirical work in the dissertation are outlined and elaborated upon.

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2. Occupational Identity: Engaging Socio-Cultural Perspectives¹

2.1 Introduction

Occupational identity is an emerging construct in occupational science. It is in the early stages of conceptualization, and is frequently presented without explication of its underlying assumptions. The purpose of this article is to critically examine the construct in order to (1) explicate the theoretical assumptions embedded in current conceptualizations of occupational identity in occupational science, (2) examine socially and culturally oriented perspectives on identity theory in light of the assumptions underpinning occupational identity, (3) demonstrate how socio-cultural theoretical perspectives enrich conceptualizations of occupational identity and (4) advance the scholarly dialogue concerning the construct of occupational identity in occupational science.

2.2 Occupation as Identity

Christiansen (1999, 2000, 2004) was the first scholar to make an explicit connection between occupation and individuals' personal and social identity in the occupation-based literature. He suggested that participation in occupation contributes to one's construction of identity and is the primary means to communicate one's identity, concluding that "when we build our identities through occupations, we provide ourselves

¹ A version of this chapter has been published: Phelan, S. & Kinsella, E. A. (2009). Occupational identity: Engaging socio-cultural perspectives. *Journal of Occupational Science*, 16(2), 85-91.

with the contexts necessary for creating meaningful lives, and life meaning helps us to be well” (1999, p. 547). Christiansen (1999) advanced four central propositions about occupation and identity: (a) That identity is an overarching concept that shapes and is shaped by our relationships with others, (b) That identities are closely tied to what we do and our interpretations of those actions in the context of our relationships with others, (c) Identities provide an important central figure in a self-narrative or life story that provides coherence and meaning for everyday events and life itself, and (d) Because life meaning is derived in the context of identity, it is an essential element in promoting well-being and life-satisfaction. This seminal work has served as an important foundation for advancing conceptualizations of occupational identity in occupation-based disciplines.

2.3 Occupational Identity

Kielhofner (2002) advanced the scholarship linking occupation and identity, coining the term occupational identity. He subsequently defined occupational identity as “a composite sense of who one is and wishes to become as an occupational being generated from one’s history of occupational participation. One’s volition, habituation, and experience as a lived body are all integrated into occupational identity” (2008a, p. 106). In his model of human occupation (2008a), occupational identity and occupational competence are interrelated and influence the success of occupational adaptation. In this sense, occupational competence is defined as “the degree to which one sustains a pattern of occupational participation that reflects one’s occupational identity” and occupational adaptation is defined as “the construction of a positive occupational identity and achieving occupational competence over time in the context of one’s environment”

(Kielhofner, 2008b, p. 107).

Unruh and colleagues have also contributed to the conceptualization of occupational identity, proposing that:

occupational identity could be conceptualized as the expression of the physical, affective, cognitive, and spiritual aspects of human nature, in an interaction with the institutional, social, cultural and political dimensions of the environment, across the time and space of a person's lifespan, through the occupations of self-care, productivity and leisure. (Unruh, Versnel, & Kerr, 2002, p. 12)

Like Christiansen (1999), Unruh (2004) made the point that in social settings, people are often defined by what they do. She illustrated her argument using a common question asked in social venues, "so...what do you do?" (p. 290). Moreover, Unruh (2004) illuminated an important distinction between people's public identities (based on work, productive occupations, and acknowledgement of the social value attached to work) and private identities (based on solitary, creative, and leisure occupations, acknowledging the personal investment attached to such occupations). Unique to Unruh and her co-authors, is the emphasis on spirituality and its potential to influence occupational identity (Unruh, 2004; Unruh et al., 2002).

2.4 Occupational Identity:

Theoretical Assumptions and Emerging Perspectives

Close examination of the occupational identity literature reveals four major theoretical assumptions embedded within the construct of occupational identity. These

are: (a) Individual at the core of identity formation, (b) Choice, (c) Productivity, and (d) Social dimensions. The following discussion examines these assumptions in light of emerging socio-cultural theoretical perspectives from within occupational science and beyond.

2.4.1 Individual at the Core of Identity Formation

Occupational identity theory emphasizes the individual self as having control over its identity. The dominant discourse focuses on self-efficacy, self-confidence, self-esteem, personal success, personal motivators, personal goals/achievements, and personality traits with respect to how they contribute to occupational identity (Christiansen, 1999, 2004; Kielhofner, 2008a, 2008b; Unruh, 2004; Unruh et al., 2002). There appears to be little reference to broader social or collective notions of identity, except to link the impact of social worlds on the developing “self”.

While a focus on the individual self and the agency of the self is essential, it is also important to draw attention to emerging tensions within theories of identity in contemporary times. In the context of growing recognition of social, cultural, relational, and discursive elements, the limitations of an individualized approach to understanding identity have begun to garner attention. Indeed, many postmodernists and poststructuralists go so far as to argue that the notion of a unitary self is a myth (Weedon, 1987), and that such a conception presupposes a self who experiences the world independently of the social world, and outside of the language and discourses in which statements about the world are made (Smith, 1999). In addition, as Sandywell (1999) pointed out, the focus on the individual self is distinct from older dialogic views of

existence.

Postmodern and poststructuralist views posit a conception of a fragmented, decentred self (Sorrell & Montgomery, 2001). Postmodern writers question whether the self is unified, singular, and self determining, highlighting that each self exists in a fabric of relations (Lyotard, 1979). Poststructuralism proposes a self that is precarious, contradictory, and in process, constantly being reconstituted in discourse each time we think or speak (Weedon, 1987). For Foucault, for instance, subjects are constituted in discourse. He argued that there is no single position from which subjects can be empowered, only particular discursive positions within power/knowledge formations. From a postmodern/poststructuralist point of view, conceptions of identity that fail to problematize the modern notion of an individuated, self transparent consciousness, fully in control of itself, are problematic (Kinsella, 2005). Postmodern and poststructuralist thinkers contend that the self is more than cognitive and rational minds ruling bodies; the self is also constituted and reconstituted in relationship and language (Kinsella, 2005).

As constructs such as occupational identity are conceptualised, it is important to recognize that, in general, occupational science research has focused more on individually oriented determinants of occupation. Expressing concern about that, Dickie, Cutchin, and Humphry (2006) advocated for approaches to understanding occupation that value collective understandings, stating that “occupation is rarely, if ever individual in nature” (p. 83), and “occupation is larger than what an individual experiences” (p. 84). Similarly, Laliberte Rudman and Dennhardt (2008) recently highlighted the emphasis on the individual self in current conceptions of occupational identity as a limitation to theory development. Others have suggested that this individual orientation may be attributed to

the history of occupational therapy and to the dominant Western focus on the individual versus socially oriented concerns about what best serves the collective, a concern which appears to be more prevalent in a number of nonwestern cultures (Molineux & Whiteford, 2006).

For instance, Iwama (2003) argued that the individualistic understandings of human agency prevalent in occupation-focused paradigms arise from European and Western values, and may be viewed as problematically ethnocentric. In contrast, in collectivist social contexts, social dimensions rather than the individual often wield greater power in influencing perceptions of what is right and proper. Who is present in a given situation and the status bestowed on the individual by the greater collective, can exert a profound influence on what is considered to be true, worth knowing and worth doing. The self is oriented toward adjusting and adapting to the social environment, rather than controlling and altering environments to suit one's self (Iwama), and this has profound implications for human agency and identity. These perspectives raise questions about the ways the collective dimensions of occupational engagement influence identity formation, and how social and cultural discourses shape people's expectations and actions with respect to occupation and the implications for identity.

An additional consideration is that depictions of occupational identity focus on future and possible selves (Christiansen, 1999, 2004; Kielhofner, 2008a), which again emphasizes self identity rather than the self as part of or as shaped by the collective identity of the culture of which one is part. The persistent focus on the individual in occupational scholarship has been criticized for its limited forms of knowing, and for the potential alienation of diverse cultures (Iwama, 2003; Molineux & Whiteford, 2006;

Laliberte Rudman & Dennhardt, 2008; Hammell, 2009). In summary, individualistic conceptions of identity may limit understanding of occupational identity, and create barriers to utilizing this construct in cross-cultural contexts. Iwama's call for culturally relevant epistemologies for the study of occupation demands a rethinking of the study of occupation, and consequently, of conceptualizations of occupational identity.

In response to these and other concerns, Dickie et al. (2006) suggested that theories developed by occupational scientists have neglected to highlight the relationship between the person, occupation and context. Rather, the focus has been on each component as a separate entity. They proposed, instead, that occupational scientists draw upon theorists such as Dewey and Bentley to adopt a transactional perspective of occupation:

A relational perspective of transactionalism means that occupation is no longer seen as a thing or as a type of self-action. It is an important mode through which human beings, as organisms-in-environment-as-a-whole function in their complex totality. The holistic view also means that occupation transforms the situation as well as the person in an ongoing and emergent way. (Dickie et al., p. 91)

In asserting the need to consider occupation beyond the individual's understanding, taking account of the relationship between social, physical and cultural contexts, Dickie et al. further problematized the individualistic view of the self.

In summary, there are a number of critiques emerging within identity theory and occupational science that might generate avenues for further scholarship exploring socially, discursively, collectively, culturally, and relationally oriented conceptions of the

self, and the implications of those perspectives for occupational identity. Further scholarship in this area would constitute a rich location for advancing a dialectically oriented socio-cultural view of occupational identity; one that considers the individual, as well as socio-cultural perspectives, with respect to the ways occupational identities are shaped.

2.4.2 Choice

Choice is another recurring theme in the occupational identity literature. The emphasis on choice comes from the assumption that identity is achieved and described, rather than ascribed and prescribed (Cote & Levine, 2002). The notion of individual choice coincides with the assumption that individuals have choices in terms of which occupations shape occupational identity. For example, Christiansen (1999) asserted that occupations contributing to identity are chosen, controlled, and goal-directed: “When we create, when we control, when we exercise choice, we are expressing our selfhood and unique identities” (p. 550). He later claimed that goals are “external influences that shape the creation of self” (2004, p. 121), further expanding that notion by suggesting that the occupations individuals participate in throughout their lives are influenced by internal drives and conscious decisions. While Christiansen (2004) mentioned genetics, experience, culture, regulatory/legal obligations, and values as factors that may impact choice, those factors were not explored in depth.

Kielhofner (2008a) and Unruh (2004) have also proposed that occupational identity is shaped by individuals’ choices/volition and cultural context, as occupational identity reflects who they are in context. Leisure choice is identified as particularly

influential in how identities are constructed and shaped. For instance, Christiansen (2004) suggested that leisure occupations are chosen more freely, allowing individuals a release from the obligations of paid work. Similarly, Unruh (2004) described how productive occupations may be balanced or offset by leisure occupations in the construction of an individual's occupational identity.

These assumptions draw heavily on American cultural values, emphasizing occupations as freely chosen rather than arising out of duty or obligation (Cote & Levine, 2002). Acknowledging the possibility of restricted or lack of choice, Kronenberg and Pollard (2005) defined occupational apartheid as "the segregation of groups of people through the restriction or denial of access to dignified and meaningful participation in occupations of daily life on the basis of race, color, disability, national origin, age, gender, sexual preference, religion, political beliefs, status in society, or other characteristics" (p. 67). From this perspective, the assumptions of "free choice" that underpin conceptions of occupational identity appear culturally bound, neglecting instances where opportunities for free choice may not exist. As Sorell and Montgomery (2001) revealed, unlike lives composed in relative isolation, under dictatorships or in circumstances where survival demands adherence to a limited range of roles, activities and beliefs, identity theories frequently portray an array of possibilities for choice. This tendency, they suggest, is indicative of the extent to which such theory is culturally bound within white, middle class, American and European culture.

Contrary to theories that posit unlimited free choice, philosopher Susan Sherwin (1998) employed a feminist perspective to examine the social factors that limit possibilities for autonomy and free choice in everyday life. She drew attention to the

complex ways in which power differentials exist and influence individuals' capacity to make autonomous choices. Sherwin challenged the authenticity of autonomous choice in the presence of both social and political realms, proposing instead a rubric of relational autonomy that recognizes the importance of the social world in shaping people's choices and identity. Accordingly, Sherwin argued that the choices available to individuals are socially informed and highly relational, and advocated for an approach that:

acknowledges that the presence or absence of a degree of autonomy is not just a matter of being offered a choice. It also requires that the person have had the opportunity to develop the skills necessary for making the type of choice in question, the experience of being respected in her decisions, and encouragement to reflect on her own values. The society, not just the agent, is subject to critical scrutiny under the rubric of relational autonomy. (p. 37)

Sherwin asserted that critical scrutiny of the ways in which social relations and society impact choice is an exercise in social justice, as it moves away from socially privileged ideals in order to decrease the perpetuation of oppression. The notion of relational autonomy problematizes the assumptions about free choice that are at the heart of individually oriented perspectives on identity, and offers a generative pathway for future scholarship with respect to occupational identity.

The degree to which individuals can exercise free choice, and the implications of free choice for the construction of identity, are particularly salient questions in relation to occupational identity. Those questions may be even more significant for people with disabilities because the social discourse around disability has the potential to limit people's choices (Wyness, 2006) and thus their opportunities to engage in occupation

(Heah, Case, McGuire, & Law, 2007). Compounding those limitations, the built environment also shapes opportunities for persons with disabilities to choose occupations, as its structures inherently enable or disable individuals (Marks, 1999; Wendell, 1996). Vigilance also plays a role in occupational opportunities, as caregivers and loved ones may feel the need to be more guarded about the occupations of people with disabilities (Baker & Donnelly, 2001; Heah et al.). In addition, potential safety risks, lack of supportive social structures, and a history of unaccommodating and discriminatory experiences influence the occupational choices of persons with disabilities (Baker & Donnelly, 2001; Heah et al.). Thus theoretical perspectives that problematize assumptions about free choice and recognize that occupational choice is often determined by social, cultural and discursive dimensions, what Kemmis (2005) called “extra-individual features”, may have important implications for advancing conceptions of occupational identity, particularly with respect to people living with disabilities.

The value placed on choice in relation to the formation of occupational identity is also rooted in Western cultural ideals of autonomy, choice and independence which, as Held (1993) pointed out, privilege “autonomy” over “relationship”. Yet, the extent to which autonomous choice actually exists is open to troubling questions. An exploration of occupational choice across gender, ethnicity, socioeconomic conditions, and culture, is a further avenue for exploration and for advancing more relational conceptions of occupational identity.

2.4.3 Productivity

Notions of productivity, industry and working towards a future are fore-fronted throughout occupational identity theory. This is evident in Christiansen's (1999, 2004), Kielhofner's (2008) and Unruh's (2004) work. Consistent with the social value attributed to work, Unruh (2004) claimed that "much of development and maturation during adolescence and early adulthood is about constructing an occupational identity based on achieving meaningful work" (p. 293), and the social recognition that comes through this achievement. However, as Darnell (2002) explained, such values are "a product of a particular social, political, and economic system deriving from Western European modernity" (p. 5). Building on that argument, Darnell questioned whether the concept of occupation in itself might be ethnocentric, applying only to the cultural context from which it is formed. Advancing conceptualizations of occupational identity solely from this perspective risks alienating people of "different cultural or class backgrounds" who do not prioritize productivity and who "access work and its relation to personal identity in commensurable ways" (p. 7). Accordingly, Darnell called for occupational scientists to engage in learning more about the cultural construction of work in order to gain a better understanding of diverse worldviews and how other people enact occupation.

Darnell's work raises a flag about the importance of incorporating what Iwama (2003) has referred to as 'culturally relevant epistemologies' within occupational constructs such as occupational identity. This is not to dismiss the significance of productivity, but rather to recognize that its relationship to identity might vary in different cultures. Jean Vanier's l'arche communities for people with disabilities offer an example. In these communities, the cultural emphasis is on belonging rather than productivity, and

the process of becoming (identity formation) is seen through a relational lens (Vanier, 1998, 2001). Occupation in this context is seen first and foremost as an avenue for cultivating belonging, with explicit recognition that identities are shaped through engagement in community.

2.4.4 Social Dimensions

Occupational identity also highlights society's influence on individual identity formation. Society becomes significant in shaping what occupations are accepted. Social influences on identity formation are revealed in the occupational identity literature through the emphasis given to the way identities are formed through social approval. For instance, key occupational identity theorists have pointed out that children seek approval from parents, peers, and society (Christiansen, 2004; Kielhofner, 2008b; Unruh, 2004), and that positive identities are fostered when individuals perceive that their chosen occupations win approval from the greater society (Christiansen, 2004). At the same time, a number of social theorists from diverse fields have begun to point to the ways in which social dimensions and relationships are not just a means of social approval with respect to occupations; rather, they may form, shape or even produce identities.

Social constructionism, for instance, seeks to illuminate how people see and understand the world in which they live, proposing that knowledge is constructed through relationships between individuals and the world around them (Gergen, 2003). Because that knowledge is culturally and historically situated, it influences perceptions of reality beyond what is interpreted at a conscious level (Berger & Luckman, 1966; Burr, 2003; Gergen, 2003; Mallon, 2007). Accordingly, identity is formed, shaped, and reshaped

through social processes and interactions, emerging “from the dialectic between individual and society” (Berger & Luckman, 1996, p. 174). According to Berger and Luckman, this dialectic continues throughout one’s lifetime, in its particular socio-historical context, with society setting limits on the organism (seen as the individual in its biological entirety) and the organism in turn, setting limits on society. This results in an identity that is socially produced (Berger & Luckman) through discourses that exist within the culture and that people engage with through language and interactions with others (Burr, 2003). From this perspective, identity can be portrayed as a fabric constructed with many different historically and culturally situated threads (age, gender, ethnicity, occupation, sexuality, to name a few). Within a particular context, there are “a limited number of discourses on offer out of which we may fashion ourselves” (Burr, p. 107), implying that people fashion their identity from the representations available within present discourses. Burr argued that “for each of us, then, a multitude of discourses is constantly at work constructing and producing our identity. Our identity therefore originates not from inside the person, but from the social realm” (p. 108). Burr also asserted that although identities are socially constructed, they are not “accidental”. Human agency plays a role, and identity formation can be political, in that it may entail promotion of or resistance to available discourses. In Burr’s view, this is a struggle we all face.

Another major contribution to discussions about the social construction of identity is Gergen’s (1994, 2000) notion of the saturated self, the populated self, and the relational self, as dimensions of identity that are products of the social world. By the saturated self, Gergen (2000) alluded to aspects of self that are the product of technological

advancements, with the variety, frequency, intensity, and duration of such relationships increasing to the point of social saturation. The results of saturation have significant (often unrecognized) influence on identity formation. The populated self, refers to “the acquisition of multiple and disparate potentials for being” (p. 69). As people become more socially saturated, they become pastiches; “imitative assemblages of each other” (p. 69) whereby memories of experiences and interactions can be drawn upon when representing the self in social situations. Gergen (2000) explained that:

We appear to each other as single identities, unified, of whole cloth. However, with social saturation, each of us comes to harbour a vast population of hidden potentials—to be a blues singer, a gypsy, an aristocrat, a criminal. All the selves lie latent, and under the right conditions may spring to life. (p. 71)

Gergen’s third notion is of a relational self “in which the self is replaced by the reality of relatedness—or the transformation of ‘you’ and ‘I’ to ‘us’” (p. 156). It is the idea that, as individuals become socially saturated, they begin to realize that the notion of an autonomous self does not exist. Instead, they become conscious of their interdependence with others, understanding that relationships are central to constructing the self (Gergen, 1994, 2000). In this light:

One’s potentials are only realized because there are others to support and sustain them; one has an identity only because it is permitted by the social rituals of which one is part; one is allowed to be a certain kind of person because this sort of person is essential to the broader games of society. (Gergen, 2000, p. 157)

Similarly, philosopher Charles Taylor proposed that the formation of identity is fundamentally relational and crucially depends on one's dialogical relations with others. He wrote that "my discovering my identity doesn't mean that I work it out in isolation but that I negotiate it through dialogue, partly overtly, partly internalised, with others" (1992, pp. 47-48). Taylor suggested that people become full human agents, capable of understanding themselves, and hence of defining an identity, through acquisition of rich human languages of expression. These include not only words but languages of art, gesture, love, and the like. These symbolic cultural symbols implicitly shape identities. People do not, according to Taylor, acquire the languages needed for self definition on their own; rather they are introduced to them through exchanges with others who matter to them. The genesis of the human mind is in this sense not "monological", not something each person accomplishes on his or her own, but dialogical (Taylor, p. 33). The dialogue invokes both agreement and struggle, as "our identities are formed in dialogue with others, in agreement or struggle with their recognition of us" (Taylor, pp. 45-46). In this conception of identity, relationships carry immense weight in people's constructions of self as they "are all aware how identity can be formed or malformed in [their] contact with significant others" (Taylor, pp. 49-50).

Such conceptions extend the idea of identity formation beyond that of participation in occupations that are socially valued within a society, as described in occupational identity literature, and point to the ways in which involvement in society, culture, and social relationships may actually shape, form, or even produce occupational identity. Thus, it is proposed that a generative area for exploration within occupational identity theory parallels an area of concern in broader discussions of identity theory, and

includes the ways in which society, social relations, intersubjectivity and diverse cultural languages of human expression also come to shape, form or produce identities. Such a perspective moves beyond recognition of the social value and acceptance of occupations, to a deeper appreciation of the relationship between society and identity, and the ways social power might contribute to the malformation or limitation of identities.

Deeper consideration of the ways in which occupational identities may be socially constructed raises immense moral and practical concerns about how societies are organized and develop. The significance of occupations that are socially valued and that people are enabled to participate in, reflect the moral commitments of communities and societies, underlining people's collective responsibility for the future identities that are potentially shaped, formed and produced.

2.5 Conclusion

In their attempts to further conceptualize occupational identity, occupational scientists must ask how emerging socially and culturally oriented perspectives on identity might influence the construct and extend beyond the current emphasis on individualistic frameworks. This examination of occupational identity has revealed four theoretical assumptions that permeate current conceptualizations. Although attention to the assumptions embedded in the concept of occupational identity provides important conceptual insights with respect to how identity is shaped through occupation, the construct of occupational identity has much room to grow. Recent scholarship in anthropology, sociology, cultural theory and philosophy, have rightly introduced socially and culturally oriented frameworks to the study of identity. Occupational scientists have

also called for greater attention to socially and culturally oriented perspectives (Molineux & Whiteford, 2006; Hammell, 2009). These frameworks point to generative possibilities for conceptual elaboration, and draw attention to socially, relationally, discursively, and culturally oriented dimensions and their importance in identity formation and conceptions of the self. Attention to such frameworks has the potential to advance a conception of occupational identity that more overtly recognizes the dialectic between individual and socially oriented dimensions in how identities are shaped.

An excerpt from Sorell and Montgomery (2001) illustrates the complexity of identity formation, and articulates the impetus for increasingly socially oriented frames:

We must remember that not everyone has the opportunity to compose a personal sense of identity. Many groups and individuals, even in this new century, spend entire lifetimes in regions of extreme political chaos, severe personal restriction, or dire economic circumstances where survival demands adherence to a limited range of roles, activities and beliefs. For these people the story of ideal personal and social identity, composed in a society that is itself trustworthy, autonomous and generative—may be a bitter parody of their lived experience. (p. 123)

Occupational science prides itself on its interdisciplinary roots. We propose that it is time to consider diverse theoretical perspectives in order to conceptualize occupational identity in a manner that is responsive to contemporary theoretical developments. Such action begins by explicating the assumptions within the current conceptual frames in order to deepen understandings, and to use this as a starting place to advance scholarship about occupational identity.

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3. Constructions of Disability:

A Call for Critical Reflexivity in Occupational Therapy²

3.1 Introduction

One of the primary goals of occupational therapy is to enable occupational engagement for people with disabilities. Within professional practice knowledge there are many explicit and implicit assumptions about disability that underpin occupational therapy philosophy and define disability in a particular way. Disability is a foundational construct that lies beneath the surface of occupational therapy practices, and tends not to be questioned by professionals in the discipline. Occupational therapy scholars such as Karen Whalley Hammell (2006) and Gary Kielhofner (2004) write about disability studies, asking occupational therapists to consider the critiques of rehabilitation in relation to occupational therapy practice. Applying this work to practice, I have embarked on a critically reflexive journey using a disability studies lens to begin to critique some of the implicit and explicit assumptions and preunderstandings in occupational therapy theory and practice. In my own practice as an occupational therapist in school health I wrestled with tensions such as these, for example, with respect to handwriting and the expectations of normalcy (outlined by the funding agencies and the school systems). As I completed my progress notes at the end of my sessions, observing my own “abnormal” pencil grasp and my far from perfect penmanship, I felt a sense of unease, guilt, and almost inadequacy. Moments such as these initiated my critically reflexive journey and

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incited me to begin to rethink notions of disability within occupational therapy, and within my own professional practice. Using critical reflexivity, this paper begins to question taken-for-granted notions of disability in order to consider how we may begin to rethink our assumptions about disability within occupational therapy theory and practice.

3.2 Critical Reflexivity

“Reflexive action changes the form of the self: a reflexive practice never returns the self to the point of origin” (Sandywell, 1996, p. xiv).

Reflexivity invites one to “turn one’s reflexive gaze on discourse—turning language back on itself to see the work it does in constituting the world” (Davies, et al., 2004, p. 361). In this process one begins to think critically about the world we take for granted. The process of reflection involves thinking about one’s practice during (reflecting-in-action) or after (reflecting-on-action) an incident has occurred (Taylor & White, 2000). Reflexivity involves these aspects of reflection, in addition to the act of interrogating one’s situatedness in society, history, culture, and how this may shape one’s values, morals, judgments at both individual and social levels. Kinsella and Whiteford (2009) suggest reflexivity surpasses reflection by introducing a critical dimension to question the conditions under which knowledge claims are accepted and constructed. Kinsella and Whiteford (2009) recently called for critical epistemological discussions within the discipline of occupational therapy in order to advance disciplinary knowledge, suggesting that it is more than a call, but a responsibility. Epistemic reflexivity moves beyond the individual toward the social, and begins to turn one’s reflexive gaze on the

social conditions under which knowledge is produced within the discipline (Bourdieu & Wacquant, 1992).

Critical perspectives have the potential to open new possibilities and new ways of seeing (Simon, 1992). To be critical, is to put current ideology up to question (common values and assumptions) and to challenge conventional social structures and initiate social action (Crotty, 2007). A critical perspective allows us to gain awareness of power relationships within society and reveals the forces of hegemony and injustice (Crotty, 2007).

The term “critical reflexivity” will be used in this paper to further emphasize the necessity to examine discourse through a critical lens and to consider the possibility of praxis, as Freire (2007) defines it, reflection and action in order to transform the world around us. Critical reflexivity not only asks one to question current ideology, but also encourages one to enact change. Critical reflexivity invites new conversations with respect to conceptions of disability, and begins to challenge current practices in occupational therapy. The objectives of this paper are (a) to critically examine how disability has been constructed in mainstream society by introducing perspectives from contemporary disabilities studies theories, and (b) to apply a critically reflexive lens to occupational therapy practice.

3.3 Emerging Perspectives on Disability

“Much, but perhaps not all, of what can be socially constructed can be socially (and not just intellectually) deconstructed, given the means and the will.” (Wendell, 1996, p. 45).

An emerging body of disability studies literature, critical theories of disability, and feminist disability literature discuss the notion of disability as socially constructed. This has been influential to the disability movement and to the development of new perspectives on disability (Marks, 1999). Social constructionist perspectives theorize disability as a social phenomenon, a product of societal constraints (Burr, 2003; Oliver, 1996; Shakespeare, 2006).

The social model of disability, made popular by the Union of Physically Impaired Against Segregation (UPIAS), distinguishes the notion of disability from impairment, such that people are “disabled” by social and attitudinal barriers and “impairment” is the biological limitation specific to the individual (Oliver 1996; Shakespeare, 2006). The terms “disabled” and “impairment” and their corresponding definitions will be used in this paper to maintain the integrity of the scholarly work from which this paper draws upon. From this perspective, people are viewed as disabled only in settings and situations where they are oppressed by societal structures and practices (Oliver, 1996; Shakespeare, 2006). This is contrary to the premise of the medical model, which has traditionally underpinned rehabilitation theory and practice (Hammell, 2006).

Traditionally, the medical model situates disability and impairment within the individual, using the biological impairment as the starting point for treatment (Williams, 2001). In rehabilitation professions, the focus of assessment and intervention has often

been on the client's functional limitations, how these limitations impact activities of daily living, and how one might overcome his or her functional deficits in order to attain goals that allow one to function as close to normal as possible (Hammell, 2006, Williams, 2001). As an occupational therapist practicing in a pediatric setting, I often questioned why children with disabilities were receiving rehabilitation services to work towards a highly subjective "norm" that they had never known to exist, ignoring their unique life contexts. When comparing the biomedical model to the social model, I was able to name this tension whereas previously it felt like a discomfort that I could not explain.

Although many occupational therapy theories, for example the Canadian Model of Occupational Performance and Engagement (Polatajko, Townsend, & Craik, 2007), encourage therapists to look beyond the individual and examine social, institutional and environmental factors, in practice this may not always be the case when working within settings with limited resources and specific institutional policies and mandates. As a therapist, I often struggled with these tensions when receiving referrals focused on remediating impairment versus looking at the broader contextual issues that could also potentially contribute to inhibiting clients' participation in occupations. Despite shifts in occupational therapy philosophy toward a more holistic model of care, at times it feels, as a therapist, that we are still overshadowed by dominant power structures strongly embedded in the systems we work within.

Merits of the social model notwithstanding, there are some critiques worth mentioning, particularly from feminist perspectives. Feminist scholars, such as Crow (1996), Morris (2001) and Wendell (1996), discuss disability as constructed by society, however they argue that the individual experience of impairment must be acknowledged.

They critique the social model as being narrow in its focus, not acknowledging the impairment experience and the realities of the struggles individuals may face, such as pain, illness and suffering at times. Feminist perspectives advocate for social and cultural change to eliminate a large part of disability within society. However, they also recognize that there may be experiences of one's impairment that cannot be "fixed" and call for the implications of one's impairment to be recognized alongside disability (Crow, 1996; Wendell, 1996). I feel this is an important insight to consider in occupational therapy, creating a dialectic between the individual and the social, recognizing that the social model has a lot to offer the profession, yet it is always important to recognize one's individual experience.

In summary, these emerging perspectives on disability offer opportunities for occupational therapists to examine their current practices from new and relevant perspectives in order to continue to reinvent practice in a socially responsible way. Using these perspectives as a frame, constructions of disability will be discussed more deeply throughout the paper.

3.4 Constructions of Disability in Today's Mainstream

Society

Drawing upon literature from several disability studies perspectives, a review of how disability has been constructed in dominant discourse, focusing on i) constructions of "nondisabled" versus "disabled", ii) predominant meta-narratives and representations of disability, iii) built environments and social structures, and iv) social and attitudinal constructions in light of disability and identity, will be discussed.

3.4.1 “Nondisabled” vs. “Disabled”

Society and culture have constructed the notion of “nondisabled” versus “disabled”, or “normal” versus “abnormal” as a means to make sense of our world and understand the disabled body (Davis, 1995, 2006; Linton, 1998; Marks, 1999). These categories are not fixed, as disability is culturally, socially and historically situated. For example, Wendell (1996) discusses the *pace of life* as a factor that contributes to the social construction of disability. She suggests that as the pace and demands of society increase over time, there becomes a point where more people are excluded from the “nondisabled” category as they can no longer meet expectations of *normal* performance (Wendell, 1996). Marks (1999) contends that social structures, practices and symbols (such as the built environment, medical model, and popular media) reinforce, reproduce, and maintain these categories making it difficult to cross boundaries and break down barriers. He suggests that dichotomizing ability and disability creates a fear of becoming disabled, which further marginalizes and oppresses people with impairments.

Rather than accepting the nondisabled versus disabled dichotomy, some scholars take a more dynamic approach to ability and disability. From this perspective, people are viewed as only temporarily nondisabled, and at some point in a majority of people’s lives one may find oneself in a disability category (Davidson, 2006; Wendell, 1996). Wendell (2006) argues that if society accepted the notion that at some point everyone would become disabled to some degree, they would be more inclined to advocate for a society that provides the necessary resources for people of all abilities to contribute as full citizens.

Siebers (2006) writes that the prospect of becoming disabled creates fear within society, secondary to how disability has been constructed; the disabled body represents the image of *Other*. This is one reason that disability has become medicalized; something that medical science must treat and control (Siebers, 2006). People with disabilities and impairments are often portrayed as unhealthy even though many of them could be described as “without illness” (Wendell, 1996). Overall, the medicalization of impairments locates disability within the individual; taking responsibility away from society and placing it onto the person deemed “diseased” (Morris, 2001; Siebers, 2006; Wendell, 1996). Siebers (2006) draws attention to the merits of social constructionism, highlighting disability as the effect of an oppressive environment and advocating for advances in social justice rather than medicine and rehabilitation alone.

There is an expectation that people with disabilities must receive rehabilitation in order to reintegrate into society. Often times in rehabilitation services, including occupational therapy, people are given objects or devices such as wheelchairs, prostheses, or splints, which are seen as means to empower people. However, Siebers (2006) notes that this can occur without consideration of the reality of living with such devices. This is not to imply that assistive devices are not useful, or that occupational therapists have gone wrong in any way, but that it is important to reflect on the meaning of such devices and the message they imply with respect to becoming closer to normal with respect to occupational patterns.

Looking back on my own practice experiences, I think about the many devices or adaptations that I prescribed to children in school and question what implicit messages might have been enacted for the child I was working with, his/her classmates and others

within his/her social networks. One particular incident comes to mind, when working with a teenager on handwriting. This client, very concerned, asked me if he would be able to attend university or college if he did not have good handwriting, after we had completed a handwriting assessment requested on the referral. The client was proficient in keyboarding yet there was not enough funding within his private school to purchase a computer to make written communication easier for him. His handwriting was not necessarily ‘perfect’, but looking at my own notes in front of me (which were barely legible in comparison) I found it hard to justify putting the client through such distress for something that seemed so trivial in the moment. Allowing him to see my handwriting and talking about my experience in postsecondary school, he was surprised and relieved that he still would be able to pursue his dreams despite what his handwriting looked like. This critical incident incited me to question norms set by society, specifically within education and occupational therapy contexts.

Finally, some scholars, for example Lennard Davis (1995, 2006), believe that there should be more emphasis on the construction of *normalcy* versus the construction of *disability*. Davis (1995, 2006) calls our attention to the fact that the concept of a “norm” implies that the majority of the population falls under the arch of a standard bell-shaped curve and those with disabilities are deviations to the norm. It is important to consider the context in which such norms have been constructed, as they are also situated in a particular historical and temporal period. I can recall an instance in practice when I conducted a gross motor assessment with a child in kindergarten. The assessment suggested that the child was well below expectations of same-aged peers, however, the child’s teacher reported that the child’s performance was comparable to others in the

class. After clinical observation of the child in class and at recess, I agreed with the teacher. There could be a variety of explanations for this, but most importantly I began to question whether such norms matched this specific context, and perhaps broader social factors were in play for this new generation.

The notion of normality has become, in Davis' view hegemonic, such that the predominant view of the dominant group is seen as 'natural' and universal for all, although it may actually be seen as a form of oppression for those outside of that dominant group. In addition, the notion of disability has also become, in Hammell's (2006) view, hegemonic, as it "equates impairment with helplessness, dependency, loss, tragedy, incompetence, inadequacy and deviancy" (p.76). Davis (2006) asserts that developing a consciousness of disability issues involves the task of reversing the hegemony of normality and take on alternative ways of thinking about 'the abnormal'. This is a challenging task, but one that may be beneficial for occupational therapists to consider in theory and practice.

3.4.2 Meta-narratives of Disability: Whose voice is represented?

Although disability is frequently perceived as something to be feared and avoided, it is often represented differently, in a way that reinforces the need to become as close to "normal" as possible. Disability is often portrayed in popular media as appearing a particular way, and is constructed by "nondisabled" individuals. Most often disability is represented by the image of "a young man in a wheelchair who is fit, never ill, and whose needs concern a physically accessible environment" (Morris, 2001, p. 9). Hutchinson & Kleiber (2000) view this image as one of *heroic masculinity*, implying that with

“aggressive action and stoic perseverance in the face of overwhelming challenge” (p. 43), one can regain identity lost through the disability experience. These “disabled heroes” are readily accepted by nondisabled society because they speak to the possibility of overcoming the impairment, giving the false impression that one can *defeat* disability (Wendell, 2006) and also reinforcing negative connotations of disability.

Morris (2001) articulates the tensions between avoiding and embracing the experience of impairment as is, asserting that it is “dangerous because to articulate any negative feelings about our experience of our bodies may be to play into the hands of those who feel that our lives are not worth living” (p.9). She goes on to say, “we are forced into situations of denying the experience of our bodies, of trying to conform to the outside world’s view of what it is to be a full human being” (Morris, 2001, p.10). Morris (2001) raises concerns that “if we don’t express the experience of our bodies, others will do it for us. If we don’t confront what we need as a result of illness, pain, and chronic conditions which inhibit our lives then health services and support services will continue to be run in ways which disempower us” (p. 11). Wendell (1996, 2006) argues that allowing the non-disabled world to decide how disability is represented, and who can be identified as “disabled” creates unequal power relations, and excludes the voices of people with disabilities, which in turn may negatively impact their lives socially, economically and psychologically.

This raises questions for occupational therapy practitioners, for example: how often do professional opinions (implicitly or explicitly) supersede opinions of clients in clinical decision-making? Does contemporary occupational therapy theory and practice privilege professional voices by design? Does the profession of occupational therapy

inadvertently encourage ‘overcoming’ disability or ‘disability heroism’, which may unknowingly reinforce negative connotations of disability? These questions are difficult to consider as a therapist. Initially for me, thinking about such questions invoked feelings of hostility and resistance, as they go against everything I feel I stand for as an occupational therapist. Yet, after deeper critical reflection I began to realize that these questions are important to reflect on. Although we practice within client-centered models we may be constrained by institutional structures and policies to act in the most client-centered way. We have been socialized in a society that has historically privileged the opinions of ‘professionals’, which could potentially influence how decisions are made in practice and how disability is constructed. Notions of ‘overcoming’ disability are inherently present within rehabilitation practices, which is problematic when thinking about perpetuation of negative connotations of disability. In my opinion, as hard as it is to question the foundations of our profession, it is with these questions and answers that we can begin to work towards becoming more socially responsible practitioners.

3.4.3 Built Environment and Social Structures

The built environment inevitably shapes the notion of disability, as its structures inherently able or disable participation. Designers and architects are often nondisabled males who fail to consider accessibility of bodies that are different from the paradigmatic norm (young, male, fit/ideally shaped, and nondisabled) (Wendell, 1996). Aesthetics are prioritized over accessibility, and it is frequently assumed that bodies will conform to structures instead of structures conforming to bodies (Marks, 1999; Wendell, 1996). On the contrary, when accessible environments are designed they often lack aesthetic appeal,

instead drawing attention to difference, both by visual and auditory make-up (for example, alarms sound when lifts take people up and down stairs in public places). In these cases, “they reinforce associations of disability as something which cannot be harmoniously included into the ‘able’ world” (Marks, 1999, p.85). Creating “accessible” environments are seen as *accommodations* versus acts that facilitate the rights of others. In practice as an occupational therapist in school health, I was called upon as a consultant when the school board was planning to make accessible rooms and washrooms. In these instances I worked with architects and school board representatives to suggest different options and adaptations to the environment. In the majority of these cases, the end result would be deemed “accessible” on paper, however in reality it was not truly accessible. In the end, many of the subtle nuances (for example, sensor-activated lights, taps, dryers, etc.) were neglected, likely on the basis of cost and convenience. These “accommodations” did not make life for the children I worked with any more accessible, as they continued to need assistance to use the toilet in the “accessible” washroom at school even though with the right design they would not be disabled in such an environment. More importantly, the children or others with disabilities were not always consulted with respect to their needs. These environments were considered accessible from a nondisabled perspective.

It has been suggested that restructuring our built world and implementing the concepts endorsed by *universal design* will assist in *deconstructing* the notion of disability (Marks; 1999; Wendell, 1996). Universal design involves architecture to provide access to the built environment for people of all abilities (Davidson, 2006). Although universal design promises access to all, it is important to consider that some

designs will permit access for some users but act as barriers to others (Marks, 1999). In this sense, we cannot construct a perfect world, but we can do our best to design environments to deconstruct disability for the greatest number of people with diverse characteristics. In addition, Wendell (1996) recognizes that “disability cannot be deconstructed by consulting a few token disabled representatives” (p. 46.), as the experience of disability varies across impairments and the notion of normality is highly embedded in our culture, making it difficult to discern what is the “problem”—the person or society. Taking a more critical look at for whom our environment is built reveals embedded assumptions of who our culture and society deems as citizens (Marks, 1999). It is also equally important to look critically at social attitudes in deconstructing disability, as the built environment is only one component of the complex creation of disability.

3.4.4 Disability and Identity: Social and Attitudinal Constructions

It has been suggested that the notion of disability, and acceptance of disability, impacts a persons’ perception of self and identity (Wendell, 1996). Perceptions of self can be both positive (identifying with others with disabilities to contribute to one’s own understanding of their experience) and negative (being labeled as disabled in society is often stigmatizing and oppressive) (Wendell, 1996). For many people with disabilities, their identities are constructed within a society in which they have often been excluded because they have been seen as deviants from the “norm” (Swain & Cameron, 1999). For this reason, many people avoid a social identity of being disabled or having a disability, and this can translate into a form of self-oppression (Swain & Cameron, 1999). Goffman

(1968), an American sociologist, writes about both “inborn stigma” (for those born with disabilities) and “acquired stigma” (for those who acquire stigma later in life). For those who are born with disabilities, Goffman explains that such individuals either are taught what to expect from society early on, or protected from society’s notions of normality and normal identity. For those who acquire disability later in life, Goffman explains that they must re-negotiate their identity. In both cases identities can be “spoiled” by stigmatization, and people with visible or non-visible disabilities attempt to manage their spoiled identities through different strategies when encountering social interactions. For example, those with visible disabilities may focus on recovering their identities as “normal” and those with non-visible disabilities may focus on whether or not they choose to disclose the extent of their disability (Goffman, 1968).

Even though many people would rather avoid the social stigma that is attached to having a disability, in many cases without such diagnosis or identity one may not receive many of the services they need (Wendell, 1996). Without such services, people with disabilities may not be able to participate in and contribute to society as they rightfully should be able to. I witnessed this tension often in practice, as parents wrestled with the pros and cons of receiving a diagnosis for their child. The pressure to obtain a diagnosis was great, because without one, the opportunity for services diminished. In addition parents wrestled with decisions of whether or not to reveal the diagnosis to their child in fear of ‘labeling’ them and separating them from their peers. Reflecting on my experience as a therapist, tensions arise when a child does not understand why they need to see an occupational therapist at school, and their classmates do not. This can result in confusion

and frustration, and in some cases resistance. This contributes to the complexity of constructing identities for persons living with disabilities.

Finally, children with disabilities may have different experiences forming identities. Literature has shown that children tend to focus on “sameness” with other children, which may be attributed to the avoidance of negative experiences being excluded by their peers and broader society (Connors & Stalker, 2007). Connors and Stalker (2007) assert “impairment effects, barriers to doing, and barriers to being”(p. 31) play a role in constructing a disabled childhood and identity, which may shape self-confidence and self-worth for the future. A dominant societal discourse illustrates childhood disability as personal tragedy and a place of extreme vulnerability, charity, and lack of agency. These images may be reproduced with each social encounter that a child with a disability engages in (Priestly, 1999). Priestly (1999) suggests that children’s experiences of dominant images of disability contribute to a child’s identity development and to the construction of disability as a social concept.

In summary, discussing notions of “nondisabled” versus “disabled”, predominant meta-narratives and representations of disability, built environments and social structures, and social and attitudinal constructions in light of disability and identity is just the tip of the iceberg when attempting to examine constructions of disability in the mainstream in relation to occupational therapy. Applying some of these ideas to current theories and practices will create opportunities for dialogue as a profession with respect to the foundations of our discipline.

3.5 Discussion

“Voices bespeak conditions of embodiment that most of us would rather forget our own vulnerability to. Listening is hard, but it is also a fundamental moral act; to realize the best potential in postmodern times requires an ethics of listening” (Frank, 1995, p. 25).

In light of what has been discussed thus far, it is evident that critical reflexivity offers generative insights with respect to the examination of conceptions of disability within the occupational therapy profession. This discussion raises issues for the profession to consider with respect to constructions of disability and normalcy, both of which are embedded within the notion of *rehabilitation*.

Rehabilitation tends to focus strongly on impairments, and remediating or “accommodating” for such impairments. Kielhofner (2004) draws our attention to three significant tensions between rehabilitation and disability studies perspectives that occupational therapists are encouraged to consider: 1. “Rehabilitation practices reinforce the idea that the disability is the disabled person’s problem,” 2. “The rehabilitation professional is cast as the expert on the disabled person’s condition, the implication being that the essence or meaning of disability is to be located in the objective descriptions of disability produced in professional classificatory and explanatory systems,” and 3. “Rehabilitation efforts enforce a version of normalcy that pressures disabled persons to fit in by appearing and functioning as much like nondisabled persons as possible” (p. 241). In addition, the notion of normalcy and standardized/non-standardized norms is an issue to consider in occupational therapy. Hammell (2006) raises strong concerns regarding the constructions of norms within rehabilitation practices. Hammell asks us to begin to think

more critically about how we define norms such as “normal” posture, gait and handwriting to name a few, and how such norms reinforce professional power and further dichotomize the nondisabled and disabled. Evidence-based practice asks therapists to rely on normed assessment to evaluate client needs, however we must consider the risks and dangers associated with planning interventions with the sole purpose of helping clients approximate norms, and ask ourselves what ideologies are we perpetuating? Is this truly our intention?

Although occupational therapists consider the person, occupation, and environment in context and are open to making adaptations in all realms, therapists are often asked to focus on the person and their impairment, secondary to the demands of health care settings that prioritize the biomedical model. When occupational therapists direct their intervention strategies towards environmental factors (physical, social, and institutional), they still tend to focus at an individual level. A critical disabilities studies perspective calls for interventions directed at socio-cultural and socio-political levels. Therapists’ participation at this level would require renaming the role of occupational therapists and becoming a profession that focuses on social justice (Galheigo, 2005; Townsend & Whiteford, 2005). A broader understanding of disability, one that is explicitly focused on social justice, socio-cultural and socio-political issues may help occupational therapists carve out and articulate their niche amongst other health care professionals and align with the aims of therapists to be truly client-centered, “that is, practice where day-by-day actions are driven by a vision of changing systems to serve better those who experience occupational injustices” (Townsend & Whiteford, 2005, p.

112). This would call for advocacy by the professional body for a fundamental change in what are considered to be “traditional rehabilitation settings” in occupational therapy.

Client-centered practice is another concept that may require reconceptualization in light of a critically reflexive examination of disability. At first glance it would appear that client-centered practice would be the answer to the existing tensions between biomedical/rehabilitation perspectives and critical disabilities studies perspectives, yet to an extent this may be misleading (Hubbard, 2004). Client-centered practice, as defined in our current system, locates the disability within the individual, and places the individual at the centre of the model. A disability studies perspective, on the other hand, calls for accountability at a societal level, and locates disability within society. It is important for the profession to reflect on and acknowledge the ways in which an unreflective adoption of the ideal of client-centered practice may unintentionally reinforce power structures and potentially contribute to forms of oppression (Hammell, 2006). As a profession, perhaps it is time to rethink and elaborate our understandings of client-centered practice, in a way that expands beyond a focus on the individual and that considers broader social structures. In addition, it is important to critically reflect, both at individual and epistemic levels, on notions of power as professionals. In a recent study conducted by Mortenson and Dyck (2006) power relations in practice were evident at both interpersonal and institutional levels, however institutional structures seemed to be more influential with respect to how occupational therapists enacted their practice. It is important to recognize, as Mortenson and Dyck (2006) suggest, that the health care system may be organized in a manner that denies true client-centered practice, a practice that seeks to share power between therapists and clients. Mortenson and Dyck (2006) call for more critical

reflection on how client-centered practice has been constructed within institutional organizations. Such reflection could potentially allow therapists to become more aware of the implications of power relations in the context of client-centered practice from a perspective that acknowledges the ways in which disability may be socially constructed, perhaps even (unintentionally) by therapists themselves. This may lead therapists in a direction of advocacy for institutional and educational change, which may appear to be daunting at first glance. However in order to see change we must begin to make change, even if the change begins at the micro-level and progresses to macro-level endeavors.

As a profession, we must also consider the language we adopt in our theories, models, and practice. The use of person first language has become routine, and it is likely unquestioned by most therapists who are under the assumption that this is what people with disabilities want. Many disability scholars argue that such language further oppresses and takes the onus off of society and on to the person. Morris (2001) asserts that people with disabilities are “disabled” (by society), and the use of language in this way “describes the denial of our human rights, locates our experience of inequality as a civil rights issue, and, at the same time, creates a space to articulate our experience of our bodies” (p.2). This is not to say one way is better than the other, but to begin to think about what political stance we want to take as a profession and how that can be represented in not only our actions, but also our language.

Wendell (1996) calls for notions of independence in rehabilitation practices to be challenged. Rehabilitation’s focus on independence inadvertently depicts dependence in a negative light, further reinforcing dichotomies between ability and disability. Some scholars draw attention to notions of interdependence, recognizing the relational aspects

of care and the reality that no one person is truly independent (Wendell, 1996). Whiteford and Wilcock (2000) suggest that occupational therapy may benefit by adopting notions of interdependence both theoretically and pragmatically, taking into account the uniqueness of each client and their family. Hammell (2006) asserts that by not contesting disciplinary preoccupations on independence, we are inadvertently reinforcing ideologies of physical independence as opposed to interdependence and reciprocity, which may potentially be offensive to people with disabilities.

Other scholars, such as Fine and Glendinning (2005), have explored notions of dependence, independence, interdependence, care and dependency. Although they acknowledge that the notion of interdependence deserves merit, they suggest rethinking the meanings that underpin the terms “care” and “dependency”, recognizing the issues of power that permeate both constructs, as these terms will inevitably still be used in policy-making and research initiatives. Both positions warrant further exploration within occupational therapy theory and practice in order to begin to challenge the predominance of independence within our practices as therapists.

Perhaps the reason why many of assumptions about disability appear not to be questioned in occupational therapy stems from a lack of exposure to different perspectives outside of our profession and from the predominance of the biomedical discourse. Hammell (2006) observed that health care professionals have been socialized in a culture where their ideas and beliefs “appear not only to be natural and self-evident but benevolent and beneficial” (p. 31). This is what makes the dominant ideology so dangerous. Without engaging in critical and epistemic reflexivity such ideas and beliefs remain pristine, unquestioned, and maintained. Reading about critical disability studies

and feminist critical disability studies literature is an eye opening experience. For myself, it shook the foundations of my professional identity, and it also became an “ah-ha” moment in which I began to understand some of the tensions that I felt as a therapist but could not name. Exposure to such literature and ideas during occupational therapy education may help to prepare future therapists for tensions they may encounter in practice in addition to helping them to become more aware and reflexive practitioners with respect to the disability experience and their roles as advocates (Franits, 2005; Kielhofner, 2005). As Hubbard (2004) suggests, “our future clinicians cannot see through a lens they do not know exists” (p. 188).

Beginning to rethink notions of disability must begin with the voices of individuals living with disability, disability activist groups and centers of independent living. One way of initiating this discussion may be to introduce disability studies literature into occupational therapy curriculum (Block, et al., 2005; Hubbard, 2004). In this sense, students will begin to *hear* from disabled persons/groups and listen to their narratives in order to understand disability from diverse perspectives. This may potentially invoke critical reflexivity at a personal level and create dialogue that can begin to deconstruct preconceived notions of disability, which have been deeply ingrained up until this point. Hubbard (2004) points out that curricula within the health professions has been developed “from the perspectives of clinician, teacher, and practitioner and casts people with disabilities into the role of patient, client, or student” (p. 187). This not only creates a dichotomy between persons with and without disabilities (Hubbard, 2004), but also reinforces and embeds notions of power, which casts those with disabilities as being “powerless”. From an educational perspective, occupational

therapy curriculum and fieldwork requirements may require more flexibility and modifications to ensure that people with disabilities can enroll in and successfully complete occupational therapy training with all of the same opportunities as their peers. This may help to breakdown such dichotomies between persons with and without disabilities, service providers and the “othering” of service recipients, and professional knowledge and lived experience of disability.

Linton (1998) critiques the applied fields of rehabilitation for their lack of attention to disabled peoples’ voices in their curricula. Linton asserts that “if rehabilitation professionals believe in self-determination for disabled people, they should practice what they teach by adhering to an active affirmative action program in their own departments; by adopting the books and essays of disabled people into their curricula; and by demanding that disabled people have an active voice in conference planning and on the platform at conferences” (p. 141).

To summarize, applying a critically reflexive lens informed by contemporary disability studies perspectives has offered opportunities to critically examine notions of rehabilitation, client-centered practice, disciplinary language, independence, and education within occupational therapy. Further examination of these issues may offer generative understandings of core constructs that inform our practice as occupational therapists.

3.6 Conclusion

“Those who authentically commit themselves to the people must re-examine themselves constantly” (Freire, 2007, p. 60).

Reflexivity, critical or epistemic, creates uncertainty, which is one reason why many object to its practice (Taylor & White, 2000). Taylor and White (2000) assert that denying uncertainty does not eliminate it; they call for professionals to confront uncertainty in practice in order to move forward. In this paper, questions and issues are raised that may create discomfort for some, and comfort for those already wrestling with these tensions. This paper was intended to do exactly so, to disturb some of the foundational notions of disability implicit and explicit in occupational therapy, and ultimately to invite occupational therapists to engage in discussions about these tensions for the advancement of our practices. A critically reflexive examination of notions of disability reveals how powerful discourse is in naming reality, and how such discourses may be oppressive. Bringing a disability studies lens to occupational therapy literature may challenge current practices and is an area that merits further investigation. Naming disability in a manner that is sensitive to humanity and the experience of persons with disability has the potential to inform models of theory and practice, which may enhance occupational therapy’s mandate as a socially responsible discipline. It is acknowledged that this will not be an easy task, as current practices are embedded within powerful institutions and discourses. This critically reflexive examination has revealed the ways in which occupational therapy and society at large are embedded in discourses that may reinforce negative connotations around disability. With this in mind, new understandings

may pose a challenge to occupational therapists and other health professionals, as well as to people with disabilities who have also accepted the dominant view. However, it is worth “making the familiar strange” to open the possibilities of making the strange familiar.

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4. Case Study Methodology

4.1 Introduction

In this chapter I outline the methodology and methods adopted for this study. In part one, I begin by considering reflexivity, and the notion of reflexive methodology. I go on to present methodological decisions made and an overview of case study as a methodology, including: background, types of case studies, critiques and misunderstandings, strengths, and as a methodology appropriate for studying occupation. Part two describes the research design and methods including: participant recruitment, participant profiles, process of consent and assent, data collection, and data analysis.

Part 1: Methodology

4.2 Reflexive Methodology

In this section, I consider notions of reflexivity, and the implications for ‘reflexive methodology’ an approach that underpins the current study. I view reflexive methodology as an approach to research in which the researcher explicitly adopts a reflexive gaze with respect to the conduct of research and its interpretation. Reflexivity has been an important topic of attention throughout this dissertation, but reflexivity is also a slippery concept, and discerning exactly what reflexivity is and how it can be integrated into a study can be a challenge.

Davies et al. (2004) suggest that engaging in reflexivity allows one to “turn one’s reflexive gaze on discourse—turning language back on itself to see the work it does in constituting the world” (p. 361). A number of thinkers contend that reflexivity involves thinking critically about the world we take for granted (Bourdieu & Wacquant 1992; Taylor & White, 2000; Kinsella & Whiteford, 2009). Definitions of reflexivity frequently speak to its’ critical nature. Kinsella and Whiteford (2009) suggest “reflexivity goes beyond pragmatic reflection to embrace a critical dimension and to carefully interrogate the very conditions under which knowledge claims are accepted and constructed” (p. 251). Maxine Greene’s (1995) image of a “cloud of givenness, of what is considered ‘natural’ by those caught in the taken-for-granted, in the everydayness of things” (p. 47) calls for reflexivity. This cloud houses languages and acts of domination, entitlement, power, and most importantly silences; silences that she suggests “our pedagogies ought somehow to repair” (Greene, 1995, p.47). Reflexivity also focuses on an interrogation of how language is used, recognizing the capacity for language “to contain and restrain thought as well as its productive possibilities” (Davies, et al., 2004, p. 364). Hesse-Biber & Piatelli (2007) suggest that reflexivity can assist researchers to critically examine how their theoretical assumptions and personal biographies shape what they choose to study and with what approach and methods.

Although reflexivity is often called for in qualitative research, Alvesson and Sköldbberg (2009) note that methodologies themselves can be reflexive. They contend that reflexive methodologies draw attention to the complexities of processes of knowledge production/generation and its relationship with the various contexts of such processes, as well as the involvement of the “knowledge producer” (p. 8). Reflexive methodologies

involve forefronting ‘careful’ interpretation of the research, calling for the “utmost awareness of the theoretical assumptions, the importance of language and pre-understanding, all of which constitute major determinants of the interpretation” (Alvesson & Sköldberg, 2009, p. 9). It also involves forefronting reflection—

turn[ing] attention ‘inwards’ towards the person of the researcher, the relevant research community, society as a whole, intellectual and cultural traditions, and the central importance, as well as the problematic nature, of language and narrative (the form of presentation) in the research context. (Alvesson & Sköldberg, 2009, p.9)

Indeed for Alvesson and Sköldberg, it is this level of reflexivity that assures the empirical value of qualitative research. And, as Hesse-Biber and Piatelli (2007) point out, it also fosters less hierarchical and more ethical, socially relevant research. This perspective is similar to that of Sandra Harding (1993) and her notions of *strong objectivity* and *strong reflexivity*. Harding (1986, 1993) acknowledges the importance of situating the self and the research, and being reflexive about our position within the research. She asserts that strong objectivity and strong reflexivity creates a reflexive science, “one that better reflects the world around us and one that acknowledges that researchers bring their biographies, their experiences, and their knowledge into the field of research” (Hesse-Biber & Piatelli, 2007, p. 497).

When beginning to consider case study as my methodology of choice, I had a unique opportunity to engage in a reflexive dialogue with Dr. Bill Green, Professor of Education at Charles Sturt University. Dr. Green challenged me to think about ethics and intersubjectivity in case study research, pointing out the importance of seeing the case

study as a text, and how the researcher plays a role in constructing that text. Thomas (2011) underlines this point when he states “case study offers understanding presented from another’s ‘horizon of meaning’, but understood from one’s own” (p.32). As does Flyvbjerg (2006) who contends that the reader should be invited to interrogate the actors’ and narrators’ interpretations. In recognizing the complexity of the intersubjective encounter and the implications for interpretation, the moral and ethical imperatives of reflexivity become even more pertinent. In considering intersubjective encounters and the process of interpretation, Alvesson and Sköldberg (2009) write:

The research process constitutes a (re)construction of the social reality in which researchers both interact with the agents researched and, actively interpreting, continually create images for themselves and for others: images which selectively highlight certain claims as to how conditions and processes—experiences, situations, relations—can be understood, thus suppressing alternative interpretations. (p. 10)

Recognizing the importance of reflecting upon my interpretations, and viewing the case study as a text, I am conscious of the need to consider the lenses and perspectives that inform my interpretations. In addition, reflection on how my interpretations are constructed, how the participants are represented, how others might interpret the data, and what/whose perspectives are absent or silenced is important. Further, I hope to interrogate my position, to the extent possible, to understand why I have rendered the interpretations I have made. As Hesse-Biber and Piatelli (2007) remind us, “reflexive researchers and writers are responsible for and indebted to the very texts that they shape, because it is the text and in it the reflexive self that is externalized, taking on a material

life of its own” (p. 497). Some of these reflections are discussed further in chapter seven and chapter eight.

The stories emerging through these case studies are represented through a combination of voices. My socio-cultural perspective (elaborated in chapter two) plays a significant role in shaping the design of the research and therefore influences the perspectives elicited from the participants. Perhaps more prominently, my disability studies perspective sees, hears, witnesses, and presents a story in a particular way, reflecting the social dimensions of disability from a critical perspective (described in chapter three). Such a perspective no doubt draws my attention to particular kinds of data, quotes and images. Being reflexive about how the process of research design, data collection, data analysis, and the act of writing and representation impacts the way the cases and case findings are taken up by the reader is an essential part of the research process. A deeper discussion about my experience engaging in reflexivity throughout the research process, and its connection with ethical research practice, is presented in both chapter seven and chapter eight.

4.3 Methodological Decisions: Why Case Study?

In order to determine which methodology would be the best fit to meet the research objectives, several methodologies were explored and considered. Originally, I debated between using various methodologies. I envisioned employing a methodology that could: attend to the complexity of each individual child, allowing for in-depth exploration of the dynamics between occupations and identities; attend to the contextuality from which identities are shaped, with particular attention to the social and

cultural dimensions; incorporate multiple perspectives, particularly the children's, parents', and integration of my own reflexivity; incorporate multiple methods, including interviews, photographs, and the creation of a fun representation such as a comic strip; be appropriate for new areas of research and contribute to emerging conceptualizations and theory about occupation and identity for children with physical disabilities; be used from a constructivist-constructionist perspective, along side my theoretical lenses (socio-cultural lens and critical disability lens); and that could translate into something practical and useful for not only occupational scientists, but also occupational therapists and perhaps other health care and education professionals. After careful consideration it became clear that case study methodology was a methodology that could meet those aims. In particular instrumental case study methodology within a broader collective case study (Stake, 1995, 2006), was chosen to investigate these phenomena. The remainder of this chapter details the background of case study methodology and collective/cross-case analysis adopted for this study, and a detailed rationale for its use.

4.4 Case Study Methodology

4.4.1 Background

Many scholars take up case study in different ways. In light of my constructivist-constructionist underpinnings, I focus more on work that aligns with this philosophical position. Stake (2000) refers to himself as a constructivist, and acknowledges that: a) knowledge is socially constructed and b) the role of the case study researcher is to “assist readers in the construction of knowledge” (p. 442). Although I would identify myself as

more of a constructionist than Stake, I tend to draw upon his work more than other scholars, as it is more closely aligned with my paradigmatic position in comparison to others who appear to have a tendency to use case study methodology from a more post-positivist perspective (Merriam, 2009; Yin, 2009). Case study research has variously been described as a strategy of inquiry, a bounded system, a unit of study, a research approach or strategy, and as a methodology (Creswell, 2007; Merriam, 2009; Stake 1995; Yin, 2009). I choose to view case study as an overarching methodology.

Case study research has been taken up by both quantitative and qualitative researchers, and has been commonly used in sociology, anthropology, psychology, education, nursing, social work, political science, business, economics, and organizational studies (Creswell, 2007; Merriam, 2009; Stake, 2000; Willis, 2007; Yin, 2009). Qualitative case study methodology uses an inductive approach to seek meaning, understanding, and rich, holistic, descriptive data about a particular phenomenon(a) (Merriam, 2009). Focusing on a case allows the researcher to determine the interaction of significant factors representing the phenomenon studied (Merriam). As Baxter and Jack (2008) highlight, case study methodology allows for the

exploration of a phenomenon within its context using a variety of data sources.

This ensures that the issue is not explored through one lens, but rather a variety of lenses which allows for multiple facets of the phenomenon to be revealed and understood. (p. 544)

The capacity of case study to explore phenomena through different lenses is an important consideration in choosing it for this research, which seeks to explore occupation and identity from multiple perspectives: child's perspective, parent's perspective, socio-

cultural perspective, disability perspective and an acknowledgement of my own reflexive occupational perspective.

Stake (1995) draws upon “naturalistic, holistic, ethnographic, phenomenological and biographic research methods” (p. xi) in the conceptualization of case study from his perspective. Stake (1995) defines case study as “the study of the particularity and complexity of a single case, coming to understand its activity within important circumstances” (p. xi). In Stake’s opinion, the qualitative case researcher seeks to highlight nuances, sequentiality of happenings, and the wholeness of the individual in context.

Merriam (2009) defines case study as “an in-depth description and analysis of a bounded system” (p. 40). Merriam (1998; 2009) further defines and characterizes qualitative case study research as particularistic (focus on a particular phenomenon), descriptive (rich, *thick*, holistic description of the phenomenon) and heuristic (illuminates the reader’s understanding of the phenomenon, bringing about discovery of new meaning, extending the reader’s experience, and/or confirming what is know about the phenomenon under study). In Merriam’s opinion, case study is employed to gain in-depth understanding of the phenomena and meaning for those involved. It is suited for research interested in process, context, and discovery.

Lastly, Yin (2009) defines case study as an empirical inquiry that “investigates a contemporary phenomenon in depth and within its real-life context” (p. 18), relying on multiple data sources and theoretical propositions to guide the research process.

4.4.2 When is it Appropriate to use Case Study?

Yin (2009) asserts that case study methodology is particularly appropriate when it is not possible to isolate the phenomenon's variables from their context. Creswell (2007) contends that case study is a methodology used to explore:

a bounded system (a *case*) or multiple bounded systems (cases) over time, through detailed, in-depth data collection involving *multiple sources of information* (e.g., observations, interviews, audiovisual material, and documents and reports), and reports a case *description* and case-based themes. (p. 73).

Case study methodology is particularly advantageous when asking “how” and “why” research questions, when exploring contemporary phenomena where behaviours cannot be manipulated (i.e. identity), when interested in contextual conditions relevant to the phenomena under study (i.e. the socio-cultural dimensions) and when the boundaries between the phenomena and context are not distinct (i.e. boundaries between identity, occupation, and socio-cultural dimensions that influence both identity and occupation) (Yin, 2009).

4.4.3 The Case

A case is an intrinsically bounded system, “a single entity, a unit around which there are boundaries” (Merriam, 2009, p. 40). Miles and Huberman (1994) define the case as “a phenomenon of some sort occurring in a bounded context” (p. 25). A case can be a single person, process(es), program, group, institution, community, event, or policy exemplifying a particular phenomenon (Merriam, 2009; Stake, 1995, 2000; Yin, 2009). Cases can be bound by time and place (Creswell, 2003), time and activity (Stake 1995),

and/or definition and context (Miles & Huberman, 1994). In this study, each case is bound by time, place, context, and definition (inclusion and exclusion criteria).

4.4.4 Types of Case Studies

Different types of case studies are described by many scholars. Bogdan and Biklen (2007) discuss historical organizational case studies, observational case studies, and life histories. Yin (2009) describes holistic (involves one unit of analysis) and embedded (involves more than one unit of analysis) case studies. Stake (1995), who I have aligned more closely with when choosing my case study design, describes three different types of case studies: intrinsic, instrumental, and collective.

An intrinsic case study, defined by Stake (1995, 2000), is employed when the researcher is interested in obtaining a deep level of understanding about one particular case; the case itself is the focus of interest. On the other hand, an instrumental case study (Stake, 1995, 2000) is employed when the researcher is interested in obtaining a deep level of understanding about a phenomenon(a), abstract construct, trait or problem. The case provides a medium to facilitate this understanding and the purpose is to advance understanding of the external interest, perhaps contributing to theory about this external interest. Collective case study (Stake, 1995, 2000) involves a compilation of instrumental case studies, similar and/or dissimilar, studied together to “lead to better understanding, perhaps better theorizing, about a still larger collection of cases” (Stake, 2000, p. 437). For this study I have chosen to conduct a collective case study, comprised of a diverse collection of instrumental case studies to examine how occupations are implicated in the

shaping of identities, and how socio-cultural factors shape opportunities to engage in childhood occupations.

4.4.5 A Collective Case Study

As previously mentioned, instrumental case studies are concerned about an external interest, in this case about occupations, identities, participation, and how socio-cultural factors shape the aforementioned. Considering that theories of occupational identity (Kielhofner, 2008; Unruh, 2004), and occupation *as* identity (Christiansen, 1999), are in the early stages of development within the study of occupation, I have chosen to examine a collection of cases that are both similar and dissimilar. This is consistent with Stake's (1995) recommendation to prioritize balance, variety, redundancy, and above all cases that provide the opportunity to learn about the phenomenon(a) of interest. Further, Merriam (2009) contends "the more cases included in a study, and the greater variation across the cases, the more compelling an interpretation is likely to be" (p. 49). With these guidelines in mind I sought to recruit children and parents purposefully, looking for children with a broad range of physical disabilities, male or female, aged 8-12, with a wide range of support needs (i.e. educational assistants, fully integrated in classroom, special education classroom, etc.), and living in both rural and urban communities.

4.4.6 Critiques and Misunderstandings about Case Study Methodology

A few of the major critiques of case study methodology include: the inability to generalize the findings; the suitability for pilot-studies not full research projects; and the emphasis on the researcher's own interpretations of the case (Flyvbjerg, 2006; Merriam, 2009; Thomas, 2011; Yin, 2009). Such critiques are common to most if not all qualitative research methodologies. I do not see these as limitations as long as the researcher takes measures to make realistic claims based on the findings (ie. not over stating the generalizability of the work), and is reflexive about the level of engagement, preconceived assumptions, and location of the researcher. Stake (1995) contends, "the real business of case study is particularization, not generalization" (p.8). Like Flyvbjerg (2006), I too contend that a comprehensive cases study attending to the particularities and complexities of a phenomenon offers generative possibilities beyond expectations of a pilot-study, in and of itself contributing to knowledge.

Flyvbjerg (2006) has written extensively about the *Five Misunderstandings about Case Study Research*. This work is important as it makes explicit the critiques of case study as a methodology as well as provides support for its use. Further, it is seminal work in case study research. The following table (Table 2) summarizes the five misunderstandings about case study methodology identified by Flyvbjerg (2006).

Table 2: Five Misunderstandings of Case Study Research (Adapted from Flyvbjerg, 2006 and Merriam, 2009)

Misunderstanding	Argument
1 General, theoretical (context-independent) knowledge is more valuable than concrete, practical (context-dependent) knowledge.	It is not possible to generate predictive theories and universals in the study of human affairs. This renders context-dependent knowledge more valuable.
2 One cannot generalize on the basis of an individual case; therefore, the case study cannot contribute to scientific development.	Formal generalization is overvalued as a source of scientific development, and the “force of example” is underestimated.
3 The case study is most useful for generating hypotheses; that is, in the first stage of a total research process, whereas other methods are more suitable for hypotheses testing and theory building.	The case study is useful for generating and testing hypotheses, as this misunderstanding is nullified based upon the previous argument. The utility of case study is not limited to these research activities alone and is dependent on a strategic selection of cases.

Misunderstanding	Argument
4 A case study contains a bias toward verification, that is, a tendency to confirm the researcher's preconceived notions.	Case study methodology contains no more bias toward verification of preconceived notions than any other qualitative methodology. Flvbjerg argues that in some cases the methodology acts to falsify preconceived notions (Cambell, 1975; Geertz, 1995; Ragin, 1992 as cited in Fyvbjerg, 2006).
5 It is often difficult to summarize and develop general propositions and theories on the basis of specific case studies.	Often it is not desirable to summarize and generalize case studies. Good studies should be read as narratives in their entirety.

Guba and Lincoln (1981) caution that “case studies can oversimplify or exaggerate a situation leading the reader to erroneous conclusions about the actual state of affairs” (p. 377). They also raise this as an ethical issue; an unethical researcher may choose to present the findings in any way they desire. One way I have attempted to attend to this caution is by utilizing reflexivity throughout the research process in order to become aware of and minimize any tendency to oversimplify or exaggerate the findings. Selecting and remaining true to appropriate quality criteria (discussed further in chapter eight) also assists in ensuring the quality of the research.

4.4.7 Strengths of Case Study Methodology

4.4.7.1 Attending to the Uniqueness of Human Experience

Case studies attend to the unique attributes of human experience, ensuring that the whole of the person is attended to, versus only the common attributes (Merriam, 2009; Stake, 1995). Even in collective case studies, each case is analyzed individually attending to common and particular details, followed by a cross-case analysis that not only acknowledges common themes, but also unique experiences (Stake, 2006). Willis (2007) contends that the primary advantages of case study research include: 1) the ability to collect rich data in context; 2) it is a holistic approach—which “supports the idea that much of what we can know about human behaviour is best understood as lived experience in the social context” (p. 240) and; 3) it can be employed without predetermined hypotheses and goals.

4.4.7.2 Application to Practice

Merriam (1998; 2009) suggests that the particularistic nature of case study research is particularly advantageous when seeking to examine questions, situations, processes or occurrences stemming from everyday practice. Merriam also suggests that case study research can enhance understanding of practice, which may lead to improvements in practice and/or informing policy. Many professional practice fields use cases as exemplars and teaching tools, including health professionals (Merriam, 2009; Stake, 2000). In my opinion, this can be seen as a strength and benefit to both occupational therapists and occupational scientists, as case study research may have practical implications for practice and education in both fields. In addition, these practical implications are important for advancing knowledge, practice, and potentially contributing to policy development initiatives in the future.

4.4.7.3 Advancing Knowledge in the Field

Some scholars suggest that case study research is particularly advantageous in areas where there has been little research, for case studies begin to offer insights and new meanings that confirm and build upon existing knowledge and theories (Merriam, 2009; Stake 1995; Yin, 2009). These new insights can be further developed to design and structure future research questions, advancing knowledge a particular field (Merriam, 2009). Given that occupational science is an emerging discipline (Clark, 2006; Hocking, 2000; Molineux & Whiteford, 2006; Molke, Laliberte-Rudman, & Polatajko, 2004; Rudman, et al., 2008; Whiteford & Hocking, 2012; Wilcock, 2003; Yerxa, 2000), in comparison to other social science disciplines that have been building knowledge for centuries, case study methodologies may prove to be beneficial for advancing knowledge

while attending to the complexities and particularities of occupation in context. Kuhn (1987) contends that in order for a discipline to be rendered effective, it must have a significant number of high quality case studies and systematic exemplars. If occupational science is interested in the study of human occupation, the complexity and particularity of what and how people *do* should be just as important as occupation in the general sense. This attention to complexity and particularity could potentially set occupational science apart from other social science disciplines that also study what people *do*. Flyvbjerg (2006) argues that “in the study of human affairs, there appears to exist only context-dependent knowledge, which, thus, presently rules out the possibility of epistemic theoretical construction” (p. 221). Flyvbjerg questions the notion of context-independent, predictive theory generation, as he contends social science disciplines have yet to be successful in that regard. When thinking about the dynamic nature of both occupation and identity formation for example, I would also question the feasibility of context-independent, predictive theory generation, and contend that context-dependent knowledge may be more generative in this regard.

4.5 Case Study as a Methodology to Study Occupation

From an occupational perspective, as an occupational scientist I am concerned about what people *do*, not just generally speaking, but particularly attentive to the complexity and particularity of *being, doing, belonging, and becoming* (Hammell, 2004; Rebeiro, Day, Semeniuk, O’Brien, & Wilson, 2001; Wilcock, 1999) both individually and socially. Given that case study methodology is designed to attend to the complexity and particularity of phenomenon, situated in a particular social context (Flyvbjerg, 2006;

Stake, 1995, 2000, 2006; Thomas, 2011) this methodology appears to be a good fit to study the nature of occupation, and furthermore occupation and the complex dynamics of identity in context.

Historically, case study methodology has been used by occupational science researchers in search of descriptive means to study dimensions of occupation (Pierce et al., 2010). Case study research is appropriate when the aim is to examine phenomena and context attending to real life experiences and situations (Salminen, Harra, & Lautamo, 2006; Stake, 1995; Yin, 2009). Salminen, Harra, and Lautamo (2006) call for more extensive use of case study methodology by occupational therapists, advocating that this research can be used to understand and develop professional practice while remaining true to the basic principles of occupational therapy. Salminen et al assert that

occupational therapy is interested in the person in their own living environment, and aims to achieve a good overall understanding of the person while also being interested in particulars, to take several viewpoints into account, and to value the subjectivity and experience of the client. (p. 7)

One could argue that the same could be said for the interests of occupational scientists. In recent years, a growing number of research papers in occupational science and occupational therapy have been published using case study methodology (Cutchin 1997, 2003; Harding et al., 2009; Shank & Cutchin, 2010; Kinsella, Bossers, & Ferreira, 2008; Lauckner, Krupa, & Paterson, 2011; Lauckner, Paterson, & Krupa, 2012; Segal & Hinojosa, 2006) demonstrating its merit as a promising methodology in the field.

4.6 Summary of Rationale

In light of the above discussion, the rationale for the decision to utilize case study methodology in this study is summarized below:

- Case study is an appropriate methodology of choice when investigating phenomena in its early stages of development and conceptualization (Stake, 1995; Yin, 2009). The construct of occupational identity (and relationship between occupation and identity) is in the early stages of development. No systematic research to date has explored this construct in relation to children.
- Case study allows the researcher to attend to social dimensions (Stake, 1995) of phenomena in a real-life context. Case study:

offers a means of investigating complex social units consisting of multiple variables of potential importance in understanding the phenomenon.

Anchored in real-life situations, the case study results in a rich and holistic account of the phenomenon. It offers insights and illuminates meanings that expand its readers' experiences. (Merriam, 2009, p. 50-51)

This research seeks to explore occupation and identity from a socio-cultural perspective, with particular attention to the social dimensions that influence participation in occupation in real life contexts.

- Case study allows the researcher to delve deeper into the complexities and particularities of phenomena (Stake, 1995, 2000), in this case, identity and the social context, both at the individual level (case-by-case) and broader social level (across cases). "Case studies often contain a substantial element of narrative.

Good narratives typically approach the complexities and contradictions of real life” (Flyvbjerg, 2006, p. 237).

4.7 Part 1: Summary

Case study methodology “offers a means of investigating complex social units consisting of multiple variables of potential importance in understanding the phenomenon” (Merriam, 2009, p. 50). For this reason, in addition to the strengths and benefits discussed previously in this chapter, I contend that case study is suitable for examining the complexities of occupation, identity, and socio-cultural context, with children with a variety of physical disabilities. In using case study as the methodology of choice for this study, my objectives are to: (1) begin to develop an understanding that contributes to existing theories and further conceptualizes the process by which occupation shapes the construction of identity in school-aged children with physical disabilities by attending to the complexities of six individual case studies, and (2) in the future, use these case studies to formulate a practical resource guide for occupational therapists, other health care professionals working in therapeutic contexts, and families with children with disabilities. It is important to note, that in no way do I intend to claim that the following six cases represent the experiences of all children with physical disabilities, however it is my strong contention that their experiences offer important insight into developing theories in occupational science and occupational therapy literature.

Part 2: Methods

4.8 Application to My Research Study

To review, the purpose of this research is to examine how occupations are implicated in the shaping of identity in children with disabilities, with particular attention to the socio-cultural factors that shape children's engagement in childhood occupations. The aim is to begin to develop an understanding of how occupations contribute to the shaping of identity in children with disabilities, with particular attention to the social and cultural factors that shape children's participation in childhood occupations. According to Stake's (1995) case study methodology, "issues" provide the conceptual structure for the case study at hand. Issue questions are the primary research questions used to organize the case(s). From this perspective, it is imperative that the researcher begin with issue questions in order to hone in on the complexity and contextuality of each case in light of the phenomena one wishes to examine. In particular, for instrumental case studies, Stake suggests that the identified issues (issue questions or statements) remain dominant throughout the research process, and the researcher should begin and end each case focusing their attention on such issues. Stake (1995) contends that "issues are not simple and clear, but intricately wired to political, social, historical, and especially personal contexts. All these meanings are important in studying cases" (p. 17). The following research (issue) questions informed this collective instrumental case study: (1) How is identity shaped through participation in everyday occupations in the lives of children with disabilities?, (2) How are socio-cultural factors implicated in children with disabilities' opportunities to engage in childhood occupations? and (3) How might a socio-cultural

perspective reveal aspects of occupation and identity that are shaped by the dialectic between individual and social dimensions?

4.9 Participant Recruitment

Recruitment for this study was conducted in partnership with a children's rehabilitation centre. This study received approval from institutional research ethics boards at both the University of Western Ontario (see Appendix A) and the children's rehabilitation centre (see Appendix B). Children and their parent(s) or guardian(s) were recruited through flyers (see Appendix C), word of mouth from members of the children centre team, and with the assistance of a gatekeeper. The gatekeeper recruited and screened potential participants from the children's centre. The contact information was passed on to Shanon Phelan upon permission of the parent if they expressed interest in participating. The sample was purposefully selected (Creswell, 2007) from the children centre's catchment area (including urban and rural areas) and consisted of two stakeholder groups: 1) children with physical disabilities, and 2) their parent(s)/guardian(s). A combination of maximum variation strategy (Creswell, 2007; Merriam, 2009) and information-oriented selection (Flyvbjerg, 2006) was used. Information-oriented selection was chosen "to maximize the utility of information from small samples and single cases. Cases are selected on the basis of expectations about their information content" (Flyvbjerg, 2006, p. 230). Maximum variation in cases was sought to garner rich data about the significance of various experiences.

4.9.1 Participants

Recruitment took place over a 14-month period. A total of 11 participants were involved in this study, six children and five parents. Refer to Table 3 for an overview of the participant profiles. The following inclusion and exclusion criteria were determined in partnership with the children's centre research ethics board.

4.9.1.1 Child Participants

The inclusion criteria for the child participants were: (a) age 8-12; (b) male or female; (c) born with a physical disability; (c) sufficient English language fluency and cognitive ability to participate in the interview process and complete sorting and categorizing activities and (d) living in the community with one or more parent/guardian at the time of study. Exclusion criteria consisted of dual diagnosis affecting cognition, diagnosis of a progressive disorder, and hospitalization at the time of study. This was to ensure that the participants were able to comprehend and respond sufficiently to the interview questions. In addition, it was hypothesized that the additional layer of a secondary diagnosis affecting cognition may contribute to the construction of identity, socio-cultural dimensions of identity and participation, and opportunities to participate in occupations in a significantly different way. It was also hypothesized that having a progressive disorder (ex. Muscular Dystrophy) may potentially lead to different occupational experiences while being able to make comparisons between different stages in one's life. In addition, hospitalization was excluded to ensure that the children were able to participate in their daily occupations and take pictures of their daily occupations at the time of study.

Table 3: Participant Profiles

Parent (Mothers)	Parent Age	Child	Child Age	Child Gender	Siblings	Diagnosis	EA Support	Community
Elaine*	45	Sarah*	11.5	F	1 (twin sister)	Cerebral Palsy	Yes	Urban
Elaine*	45	Laura*	11.5	F	1 (twin sister)	Cerebral Palsy	Yes	Urban
Sandra	59	Teresa	10	F	4 (2 brothers, 2 sisters)	Spina Bifida	No	Rural
Leslie (Adoptive Mother)	49	Elissa	12	F	3 (brother, 2 sisters) (+2 from biological mother)	Spina Bifida	Yes	Rural
Judith	41	Beth	10	F	1 (sister)	Cerebral Palsy	Yes	Rural
Simah	41	Amar	10	M	3 (sister, two brothers)	Hypoplastic left heart (and CVA 13 days after birth)	Yes	Urban

Key: *Elaine is the mother of both Sarah and Laura (twins)

4.9.1.2 Parent(s)/Guardian(s) Participants

The inclusion criteria for the parent participants were: (a) primary caregiver(s), (b) sufficient language fluency and cognitive ability to participate in the interview process, and (c) one or both primary caregivers available to participate in the interview process.

4.10 Data Collection

“There is no particular moment when data gathering begins. It begins before there is commitment to do the study: backgrounding, acquaintance with other cases, first impressions” (Stake, 1995, p. 49).

As Stake (1995) poignantly describes, data collection begins long before contemplating the study design. In the tradition of reflexive research, I believe data collection began with my first experiences as a child and in practice as an occupational therapist (refer to chapter one). I recognize that I bring these experiences with me in both data collection and analysis.

Formally, for this study, data collection was conducted in two phases (described in more detail below) and consisted of elicitation of both child and parent perspectives. Case study methodology traditionally employs multiple data sources (Merriam, 2009; Patton, 1990; Stake 1995, 2006; Yin, 2009). Data sources for this study included: results of the Pediatric Activity Cards Sort assessment (Mandich, Polatajko, Miller & Baum, 2004), photoelicitation interviews (Dell Clark, 1999; Harper, 2002; Prosser & Burke, 2008) with the children, semi-structured interviews with both children and parents,

photographs taken by the children, comic strips created by the children, photograph logs completed by the children if applicable, and reflexive field notes and observations taken by the researcher.

All interviews were audio recorded and transcribed verbatim. Two children (Beth and Amar) had physical disabilities that affected their verbal communication. For this reason, additional permission from the ethics review board was sought to video record sessions with these children to aid in transcription. Beth did not use an augmentative communication device. Amar used two augmentative communication devices at school (not at home). One was a Vantage communication device and the other was a communication book with pictures. For the first two sessions completed with Amar, neither devices were available as the devices remained at school for the summer holidays. The third session with Amar was conducted at the beginning of the school year, therefore I requested to use the devices during the session. The devices were tried, but with limited interest from Amar, therefore abandoned in the session. I continued to use the same strategies to communicate, with the help of Amar's family members for translation purposes. In addition, I completed reflexive field notes (audio recorded and written) after each session, recording observations and personal reflections. These notes were also included as data.

A detailed description of the data collection and methods is described below. In chapter five an in-depth discussion of the photoelicitation method is presented as well as practical considerations for using this method, and corresponding ethical considerations.

4.10.1 Phase One: Children's Perspectives

Three sessions were conducted with each child. All sessions were completed in the child's home environment. Stake (1995) recommends when a case is a person, the home and family are usually important contexts to observe. Interviews conducted in the home provided the opportunity to observe the child's participation in daily occupations, interactions with others in familiar environments, and to gain a better understanding of the participant's contexts and resources. In particular, the social context, cultural context, and physical context were deemed important to consider.

4.10.1.1 Session One

First, informed consent was obtained from the parent(s)/guardian(s), and assent was obtained from the child participant. The details of the study were discussed with both the parents and the children during the first session. At this point letters of information were provided (refer to Appendix D) and signed consent was obtained from the parent (for his/her own participation, and on behalf of the child for his/her participation) (refer to Appendix E). Assent forms were reviewed with the child and written assent was obtained from the child (refer to Appendix F). During this process I encouraged both parents and children to ask any questions they might have and clearly explained that participation is voluntary, outlined confidentiality and privacy procedures, and reiterated that they may withdraw from the study at any time. It was my primary concern to ensure that the child understood that under no circumstances will anyone be mad if she/he chose not to participate at any time. Copies of the letter of information, consent and assent were provided for participants to keep for their records.

Refer to Appendix G for the session one interview guide. Occupational profiles were obtained by using the Pediatric Activity Card Sort (PACS). The PACS is an occupation based, child-centered tool that uses photographs to identify: a) occupations that the child is currently participating in and b) occupations that the child wants to do, needs to do, or is expected to do (Mandich, Polatajko, Miller & Baum, 2004). It is also used as a research tool to highlight patterns in occupational participation (Mandich et al, 2004). The PACS was used to get a sense of the occupations children participated in, to introduce children to the idea of using photographs, and to build rapport.

Children were given digital cameras to take photographs of their daily occupations over a two-week period. A camera orientation session was conducted with parent and child to explain the details of the camera use and consent procedures. Children were asked to take approximately 30 photographs of the daily activities that represent “who you are”. Photograph log books were provided to record details about the photographs, but were considered optional. The following questions were provided in the log book to be used as a guide, however children were encouraged to write freely: Why is this activity/picture important?, Who took this picture?, Why did I choose to take this picture?, What is happening in this picture?, Who do I do this activity with?, Who helps me with this activity?, Where do I do this activity?, When do I do this activity?, What do I like/dislike about this activity?, and What would I feel like if I couldn't do this activity?

The researchers acknowledged that depending on the nature of the child's disability, it may be difficult for them to operate a camera and/or take pictures by themselves. For this reason, the researchers provided the option for an adult to take the

picture with the child as long as the child directs the process and confirms the picture on the camera viewer.

The child participant (photographer) and parent were also provided letters of information, consent, and assent forms to hand out to anyone that may appear in a photograph, in a marked folder with instructions. They were instructed to invite the person to be photographed to review the letter of information and decide whether or not they would like to participate in the study (be photographed). Pictures were to only be taken with the person's signed consent. If the photographer would like to take a picture of a minor, consent was to be obtained by a parent/guardian first, followed by assent obtained by the child. It was explained that at this time both the parent of the participant and the child appearing in the photograph must be present. The parent of the participant was responsible for obtaining consent from the parent of the child appearing in the photograph. All forms were provided in advance, and are attached in appendices H, I, and J. Copies of the letter of information, consent and/or assent were provided for participants to keep for their records.

4.10.1.2 Session Two

The cameras were collected after the two-week period, and the photographs were developed and used in photoelicitation interviews (Dell Clark, 1999; Harper, 2002; Prosser & Burke, 2008). Refer to Appendix K for a copy of the session two photoelicitation interview guide. Photographs were then used to develop occupational portraits, a compilation of photographs using the *Comic Life* (Version 1.5.4) software program. As Prosser and Burke (2008) contend, "words are the domain of adult researchers and therefore can be disempowering to the young. Images and their mode of

production, on the other hand, are central to children's culture from a very early age and therefore empowering" (p. 407). For this reason, photoelicitation interviews (PEI) were used as a method within case study methodology to examine occupation and identity from a child's perspective. Photoelicitation is a useful tool for studying identity as it "offers participants an opportunity to 'show' rather than 'tell' aspects of their identity that may have otherwise remained hidden" (Croghan, Griffin, Hunter, & Phoenix, 2008, p. 1). See chapter five for a comprehensive discussion about the photoelicitation method.

4.10.1.3 Session Three

Semi-structured interviews were conducted with each child to further probe aspects of their occupations and identities. Refer to Appendix L for a copy of the session three semi-structured interview guide. The occupational portrait developed in session two was used to facilitate in depth probing of the child's participation in specific occupations, with a particular focus on descriptions of how such participation might shape identity.

4.10.2 Phase Two: Parent(s)' Perspectives

Semi-structured interviews were conducted with the primary caregiver of each child participant (in this study all of the mothers elected to participate). Drawing on a socio-cultural perspective, these interviews were designed to elicit data regarding the social and cultural dimensions that may contribute to participation in occupation and the shaping of children's identities. Refer to Appendix M for a copy of the semi-structured interview guide used to elicit parents' perspectives.

4.11 Data Analysis

In-depth data analysis was conducted for each case (Stake, 1995), followed by a cross-case analysis (Stake, 2006; Yin, 2009). Data analyzed for each case included: results of the PACS, transcribed photoelicitation interviews with the children, transcribed semi-structured interviews with both children and parents, photographs taken by the children, comic strips created by the children, photograph logs if applicable, and reflexive field notes and observations recorded by the researcher. In total 18 interviews (619 pages of transcribed data), 6 PACS assessments, 3 hand-written photograph logs, 176 photographs, and 6 occupational portraits (comic strips) were considered. Baxter and Jack (2008) caution researchers about the danger of analyzing data sources independently. In case study analysis, data from multiple sources are converged in the analysis process as opposed to being handled individually. Data are converged in an attempt to understand the case as a whole—not as various parts or contributing factors that influence the case. For example, the photographic data was not analyzed on its own, but rather was considered alongside the PACS and interview data. This strengthens the findings as “the various strands of data are braided together to promote a greater understanding of the case” (Baxter & Jack, 2008, p. 554). Case study methodology can adopt various types of analysis techniques (Merriam 1998, 2009). Merriam suggests that one could combine grounded theory techniques within case study methodology, analyze the data from critical perspectives, and present a person’s story within the case study. Data can be used to develop conceptual categories or to illustrate, support or challenge theoretical assumptions which may lead to contributions to developing substantive theories or integrated frameworks (Merriam, 2009). It is common for researchers to draw

on grounded theory analysis techniques when employing case study methodology (Cutchin 1997, 2003; Shank & Cutchin, 2010; Lauckner, Krupa, & Paterson, 2011; Lauckner, Paterson, & Krupa, 2012).

Data analysis for this study was informed by grounded theory techniques (Charmaz, 2006; Straus, 1987) and concept maps (Daley, 2004; Kinsella, Bossers, & Ferreira, 2008) were used to visually represent emerging core categories and sub categories. Specifically, Charmaz's (2006) approach to analysis was selected to remain consistent with Stake's paradigmatic position, as well as my own paradigmatic position. Charmaz's (2006, 2008) approach to analysis is rooted in a constructivist, and at times a constructionist, paradigm. Charmaz (2006) states:

I assume that neither data nor theories are discovered. Rather, we are part of the world we study and the data we collect. We *construct* our grounded theories through our past and present involvements and interactions with people, perspectives, and research practices. (p. 10)

Charmaz (2006) emphasizes the importance of recognizing that any theorizing “offers an *interpretive* portrayal of the studied world, not an exact picture of it” (p. 10). In recent work, Charmaz (2008) explicates her constructionist assumptions:

1. Reality is multiple, processual, and constructed—but constructed under particular conditions.
2. The research process emerges from interaction.
3. The research takes into account the researcher's positionality, as well as that of the research participants.

4. The researcher and researched co-construct the data—data are a product of the research process, not simply observed objects of it. (p. 402)

Charmaz (2008) asserts that a social constructionist approach to data analysis strengthens the method by focusing its attention on context, action, and interpretation during analysis. For these reasons, I have chosen to adopt Charmaz's (2006) approach to analysis as it is aligned with both my philosophical location and theoretical perspectives, and it also coincides with Stake's (1995) approach to case study (Lauckner, Paterson, & Krupa, 2012).

Concept maps (Daley, 2004) are visual depictions of emerging constructs for consideration. Concept maps were used as a strategy to analyze categories, visually represent the interconnections between categories (Daley, 2004), and to compare and contrast cases (Kinsella, Bossers, & Ferreira, 2008). See Appendix N as an example. Daley (2004) contends that using concept maps allows the researcher to forefront the meaning of the interview within the data analysis due to the interconnections displayed in each map. Daley also cautions that the complexity of the maps may lead to difficulty: reading the map, determining what concepts are of critical importance or secondary importance, and seeing all of the connections as a whole. She recommends using other data analysis strategies with concept maps. In light of these cautions, concept maps and grounded theory techniques were used together.

4.11.1 Stage One: Individual Case Analysis

In line with both case study and grounded theory traditions, data collection and analysis occurred simultaneously (Baxter & Jack, 2008; Charmaz, 2006; Stake 1995, 2006). The coding of data was completed in three phases:

4.11.1.1 Phase One: Initial Coding

Line-by-line coding involved naming each line of the written data. This approach encourages the researcher to remain open to the data and to detect subtle nuances (Charmaz, 2006). In this phase the researcher looks for tacit assumptions, implicit actions and meanings, compares data with data, and begins to identify gaps in the data (Charmaz, 2006). In vivo codes (specialized terms used by participants) (Charmaz, 2006) were used when possible. This assisted in preserving the meaning participants attributed to their actions and processes.

4.11.1.2 Phase Two: Focused Coding

Coding during this phase was directed, selective and conceptual (Charmaz, 2006). Focused coding begins to synthesize larger amounts of data: “Focused coding requires decisions about which initial codes make the most analytic sense to categorize your data incisively and completely” (Charmaz, 2006, p. 58). It is during this phase that categories and sub categories begin to emerge. These categories and sub-categories were visually represented on concept maps, one for the child’s perspective and one for the parent’s perspective, for each individual case.

4.11.1.3 Phase Three: Theoretical Coding

During this phase the researcher looks for possible relationships between categories developed in focused coding (Charmaz, 2006). Charmaz (2006) suggests the

use of theoretical codes “to help you clarify and sharpen your analysis but avoid imposing a forced framework on it with them. It helps to interrogate yourself about whether these theoretical codes interpret all of the data” (p. 66). In this phase, categories and sub categories were collapsed to create broader core categories. These core categories were visually represented on concept maps. The analysis process was iterative, and the researchers elected to use reflexive notes and reflexive dialogue sessions (between student and supervisor) to further analyze and clarify connections, raise questions, share ideas, explore concepts, develop emerging categories, and consider gaps.

4.11.2 Stage Two: Cross-case Analysis

Cross-case analysis “seeks to build abstraction across cases” (Merriam, 2009, p. 195). Concept maps (Daley, 2004; Kinsella, Bossers, & Ferreira, 2008) (12) were analyzed across cases, comparing core categories and sub-categories while keeping the three main research questions in the forefront. Core categories were synthesized to represent findings across cases. Both commonalities and unique features that transcended all cases were considered to best represent the cases and their subtle nuances. All of the data was analyzed again to refine the core categories, and constant comparative analysis techniques (Charmaz, 2006) were used to distinguish relationships between core categories, between core categories and sub-categories, and between sub-categories. This was completed to ensure the final core categories were representative of all cases and conceptualized the data from both child and parent perspectives (Merriam, 2009).

4.12 Conclusion

In this chapter an overview of the methodology and methods of the empirical aspect of the dissertation has been presented. The following chapters will further discuss photoelicitation as a method (chapter five), present the findings as a manuscript (chapter six), discuss reflexivity and ethical considerations (chapter seven), and will conclude with additional insights, implications, and directions for the future (chapter eight).

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5. Photoelicitation Interview Methods and Research with Children: Possibilities, Pitfalls and Ethical Considerations³

5.1 Introduction

This chapter considers the rationale and practical issues in using photoelicitation interviews, in the conduct of research with children. We begin with an overview of photoelicitation and consider its promise as a method when conducting research with children. This is followed by a discussion of: pitfalls and considerations in using photoelicitation methods; confluences between photoelicitation and photovoice; practical examples of current research using photoelicitation interviews; ethical considerations and; practical considerations when conducting visual research with children. The chapter concludes with our perspective that photoelicitation is a promising method as a means to elicit children's voices in research, and that it is best used within a broader methodological framework.

It is interesting to note, as Prosser & Burke (2008) do, that “Words are the domain of adult researchers and therefore can be disempowering to the young. Images and their mode of production, on the other hand, are central to children's culture from a very early age and therefore empowering” (p. 407). Given this insight, the potential of visual

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methods when conducting research with children takes on a practical significance (i.e., gathering meaningful data), as well as a potentially moral one (i.e., overcoming disempowerment).

5.2 What is Photoelicitation?

Photoelicitation is a method of visual data collection used in combination with an interview process. Images or photographs created by participants, researchers, or drawn from the media, are used within interviews to draw out the viewer's response (Harper, 2002; Prosser & Burke, 2008). Photoelicitation interviews (PEI) draw attention to the subjective meaning of images for participants, and provide an entry point for understanding participants' social worlds (Clark-Ibanez, 2004). Participants are often asked to take a sequence of photographs which tell a story about their understanding of social phenomena and draw attention to contextual issues (Harper, 2000). Frohmann (2005) and Harper (2002) point out that photographs taken by participants can also be seen as a window to the self, connecting the self to society, culture and history. Meanings are elicited and constructed through the use of photographs and through dialogue between the researcher and the researched. Thus, PEI is seen as a means of collaborative interpretation about the social phenomena being studied (Evans, 1999).

Historically, photoelicitation has been employed in anthropology, however it is now becoming more common in visual anthropology and visual sociology research (Epstein, Stevens, McKeever, & Baruchel, 2006; Frohmann, 2005; Harper, 2002). It is important to distinguish that photoelicitation is a method rather than a methodology. A research method is a concrete technique or procedure used to gather data, whereas a

methodology is philosophically and theoretically informed, and represents the process of design underpinning the research (Crotty, 2003). While predominantly used as a method within ethnographic methodologies, PEI is also used with action research, narrative inquiry, phenomenology, case study, grounded theory and other methodological approaches.

Using PEI without a methodological framework may be likened to setting sail without a map; methodology links the choice and use of PEI methods to the broader epistemological, philosophical and theoretical assumptions of the research design (Crotty, 2003). The use of PEI methods alone creates the danger of a purely utilitarian and technical focus, whereas the methodology informs indepth and quality research engagement (Jaye, 2002).

5.3 Photoelicitation Interviews in Research with Children

Using photography in research with children may allow researchers to learn more about complex social issues influencing children's lives. Children may find it difficult to express their experiences with abstract social issues verbally. For example, it may be difficult to talk about dimensions of identity such as appearance, style, culture, and gender (Croghan, Griffin, Hunter, & Phoenix, 2008; Hethorn & Kaiser, 1999). The use of photographs allows children to approach the social and cultural dimensions of their experience in different ways, potentially generating rich discussions. Croghan, et al. (2008) point out that PEI are useful for studying identity as it "offers participants an opportunity to 'show' rather than 'tell' aspects of their identity that may have otherwise remained hidden" (p. 1).

Taking a sequence of photographs to represent a visual narrative can also tell a story about a person or phenomenon. Therefore, giving cameras to children may prove empowering to the extent that it offers them the opportunity to create their own narratives and to consider their personal expressions with respect to the phenomenon under investigation (Prosser & Burke, 2008).

PEI not only allow for a unique representation of narratives, but also give participants a chance to become active in the research process, an issue of particular importance in research with children. The assumption of the PEI is that it has the potential to break down power imbalances between the researcher (adult) and the researched (child). Power may be shared with the child through participant-generated photographs, making it possible for the child to have some control over the research process (Dell Clark, 1999; Epstein et al., 2006; Frohmann, 2005). In addition, PEI methods can potentially overcome the limitations of language and memory by offering a visual cue within the interview. This is particularly important when undertaking research with children as limitations in these domains can present significant challenges depending on their developmental stage (Cappello, 2005; Dell Clark, 1999; Epstein et al., 2006).

Photoelicitation has been successfully used with children to tap into their unique perspectives (Burke, 2005; Cappello, 2005; Epstein et al., 2006). In a study conducted by Darbyshire, Macdougall, and Schiller (2005), focus groups, visual maps, and photographs were employed to examine children's perceptions and experiences of place, space, and physical activity. The researchers found that without the use of maps and photographs, important aspects of children's activities would not have been revealed (i.e., the role that

pets play with respect to participation in physical activities). They also contend that flexibility and creativity in data collection methods are essential when undertaking research with children. These researchers stress the importance of engaging in discussions about visual data with children to gain an understanding of the cultural, social, and geographic context. Such dialogue can help researchers to reveal the voice of the child.

5.4 Pitfalls and Considerations of Using PEI in Research with Children

Despite the potential advantages of using PEI with children, it is also important to acknowledge that the approach is subject to unique limitations. For instance, at times this method can be influenced by parents or caregivers (for a variety of reasons) which may reduce the child's control in the research (Barker & Weller, 2003; Clark-Ibanez, 2004). Moreover, the researcher's decision regarding who will take the photographs will also influence the power balance. For example, while Clark-Ibanez (2004) suggests that researcher-produced photographs or images may be useful when conducting theory-driven research, they also reduce the child's influence. On the other hand, in more inductive research, participants can be asked to take their own pictures; these are sometimes known as photoelicitation "autodriven" interviews (Dell Clark, 1999). Ideally this technique enables the child to "drive" the interview process so that the phenomena discussed are relevant to the child and the child maintains a sense of control. So 'who' is taking the pictures, and explication of the rationale for anyone other than the child taking pictures (if the study design calls for the child's perspective) becomes a significant

consideration in photoelicitation research (Burke, 2005; Clark-Ibanez, 2004, Dell Clark, 1999). Such issues may have implications for whether or to what extent the ‘voice’ of the child is present in the work.

The researcher must also be sensitive to children falling into the teacher-student role, where they feel they must be on their best behaviour and provide information that they think the ‘teacher’ wants to hear (Burke, 2005; Cappello, 2005). Therefore the establishment of a relationship that is distinct from the teacher-student relationship, and finding ways to elicit responses from the children that represent their own perspectives is important. For instance, in our current study using PEI with children with disabilities, we have found that the children automatically regarded the researchers as a ‘helper’ (support staff) who would be coming to visit them on a regular basis, just like their care workers who come for respite or range of motion therapy interventions. This situates the researcher in a particular role with a certain amount of authoritative power from the point of view of the child. It also implies that the researcher is there to ‘help’ the child, which may not necessarily be the case. It is therefore important to establish and clarify one’s role as a researcher to ensure that the child knows how the researcher’s presence in his/her life is distinct from that of others. The child should understand that the relationship is a voluntary one, that he or she can choose to participate or withdraw at any time, and that the researcher will only be involved in their lives for a short period of time. This is also where rapport building becomes a key component to the research process, a topic discussed later.

Another potential challenge is that using photoelicitation relies heavily on what can be captured on film. In the context of studying something like identity for example,

this raises questions such as “what parts of identity are not visible” (Harper, 2002, p. 18). Because photographs represent only one moment in time, what is excluded from the pictures and why become important questions for researchers to explore with participants.

A final possible limitation is that what children do is often seasonal in nature; therefore, depictions of the phenomena under investigation may not be truly representative, and seasonal variations will likely influence the data collected. This is an important consideration in the design of the study, and may call for interviews that elicit stories beyond what is seen in the pictures and use of questions about seasonal events being built into the interview guide.

5.5 Conflations: PEI and Photovoice

Photovoice is another visual approach that is becoming more frequently used in qualitative research. This approach is sometimes conflated with PEI, yet there are differences between them that are significant. As discussed above, PEI is a research method that can be used within a variety of methodologies. Photovoice on the other hand is not a method, rather it is usually depicted as a methodological approach within the school of community-based participatory action research (Catalani & Minkler, 2010; Wang & Burris, 1994, 1997). According to Wang and Burris (1997) the three main goals of photovoice are to use photographs: to enable people to record and reflect their community’s strengths and concerns; to promote critical dialogue and knowledge about important community issues through large and small group discussion and; to reach policy makers (p. 370). In photovoice research, participants always take their own

pictures, and these pictures are used as a starting point in the interview or focus group, and to initiate ideas to enact change (Wang & Burris, 1994, 1997).

Like PEI methods, photovoice has evolved since its original emergence as a methodology, and is not a unified field, or a definitive concept; what it entails can be contentious or interpreted differently by different people (Catalani & Minkler, 2010; Prosser & Burke, 2008). In a systematic review of photovoice literature, Catalani and Minkler (2010) found that a large majority of researchers using photovoice drew upon the seminal work of Caroline Wang and her colleagues. Some photovoice projects modify traditional approaches to fit specific research questions and populations; this has resulted in varying levels of participatory involvement (Catalani & Minkler, 2010; Frohmann, 2005; Oliffe & Bottorff, 2007). In most photovoice research projects people are asked to take photographs and discuss them within large or small groups as a means to enact social action and policy change (Catalani & Minkler, 2010; Wang & Burris, 1994, 1997). However, some photovoice research projects, with less of a participatory action focus, have used one-to-one interviews as a method, specifically using photoelicitation techniques (Catalani & Minkler, 2010; Baker & Wang, 2006). Only the more participatory projects encompass all three of the goals of photovoice research originally outlined by Wang and Burris (1997). This can create tensions regarding whether or not a study design is truly representative of photovoice methodology or moving more toward the use of photoelicitation method. So, although depictions of these two approaches are sometimes conflated and contested in the literature, we view photoelicitation as a method that can be used in combination with many methodological approaches and photovoice as a methodology for community based action research.

5.6 Photoelicitation Interviews:

Examples of Research with Children

We are currently working on a case study research project, using photoelicitation interviews as a method to examine identity with children with physical disabilities. We have asked children to take pictures of activities they participate in, and are conducting interviews using the children's pictures to elicit discussion about what they do and to consider the implications for how identities are shaped. In addition a comic software program, Comic Life (Version 1.5.4) is being used to create portraits containing ten of each child's pictures. Using the Comic Life program, the child can add titles, speech bubbles and thought bubbles to their pictures. The combination of the pictures and the child's words are powerful and offer representations of her/his perceptions. In the current study, an interview using the photographs taken by an 11-year-old girl with cerebral palsy, created an opportunity for her to share what was important to her in the moment, as well as at the time the photographs were taken. In addition, discussion of her photographs allowed her to exert some control over the direction of the interview. For example, when asked what she wanted to put in one of the bubbles, she replied "I don't know what to say ... whenever I say it, it sounds stupid". When offered the opportunity to type her comment without saying it out loud, she was able to articulate her thoughts. She was then able to share her thoughts about her disability through discussion about the picture and text, versus talking directly, which she, like many children, finds difficult to do. The photograph, and her words, provided a rich starting point to develop insights into disability and self image, social perceptions of disability and the child's own perceptions of her disability which may not have otherwise been discerned.

A unique advantage to using photographs in interviews is that you may learn something new about the phenomena that may not have come up in general conversation. The pictures themselves and the questions prompted by the pictures can reveal unique aspects relevant to the child's life. For example in our study, we received several pictures pertaining to Halloween, a North American holiday that falls each year on October 31st. In one picture, an 11-year-old child with cerebral palsy is with her carved pumpkin. What is not seen in the picture is the person who helped her carve the pumpkin, or how this might make this activity more meaningful to the child. The picture facilitated a valuable interview question which revealed a relational dimension to this activity; when asked who helped her carve the pumpkin, she excitedly replied “my Dad did!”. Up until that point, the child had not mentioned her Dad, perhaps because her Dad is often at work in the evenings and weekends, and it appears that her Mom is usually home and helps her with a majority of her activities.

Photographs can be used together to tell a story - to depict a participant's narrative. For children this can serve as a window into more discussion about the phenomenon of interest. In our study, children are creating comic strips using their photos and developing a narrative of their everyday activities that are of particular importance to him/her. Interestingly, the comics are not only full of activities that children like, but often include activities that they do not particularly like, such as homework. This observation may not have arisen through conversation alone. In one particular comic, the homework picture was included in the top ten pictures (out of 15) that the child deemed important to tell a story about who she is. In this particular narrative, most of the pictures take place at home or at the place where she rides horses.

Yet, there are many other contexts that she inhabits and many interesting reasons why they do not appear in the pictures. This too is valuable data, in that what is invisible may be just as important, or perhaps even more revealing, than what is. Questions that probe the ‘absences’ in photographs taken by children offer potentially important insights.

5.7 Ethical Considerations in Conducting Visual Research with Children

There are a number of ethical considerations to bear in mind when conducting research using PEI with children. Some of these issues are important with respect to research with children generally (see Mishna et al, 2004), while others arise more particularly when using PEI. Our attention here is with the latter in particular with the issues of disclosure and representation in PEI research.

PEI can be problematic in connection with anticipating potential risks associated with disclosure, pertaining to both the photographs themselves and the actual interview. Mishna et al. (2004) assert that these risks may be more pertinent in research with children. Considering that children may not have the capacity to anticipate the information they may be asked to disclose, they may not understand the potential risks and benefits. Therefore it is important for the researcher to anticipate and explain potential risks and benefits in a way that is meaningful to the child. Creating an environment that is too comfortable may lead to the unintentional disclosure of information (Mishna, et al.).

The issue of representation in photovoice ethics is discussed by Wang and Redwood-Jones (2001). They are concerned that researchers can place participants “in a

false light by images and by words” (p. 566). Researchers, therefore, must be sensitive to how the participants are being represented and the potential implications. It is important to acknowledge that researchers play a role in interpreting and representing the research findings, and that they, therefore, depict their interpretations as only one of the many possible representations. In addition, depending on the context, measures might be undertaken to hide the identity of the child, such as blurring the face or blacking over the eyes, or a decision might be made not to use the photographs but rather to draw on other forms of data in representing the findings.

5.8 Reflections on Engaging Children in the PEI Method

In this section we reflect on practical considerations for engagement in the PEI method, including: flexibility, sensitivity to time demands, attention to developing rapport with the children and the use of digital versus disposable cameras.

5.8.1 Flexibility

We have noted that using the PEI method with children requires a great deal of researcher flexibility, both in the design of the study and within each individual session. It is helpful to design semi-structured interviews to guide the sessions, but to know that the interview will likely take on a life of its own guided by the child’s uses of, and responses to, the photographs. We have found that the best interviews allow the child to shape significantly the interview process and the direction of discussion. We often ask questions in a round-a-bout or creative manner.

Building follow-up interviews into the research design is helpful, as what is planned in one session may have to happen in another, depending on the child's mood, interest and the directions in which stories unfold in response to the photographs. This also allows the child to decide if and when he or she wishes to talk about a certain topic and may prevent unintentional disclosure.

Another reason why flexibility is essential is that asking a child to do something they do not want to do may adversely shape the data. In the moment, a researcher might decide to stick to the original plan to keep things running smoothly, however this may not be beneficial in representing the overall picture. For example, Shanon began to ask a child the first question on the interview guide, "tell me about yourself and the things you like to do". The child responded, "this is stupid". Instead of persisting with the question Shanon skipped the first few questions and immediately began introducing the pictures. The child was waiting to see her pictures, and this completely changed the tone of the interview to more of a positive and fun atmosphere. Shanon was then able to ask some questions while looking at the pictures, and saved some questions for the following session.

5.8.2 Time

PEI method can be time consuming to do properly, so it is important to consider not only the researcher's time within the study, but also the significant time commitment for children and families involved. It is not always easy for parents to create time for children to take pictures and they may forget or encourage children to take all their pictures at the beginning or end of the time period (Dell Clark, 1999). Dell Clark suggests

that researchers acknowledge the time commitment involved and be aware (and accepting) that dynamics within the home, time of year and other family commitments may mean that they are not always able to obtain as many pictures as they might desire. The possibility of time constraints affecting the quality and quantity of visual data is worth considering, and provides an additional reason why it is crucial to ask about the pictures that are missing or the pictures that children may have wished they had taken. All of this provides valuable data.

5.8.3 Rapport Building

Building rapport is particularly important in undertaking the PEI method, thus spending time to get to know the children is central. Knowing and asking them about their interests goes a long way. We have found that children love to talk about what is meaningful to them when they feel comfortable with the person they are talking to. It is also advantageous for researchers to be familiar with popular media so that they can relate to the children's likes and dislikes. Knowing about the latest popular movie or pop-star opens up avenues for conversations and helps to build credibility from the perspective of the child. Building rapport requires flexibility, in the sense that researchers may have to leave behind some of their affinities for structure and order. For example, Shanon was asked to hold a family guinea pig in the middle of her interview session, whether she was comfortable with it or not. It was clear that this was important to the child in that moment, and so she did hold it! Shanon discovered that instead of becoming anxious about the session not going as planned, she could embrace the guinea pig, have

fun with it and take it as an opportunity to develop rapport and thus see into the child's world.

How the researchers present themselves can assist with minimizing power imbalances, for example, the language they use, the clothes they wear, their body language and the nature of their interaction with the child are significant. The context of the interview also can set the tone (Burke, 2005; Epstein et al., 2006). Often data gathering is conducted in the most comfortable and natural environment for the participants, that is, in their homes, however it is also important to consider where in the home the interview should take place. For example, interviews that take place at the kitchen table may appear to be more formal than interviews that take place on the floor in the playroom. The nature of the interview can change dramatically depending on the day of the week, time of day, or what has happened during the day prior to the interview session. For example, an interview on Saturday afternoon may be more engaging than one that takes place Friday evening after a week of school. Nonetheless, some of these considerations are not easily negotiable, especially with busy families.

5.8.4 Digital Cameras versus Disposable Cameras

When designing the research study, a decision needs to be made about what type of camera (digital cameras versus disposable cameras) and the design of camera to be used. Considerations include whether the camera is user friendly for participants and whether the functions meet the research needs (durability, quality, versatility). We have found multiple advantages to using digital cameras over disposable cameras, especially for children with physical disabilities. With a digital camera, there are an almost

unlimited number of pictures that can be taken. Participants receive immediate feedback about the quality of the pictures and can delete pictures that do not turn out, or that do not adequately represent the image they intended. On the other hand, when using a disposable camera, the child does not receive immediate feedback and could easily click a whole roll of pictures without realizing it. Other advantages of the digital camera include the possibility for children to confirm the picture using the LCD screen on the camera if they want to be in the picture (which they often do) or if they are unable to take the picture for accessibility reasons. Digital cameras, however, are more expensive which may create a challenge depending on availability of funding for the research. If considering less expensive cameras, it is important to think about the quality of the images and how the photographs will be used. For example, if prints are to be used in publications or art shows then cameras that produce good quality prints will be necessary. Although the start-up costs are more expensive, digital cameras are reusable and make a good investment for researchers interested in undertaking ongoing research projects using visual methods. Most children are familiar with digital cameras, which may also be an advantage. In addition children are able to obtain a copy of their pictures easily on their home computer. There are also many fun software programs for kids that use digital pictures, for example, the Comic Life software program we mentioned earlier.

5.9 Conclusion

In this chapter we have examined the possibilities, pitfalls, ethical considerations and applications of PEI in the context of working with children. Given Prosser & Burke's (2008) insight that images and their mode of production are empowering to children, the

possibilities of photoelicitation interviews to encourage the 'voice' of children demands attention. Nonetheless, researchers must be cautious about the potential for power imbalances, unintentional disclosure, and issues of representation, with the children involved. We contend that, in the interests of quality research, use of the PEI method on its own is insufficient. Rather this method is most fruitfully used within a well-articulated methodological framework.

5.10 References

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6. Childhood, Identity, and Occupation: Perspectives of Children with Disabilities and their Parents⁴

6.1 Introduction

Occupational Identity (OI) is an emerging construct in occupation-based literature, and can be defined as “a composite sense of who one is and wishes to become as an occupational being generated from one’s history of occupational participation. One’s volition, habituation, and experience as a lived body are all integrated into occupational identity” (Kielhofner, 2008, p. 106). OI is shaped, constructed, and reconstructed by abilities, interests, roles, relationships, routines, and by one’s social, cultural and physical environments (Kielhofner, 2008). Christiansen (2004) argues that it is imperative to construct and continually reshape an identity that not only meets social and cultural values, but also meets one’s personal values, as this can be considered a *fundamental life need*.

⁴ A version of this chapter has been submitted for publication: Phelan, S., & Kinsella, E. A. (Submitted April 20, 2012). Childhood, identity, and occupation: Perspectives of children with disabilities and their parents. *Journal of Occupational Science*.

6.2 Development of Occupational Identity through Childhood

Scholars have acknowledged that childhood is a time when (occupational) identities begin to take shape (Christiansen, 1999; Kielhofner, 2008; Unruh, 2004), yet they do not elaborate to a significant extent on its development through childhood. It has been suggested that (occupational) identity begins to develop as children take on different roles, as a player, male or female, family member, student, friend, and/or group member (Christiansen, 1999; Kielhofner, 2008). Cultural messages pertaining to values, awareness of social approval/disapproval of actions and corresponding social value of participation begin to influence children's occupational choices at a very early age (Christiansen, 1999; Kielhofner, 2008). Unruh (2004) suggests that in childhood, construction of OI is centered on mastery of self-care occupations, and preferred leisure occupations may convey something about who a child is *becoming* (Unruh, 2004). In later childhood, children begin to choose personal projects such as learning to play a musical instrument or joining a team, which according to Kielhofner (2008) contribute significantly to the construction of their OI. He also contends that experiences of failure and success contribute to the child's perception of knowledge, capacity, and self-efficacy.

6.3 Occupation and Identity: Current Research Trends

The majority of existing OI research has focused on the occupational identities of adults and older adults (Howie, Coulter, & Feldman, 2004; Laliberte-Rudman 2002; Lysack & Seipke, 2002; Magnus, 2001; Reynolds, 2003). This has left a significant gap

in terms of advancing knowledge with respect to children and OI, as no research to date has systematically studied how occupation is implicated in the shaping of identity(ies) for children. Advancing both the conceptual frameworks, and research into the relationship between occupation and identity in childhood is a significant area of scholarship that requires further attention in occupational science.

6.4 Individual Perspectives on Identity

Traditionally, there has been an emphasis on researching occupational constructs using individualistic frameworks (Hammell, 2009; Hocking, 2012; Iwama, 2003; Molineux & Whiteford, 2006, Phelan & Kinsella, 2009; Laliberte Rudman & Dennhardt, 2008). Historically, traditional identity theory work, such as that of Erik Erikson, maintains a strong focus on the individual, with the social dimension playing a minor role. Erikson's (1963) work has been widely cited in many fields and is viewed by many as seminal work on identity formation. Erikson asserts that through the relationship between the self and society, identity formation begins in childhood, and proceeds throughout the lifespan. Erikson contends that the individual must successfully negotiate crises that are internal to the "self" at each stage of identity formation. His work reveals a prominent emphasis on the "self", with many references to self-identity, becoming more him/herself, seeking self-consistency, and self-awareness. Erikson's work considers the impact of social worlds on the developing "self", but does not explore broader notions of social or collective identities.

Current conceptualizations of OI appear to have implicitly adopted a similar stance with respect to depictions of the self, highlighting the contributions of self-

efficacy, self-confidence, self-esteem, personal success, personal motivators, personal goals/achievements, and personality traits and how they shape OI (Christiansen, 1999, 2004; Kielhofner, 2008; Unruh, 2004; Unruh, Versnel, & Kerr, 2002).

6.5 Social Perspectives on Identity

Identity theorists drawing on socio-cultural perspectives call for more socially oriented perspectives to study how identities are formed, shaped and reshaped through social experiences (Berger & Luckman, 1966; Gergen, 2000, 2009; Taylor, 1992). Berger and Luckman (1966) contend that identity is socially produced; continuously constructed, shaped, and reshaped through social processes and interactions. They propose a dialectic between the individual and society that constructs and reconstructs identity. For Gergen (1994, 2000) the self exists as a product of relationships. Gergen (2000) notes that in the past “children remained children” (p. 64), as adults were able to shelter them from the complicated private lives of adults. However, with the surge of technological innovations this is no longer possible. This change in the social world inevitably impacts how children’s identities are constructed in today’s society.

6.6 Description of the Research

Taking into consideration that i) there is little research on how occupations are implicated in the formation of identity in children and ii) there is little research on OI from a socio-cultural perspective, the purpose of this research was to undertake exploratory research on this topic. This research adopts a socio-cultural perspective; a perspective that attends to socially, relationally, discursively, and culturally oriented

dimensions of identity formation (Phelan & Kinsella, 2009). Such a perspective recognizes a dialectic between individual and socially oriented dimensions in how identity is shaped. Two main questions inform this research: "How is occupation implicated in the shaping of identity for children with disabilities"? and "How might a socio-cultural perspective reveal aspects of occupation and identity that are shaped by the dialectic between individual and social dimensions?".

6.7 Methodology

Collective case study methodology was used to explore the relationship between occupation and identity with children with disabilities. Collective case study (Stake, 1995, 2000, 2006) involves a compilation of instrumental case studies, similar and/or dissimilar, studied together to "lead to better understanding, perhaps better theorizing, about a still larger collection of cases" (Stake, 2000, p. 437). Instrumental case study (Stake, 1995, 2000) is employed when the researcher is interested in obtaining a deep level of understanding about a phenomenon(a), abstract construct, trait or problem.

6.7.1 Participant Recruitment

Recruitment for this study was conducted in partnership with a local children's rehabilitation centre. The study received approval from institutional research ethics boards at both the university and the children's rehabilitation centre. All children and their parent(s) or guardian(s) were recruited with the assistance of a gatekeeper at the children's rehabilitation centre through flyers and staff members' word of mouth. The

sample was purposefully selected from the children centre's catchment area (including urban and rural communities).

6.7.2 Participants

A total of 11 participants (see Table 4) were involved in this study, six children and five parents. The inclusion criteria for child participants were: (a) age 8-12; (b) male or female; (c) born with a physical disability; (c) sufficient English language fluency and cognitive ability to participate in the interview process and complete sorting and categorizing activities, and (d) living in the community with one or more parent/guardian at the time of study. The inclusion criteria for parent participants were: (a) primary caregiver(s), (b) sufficient language fluency and cognitive ability to participate in the interview process, and (c) one or both primary caregivers available to participate in the interview process.

Table 4: Participant Profiles

Parent (Mothers)	Parent Age	Child	Child Age	Child Gender	Siblings	Diagnosis	EA Support	Community
Elaine*	45	Sarah*	11.5	F	1 (twin sister)	Cerebral Palsy	Yes	Urban
Elaine*	45	Laura*	11.5	F	1 (twin sister)	Cerebral Palsy	Yes	Urban
Sandra	59	Teresa	10	F	4 (2 brothers, 2 sisters)	Spina Bifida	No	Rural
Leslie (Adoptive Mother)	49	Elissa	12	F	3 (brother, 2 sisters) (+2 from biological mother)	Spina Bifida	Yes	Rural
Judith	41	Beth	10	F	1 (sister)	Cerebral Palsy	Yes	Rural
Simah	41	Amar	10	M	3 (sister, two brothers)	Hypoplastic left heart (and CVA 13 days after birth)	Yes	Urban

Key: *Elaine is the mother of both Sarah and Laura (twins)

6.7.3 Data Collection

6.7.3.1 Phase One: Children's Perspectives

Three sessions were conducted with each child.

Session One:

Occupational profiles were obtained by using the Pediatric Activity Card Sort (PACS) (Mandich, Polatajko, Miller & Baum, 2004). The PACS, a collection of photographs of children's activities, was used to gain a sense of the children's occupations, to introduce children to the use photographs and to build rapport. Children were provided with digital cameras to take approximately 30 photographs of their daily occupations over a two-week period. Children were asked to take photographs of the daily activities that represent "who you are". Optional log books were provided to record details about the photographs. Given that it may be difficult for some children to operate a camera, an option was provided for an adult to take the picture as long as the child directed the process and confirmed the picture on the camera viewer.

Session Two:

Photographs were developed and used in photoelicitation interviews (Dell Clark, 1999; Harper, 2002; Prosser & Burke, 2008). Photoelicitation is a useful tool for studying identity as it "offers participants an opportunity to 'show' rather than 'tell' aspects of their identity that may have otherwise remained hidden" (Croghan, Griffin, Hunter, & Phoenix, 2008, p. 1). Occupational portraits, drawing on a compilation of photographs, were developed using a software program entitled *Comic Life* (Version 1.5.4).

Session Three:

Semi-structured interviews were conducted with each child. The occupational portrait was used to facilitate in depth probing of the child's participation in specific occupations, with a focus on how such participation might shape identity.

6.7.3.2 Phase Two: Parent(s)' Perspectives

Semi-structured interviews were conducted with the primary caregiver of each child participant (in this study all of the mothers elected to participate). Drawing on a socio-cultural perspective, the interviews were designed to elicit data regarding the social and cultural dimensions that may contribute to participation in occupation and the shaping of children's identities.

6.7.4 Data Analysis

In-depth data analysis was conducted for each case (Stake, 1995), followed by a cross-case analysis (Stake, 2006; Yin, 2009). Data analyzed for each case included: results of the PACS, transcribed photoelicitation interviews with the children, transcribed semi-structured interviews with both children and parents, photographs taken by the children, comic strips created by the children, photograph logs if applicable, and reflexive field notes and observations recorded by the researcher. In total 18 interviews, 6 PACS assessments, 3 photograph logs, 176 photographs, and 6 occupational portraits (comic strip) were considered. In case study, data from multiple sources are converged in the analysis process. This strengthens the findings as "the various strands of data are braided together to promote a greater understanding of the case" (Baxter & Jack, 2008, p. 554). Case study methodology can adopt various analysis techniques (Merriam, 2009). It is

common for researchers to draw on grounded theory analysis techniques when employing case study methodology (Cutchin, 2003; Shank & Cutchin, 2010; Lauckner, Paterson, & Krupa, 2012).

Analysis for this study was informed by grounded theory techniques (initial coding, focused coding, theoretical coding, constant comparative analysis) (Charmaz 2006; Straus, 1987). In addition, concept maps (Daley, 2004; Kinsella, Bossers, & Ferreira, 2008) were used to visually represent emerging core categories and sub-categories. Concept maps were created for each case. Concept maps (12) were analyzed across cases, comparing core categories and sub-categories, keeping the two main research questions in the forefront. Core categories were synthesized to represent findings across cases. Both commonalities and unique features were considered to best represent the cases and their subtle nuances. All of the data were analyzed again to refine the core categories, and constant comparative analysis techniques (Charmaz, 2006) were employed to distinguish relationships between core categories, between core categories and sub-categories, and between sub-categories. This was completed to ensure the final core categories were representative of all cases and both child and parent perspectives.

6.8 Findings

The construct of occupation implicitly frames all of the data collected in this study and informs the categories generated in the analysis. Six major conceptual categories representing occupation and identity emerged from the cross-case data analysis. A summary of the categories is presented below.

6.8.1 Perceptions of Self and Other: Living with Disability

Throughout the sessions, children rarely spoke about their disability unless asked directly. Avoidance of discussions about disability was common across all participants. Sarah and Elissa spoke indirectly of their disabilities and changed the subject quickly if disability was brought up in conversation. Teresa briefly talked about her disability as a reason activities like jumping into the pool were hard for her. Beth spoke more about her *abilities* and about not caring what others think about her disability. Amar seemed unaware of his disability as possibly being perceived as “different”. Finally, Laura spoke about disability the most, as something she “hated”.

Recognition that disability is something to be lived with was a recurring theme. Laura described her disability as something she would like to get rid of stating “You know what, there is one thing I want to do in the future? Get rid of my disability. Yeah it drives me crazy”. Yet, she also noted that it is something she can’t ignore:

I hate having a disability but you know what my EA said, she said that ‘if you want to get rid of your disability, you have to try to ignore your disability and fight back’. I thought that was...a cool idea, but I don’t know if it’s a good idea...and she said...‘who’s going to win the disability or you’ and I said ‘my

disability' and I was right, so I have to try and it's not like I can ignore my disability.

Laura's mother, spoke of Laura's struggle to make sense of what living with a disability means by becoming aware not only of her own disability, but also of other peoples' disabilities:

She really sees her disability as a barrier. In the last year it has become a real thing...I think she struggles with her identity in terms of 'I have this disability' or 'I have these problems' and, you know, she wants them to go away.

I think she hates it [disability] right now...she really talks about how she doesn't want to have [it]...she doesn't like her disability...for herself but then [for] other people...all of sudden she is like 'Wow, she has a disability?'... 'Oh mom, she has a disability'...for years she has had some friends and she wouldn't even notice...she is more aware of it.

The children expressed different understandings of their disabilities, in relation to how they perceive themselves and how others perceive them. Beth appeared to be quite confident in her abilities and expressed a tension between her abilities and how others perceive her. Her strategy was to surround herself with people who *know* her, and *who* she is.

Shanon: Does your teacher expect you to do certain things at school.

Beth: Do my work and I can do that fine, because sometimes people underestimate me.

Shanon: Sometimes people underestimate you?

Beth: Ya.

Shanon: About what? The things you can do?

Beth: Ya

Shanon: And what do you think about that?

Beth: I don't care what people think about me

Shanon: Do you find that at school sometimes?

Beth: No not a lot. Because I only hang out with people who *know* me.

Beth's mother Judith identified the same tension:

Definitely people underestimate her intelligence. Just sort of on a general level.

But if they know her, they're fine. Like if people get to know her, they treat her normally, but it's usually if she's meeting new people or something like that.

Judith also spoke about Beth not seeing herself as "disabled", stating that she doesn't dwell on it, and it takes something really obvious for her to think about her disability in that way.

I don't think she perceives herself as disabled...we were in the car on the way home and she wanted to tape herself talking. And she did, using my phone. And then I played it back for her and she said, that doesn't sound like me...So I don't think she perceives herself as disabled necessarily. And it has to be something really obvious...to make her think about it. She doesn't dwell on it.

Amar appeared not to have a depth of awareness about his disability or how others might perceive his abilities. His mother Simah spoke about his perception “He thinks that he can do everything...if I told him you can’t do it...he would say ‘No, I can’”. She also discussed her struggle with knowing how to talk about disability with her son:

Shanon: What does Amar understand about his disability?

Simah: I have no idea. Because I don’t know how I am going to talk with him about that. Maybe in the future when he is grown up...if he is feeling he is different.

Interestingly some parents pointed out a tension between trying to create an environment where their child could live a “normal” life, when others give them special treatment. In Judith’s words:

Beth has had a lot of good will. Is it because Beth is who she is or is it because Beth’s disabled? So far as opening doors, I don’t know if it’s her or if it’s her disability and people are trying to make space for her. But she’s definitely, you know, been given opportunities...because of her disability too, and she might not recognize that.

6.8.2 Family Identity, Tradition and Culture

Family was a prominent theme throughout all of the interview sessions. Both children and their parents described the things they do as a family, and the influence of tradition and culture. Parents spoke of “the family” as an influential factor shaping their

children's identities. In Elaine's words: "I guess then she [Sarah] sees herself through her family... Her sense of identity, I guess, comes from how she sees herself in her family".

Children and parents spoke of how they enjoyed spending time "hanging out together" as a family.

Elaine: Yeah she [Sarah] likes to do things, family things, like going out for dinner and she just really likes when we're all home together, just hanging out.

We have a Saturday night and Dad's on days and you know we'll all get together and watch a movie and have popcorn. She really likes those family nights.

Doing everyday activities with Mom was a strong theme that all children identified with:

Teresa: With my mom... I go shopping a lot. And going to the post office with my mom. Just running errands with mom and I bake with my mom. Like say if we're in [the city] and we have lots of time we'll go shopping and do a mall crawl.

When asked if there were any special activities that Elissa did just with her Mom, she responded "Everything. Except go to school. Sadly she won't go to school". When her mother Leslie was asked the same question she shared the same perspective "She even follows me to the washroom [laughs]. No, we do everything together... a lot together activity-wise, the two of us".

Doing things with Dad seemed to be something "special", something children looked forward to; the fathers in this study were often busy or spent much time at work. When Simah was asked about activities that Amar and his father shared, she responded

“My husband doesn’t have time a lot for them so...Just swimming with my husband”.

Judith had a similar response, “She plays computer games with her dad. He’s usually only home on the weekends, so they don’t have a lot of time”.

The time spent with Dad was perceived as special, by both children and parents:

Teresa: I started doing [horseback riding] at first because I want to be more like my dad. And started hunting because I kind of connect with him and stuff. I do horse back riding because he grew up with horses his whole life and he still knows how to ride and I want to know how to ride so like if we both get horses we can both ride together. And I go hunting with him because he’s been doing it his whole life...And I want to make some times so we can have like a daughter-daddy date.

Elaine: Like when I took Sarah to the movies the other day, she [Laura] didn’t want to go because she knew the alternative was that she could hang out with dad, even though they didn’t do anything, just hanging out with him.

All of the children who participated had at least one other sibling. Siblings and other family members (e.g. cousins) frequently played a role in what activities the children participated in. Children often chose certain activities because other siblings or cousins participated in them. For example, Teresa expressed “I’m doing voice because I want to be more like my older sister because she’s a really good singer”. When asked why playing hockey was important, Amar became excited and pointed to his cousin in one of his pictures who is a professional hockey player. Parents also spoke about the roles siblings played in their children’s lives. In Leslie’s words:

Shelly [sibling] bought the treadmill. Oh, she [Elissa] had to have an elliptical. 'What are you doing Shell?' 'I'm just going to get on the treadmill' 'Oh, I'm going down to get on the elliptical'...And, I don't think she would normally do [that], but 'Shelly's doing it so I'm going to do it too'.

Children also talked about their siblings as being supportive, being role models, and doing a lot for them. In Teresa's words, "My sister is the most supportive, because she took four years of opera so she's probably glad that I like singing". Elissa also wrote, [from photograph log] "This picture is important because it is of my big brother who is one of my role models...he does a lot for me".

Although most of the children expressed doing certain activities because a parent or sibling(s) did the same activities, children also were described as "being themselves". When Judith was asked if Beth ever expressed wanting to be more like her parents or sister, Judith responded, "No. She's always just been Beth".

Family tradition and culture also permeated the things children did or wanted to do in the future. This seemed to be particularly important for parents. Judith expressed, "I think Beth has made some excellent choices of things that are meaningful to the culture of our family. So, I'm pleased with whatever she chooses. She hasn't really chosen anything that I wouldn't support".

Carrying on a family tradition was brought up by both children and parents. Tradition influenced the kinds of activities children were exposed to and encouraged to do, even if they did not choose these activities on their own:

Simah: I like sports, I want to let my kids do it. My husband too...I played [sports] in school, volleyball, badminton, and sometimes basketball, so I like to do

all kinds of sports. My brother, he plays basketball and my nephew too, so everybody likes [sports]. This is what my mom taught my brother and me. When the kids play sports, they are full so they don't...[get into trouble].

Sandra also spoke of family tradition "She [Teresa] plays the piano. And she does alright at it, she complains about it, but it's something that's really important in our family, to do, and she's not getting out of it".

Creating family traditions was something that children also identified as important. When talking about her stuffed animal collection, Elissa stated "I'm going to give that one to my kid, 'cause that's the first one I got". Beth also talked about passing on her occupations to her kids:

I am going to raise my kids to like tobogganing...No excuse, teach them how to toboggan. Swimming definitely, by the age of three. Learning how to swim by me. We will do recycling too, of course. I will pay them five bucks to be in eco club even if they don't like it.

6.8.3 Relational Identity: A Sense of Belonging

All parents discussed the role of peers in their children's lives, and how children would often compare themselves to or want to be more like their peers. For example, Elaine expressed: "I guess she [Sarah] sees herself in relation to her peers at school. She definitely compares herself to them".

None of the children indicated a large group of friends, but talked more of one or two "best friends". When asked if Laura liked to do things with friends, she responded "Yeah, her name is Ashley. She's not *your* best friend, she's *mine* and no one can steal

her”. Judith, Beth’s mother also spoke of this “She has one best friend, John, who often comes here and she goes there. And then we have sort of less associated friends that are in to play too”.

Some children spoke of struggles with making friends, and for the need to trust friends. Teresa expressed:

I like to have sleepovers with a couple friends not too many. And I only have sleepovers [with friends] that I trust that will be nice to me. I do these groups every month with these girls and I only take my truest friends, like really good friends. Like I have a friend that I’ve known since I was three, so I take her a lot.

Elissa in particular, described her best friend like a sister [from photograph log]:
This picture is important to me because I am with my best friend. I chose to take this picture because she is a big part of my life. If I couldn’t hang out with her I would be sad because I think of her as my sister.

Seeking a sense of belonging and “fitting in” was a predominant theme that was discussed both directly and indirectly by parents and children. Teresa stated, “I sort of act cool in front of my friends because I want to be like them and I want to kind of connect with them but its not working out for me”. Sandra, Teresa’s mother, also spoke of this: “She likes to have friends, but...one day they’re nice, and the next day they’re not, and it really bothers her. You know, it affects your sense of identity as well”.

Leslie also spoke to seeking a sense of belonging when talking about Elissa:

So I mean she's her real person but I think she does a lot of... you know, [her best friend] could say, "the sky's black" and she would totally agree. I don't know if it's wanting to belong, the fear of, I don't know.

Children also became interested in new activities because of their friends, as Simah described, "He [Amar] would like to do soccer...because his friend likes to play soccer".

Relationships with animals was a predominant theme. All six children had at least one pet, three participated in horseback riding, and one child was enrolled in horse back riding. Children were often engaged in the care of their pets:

Elaine: Sarah's willing to help feed animals, she likes doing that. So as much as possible I get her to help take care of the pets. That seems to be the thing that she wants to do, she wants to feed them, she wants to take care, you know be their caregiver.

Four children included pictures of animals in their occupational portrait meant to describe "who I really am". Pets were something that children expressed identification with, as not only something to take care of, but someone to play and spend time with.

Elissa: I've never gone without a pet. If we don't have a cat, we have a dog, and if we don't have a dog, we have a cat. Or fish.

Shanon: Could you imagine not having a pet?

Elissa: No that is terrible. Not happening. Even a hamster would suffice. I need some type of pet. Preferably one that I could play with.

Children also expressed relationships with popular culture and trends that their peers were interested in. All children spoke about popular movies, movie or television characters, and musicians. For example, Elissa collected magazines and posters of pop-stars. When asked if there were certain activities that make her who she is, she replied, “Hang up posters, because posters are like, my personality”. Many pictures of her posters were included in her occupational portrait. She described one picture, “He is awesome and I have a new poster of Cody Simpson. He’s a singer...He writes songs like Justin Bieber, so he’s awesome”.

Popular culture seemed to not only influence children’s identities in the moment, but also potentially in the future. In Elaine’s words,

The secretaries at the school call her a fashionista because she will go in there and just comment on their outfits and their earrings and their makeup...they call her the little fashionista girl. She is putting it in her head for you know later... ‘I am going to do this when I am older’.

6.8.4 Pride, Success, and Seeing things through...

A sense of pride in accomplishments was a prominent theme. Children frequently indicated being proud of leisure activities that they perceived they were good at and enjoyed. For instance Laura stated “I am proud of swimming because I love it, it’s the best thing for me”. Teresa spoke of being proud of choir because others were proud of her, “Choir because...everybody’s proud of me after a concert, because I made it through and stuff”.

Some parents talked about children's determination. In Judith's words: Beth's also very determined. So if she has a goal ahead of her she usually achieves it and works hard toward that....Like, if something moves her, then she moves. And she takes pride in what she does.

While other parents talked about children being satisfied with doing things "good enough". From Sandra's perspective, "Teresa doesn't have, she's not driven, you know, to do things really, really well. If it's okay, then she's satisfied with that. You know, not really striving to do her best all the time".

Children also talked about awards they had won. During the middle of a session with Amar, he ran to his room to bring all of his awards from track and field and hockey. As part of his occupational portrait, he included a picture of himself receiving an award at a community hero award ceremony, with the caption "I like to get awards". When Elissa was asked what she was proud of, she responded: "Winning. Like, I got a fourth place ribbon in track and field, so I've won that".

Being successful at activities seemed to be important to both children and their parents. Laura's caption on her picture of swimming was "I am on a roll!", she went on to say "Yeah, it means I am just doing great". Beth seemed to seek success and mastery, "Well at my school I mastered everything [on the playground] and there's only three things to do so it can get boring after a while, doing the same thing". She went on to talk about looking for new parks with different activity options. Some parents talked about success and their perception of how it might shape their child's sense of identity. Elaine stated:

The things that she [Laura] is really successful at give her that positive sense of identity. And now she has become really successful at the swimming and become really successful at her art. She definitely sees herself in a really positive light as an artist.

The idea of “seeing things through” was particularly prominent across parent perspectives. Elaine describes a scenario with Sarah:

The skiing, she’s decided this year that it really isn’t something that she wants to continue. But because we had started the season and put money into it, volunteers...and because we had signed her up and she had wanted to do it, she had to continue at least for this year. So that was a big fuss that she didn’t want to go, but I made her go. And now she doesn’t have to do it again if she doesn’t want to. So if they say they want to do something and you sign them up and put money into it, and time, then they have to do the whole thing.

Sandra described a similar scenario:

She [Teresa] would just fight you tooth and nail, every time we went [Horseback Riding], and it’s like, no, you don’t quit, you know, you see it through to the end, and then you re-evaluate it. So we saw it through to the end of May.

6.8.5 Growing Up and Keeping Up

Growing up is a part of *becoming*, and may potentially play a role in shaping identity in many ways. In this study, parents described how they were beginning to see

gaps between their children and same aged peers; socially, academically and physically with respect to “keeping up”.

Elaine: Age is playing a huge role in it...I don't think she saw herself as different, or at least she didn't ever really talk about it until she was in grade five, and now she has become more aware of her identity. Things get harder too, and I think that is part of the reason. Like the social things, the academic part as you go into further grades, it gets a lot harder...To keep up, so...that has become a struggle and she is quite aware of that.

Sandra: As you get older, and the emphasis is on your peers, and the kids that you're with in a group are probably younger than you, which makes you feel kind of out of place. Although, Teresa's not done too badly, I was worried about that, but it hasn't been too, too bad that way.

As part of growing up, children negotiate their independence, wanting to choose their activities and do activities with their friends “on their own”.

Elaine: When they were younger I think I just pretty much chose activities... now of course they are getting older and wanting to pick their own things.

Some children indicated ways in which they question boundaries and look for more independence to participate socially with their peers. For instance Elissa expressed “I'm not allowed to go over to her house...I'm not allowed to go on the highway by myself...it's like, well I've been on it”. Beth also described an instance:

Beth: We ride a tube, go boogie boarding, and jump off the pier. [at the beach]

Judith: Jump off the pier?

Beth: Jump off the pier. We're not too young.

Parents talked about negotiating independence as well, and what is to be expected “at this age”. Elaine described a scenario that Laura experienced:

There were some kids in the variety store the other day and she was just shocked that they were without their parents. From her class, and I think she was just really surprised and envious. ‘Wow, where is your mom?’. Because everywhere that she goes there is some adult. So I could see her being really surprised that these young girls, who were probably 11, were by themselves in the store and she said “Wow, are you ever lucky”. She was looking around like where is your support worker, where is your parents?

Children also talked about growing out of old activities and into new ones. Elissa mentioned “I don’t like playing with Barbies no more. The only doll I play with is my voodoo doll”. Beth referred to a picture she had taken “I don’t know what to say because I don’t like to do what is in the picture anymore [Her doll]...it’s just that I am growing up and I kind of want to do some other things with my time”.

6.8.6 Identity as Dynamic

Children talked about many occupations in the past, in the moment, and in the future. These occupations were dynamic and were not necessarily predictable.

All of the children and their parents referred to activities or events in the past. For example, Laura made reference to past experiences at school, “You know what; I wish I was still in grade five. I wish I hadn’t moved on because grade five was so much fun”. Elissa spoke of an event in the past that influenced her relationship with a peer: “My friend Marcia and I used to like make up [dances], that’s something I don’t do anymore, hang out with Marcia. We used to hang out a lot, but then her parents got divorced”.

Parents also spoke about activities in the past, and how children talk about them from time to time. In Elaine’s words: “Sometimes Laura talks about activities and it is not that she can’t do them it is just that she is not at the moment, you know? ... she just isn’t ...engaged in it at the time”.

Being “in the moment” was a predominant theme throughout all of the interviews, and at times from one interview to the next. Children seemed to talk about what they were “into” that day. For example:

Sarah: I don’t know why but I am suddenly obsessed with aliens.

Shanon: Starting today?

Sarah: Yup. I am going to write a book about a town that was invaded by aliens.

Beth identified getting her green belt in karate as one of the five most important things that she wanted to do. By session three she had expressed, “I quit that [karate]. I just found a new interest that was baseball. I like baseball”. Judith had also made reference to this change, “And she’s given up karate and swimming this year. So she’s moving through a change now. She decided”.

Parents also commented on how their children would quickly lose interest in activities, find new interests and give up old ones, or revisit old activities after time had

passed. Leslie spoke about how much Elissa loved camping until just recently. Elaine described a scenario about an activity Sarah and Laura had recently revisited:

Every few months, you know they pick up a different thing. But lately they got hooked on this computer game. And we have an x-box and for a while it just sat there gathering dust and now all of a sudden it's come out of its shell and they both just want to go down there and play x-box, so those two things right now are just "the thing".

Being in the moment also seemed to be connected to what was popular in the media at the time. When asking Elissa about the activities that she felt made her "who she is", she responded:

My TV shows, like Vampire Diaries and Glee. They are the best ones on TV, and they are over now. Cause everybody knows that I like vampires and I like singing. And listening to music, everyone knows I like Justin Bieber.

Children and parents also talked about activities they wanted to do in the future. Some children talked about new and prospective activities. For example Laura talked about her future as it pertains to school: "Do you think I'll go there [name of school] when I am in university... I'm not sure if I want to go to university, do you have to go college or do you not?". Teresa identified future activities that she wanted to do: going to the cottage, listening to music, and watching and playing basketball, "but like not when I'm 87".

Beth talked about more independence in the future in an activity that she currently participates in. When her mother asked her if she thought they would be riding the tag-a-long bike together when she was older, Beth replied: “No [laughing]. I will be riding a trike. Ya, or a bike with training wheels”.

Parents described how they played a role in organizing future activities. For instance, Judith stated: “We’re kind of at the start of her next year of activity. She’s going to be joining the London Track Club. So she’s looking forward to that and she’s going to start horseback riding tomorrow”. Judith also explained that Beth was starting these new activities because she was interested in participating in the Paralympics in the future.

6.9 Discussion

6.9.1 Occupational Identity: A Complex Phenomenon

The findings of the study have implications for how we think about the relationship between occupation and identity, and provoke questions about whether we should conceive of "occupational identity" (Kielhofner, 2008; Unruh, 2004), “occupation *as* identity” (Christiansen, 1999, 2000, 2004) or consider "occupation *and* identity".

Three interesting dimensions arise from this study and contribute to emerging discussions about how occupation might be implicated in the shaping of identity for children with physical disabilities. The discussion focuses on what the participants *do* and how social forces shape what they *do*. The occupational perspective on identity permeates through this focus in the discussion.

6.9.2 Identity and Disability

The findings revealed how disability and perceptions of disability may play a role in shaping children's occupations and identities. Children discussed disability in different ways and from different perspectives, from, anger to ambivalence. The absence of disability in conversation may be attributed to children's tendency to focus on aspects of their lives that were similar or the same as their same-aged peers, for example winning awards, having pets, listening to music, playing sports, watching movies etc. (Connors & Stalker, 2007). Overall, it appeared that children were seeking a sense of belonging (with family, friends, peers, and pets) and by drawing upon *sameness* (Connors & Stalker, 2007) they may be able to relate to others and to participate in their social and cultural worlds.

Social constructions of disability add to the complexity of identities and occupations. Siebers (2006) writes, "the disabled body is no more real than the able body—and no less real" (p. 180), yet society is constructed in a manner that marginalizes people with disabilities, distinguishing them from the *norm* and labeling them as *Other* (Davis, 2006; Wendell, 1996). Disability may be constructed in a way that creates barriers to participation *in* and contribution *to* society. This inevitably impacts how children perceive themselves and what they can *do*, and also how others perceive them and their abilities. This was evident in Beth's awareness of how others underestimated her abilities.

The representation of disability, the built environment, along with social and attitudinal barriers, all contribute to the social construction of disability (Swain & Cameron 1999; Goffman, 1968; Morris, 2001; Marks, 1999; Phelan, 2011; Wendell,

1996, 2006) and potentially to one's identity when living with disability. In turn, each play a role in determining the occupational opportunities one may choose and participate in, which may also shape identities. Childhood disability discourses primarily focus on notions of tragedy, vulnerability, medicalization, overcoming, and otherness (Priestly, 1999). Children encounter such discourses in school and community settings. This was seen in Laura's example of wanting to get rid of her disability and her educational assistant encouraging her to "fight back". Priestly (1999) suggests that children then begin to acquire these discursive categories, which contribute to the shaping of their identities and the construction of disability as a social construct. Children with disabilities not only face the challenges of childhood in a world constructed for children who meet a particular normative developmental standard, but also have to contend with social constructions of disability. This may also influence the nature of children's occupations, opportunities, choices, and identities.

6.9.3 Identity as Social

It is significant to point out that in both Erikson's work and the OI literature, the reference to social influence in identity formation, is primarily focused on societal approval or societal value of occupations, particularly productive occupations. For instance, most OI theorists have pointed out that children seek approval from parents, peers, and society (Christiansen, 2004; Kielhofner, 2008; Unruh, 2004). Children in this study sought social approval through winning awards and being successful in school and leisure activities. Particularly, Teresa expressed being proud of an activity because others were proud of her for doing the activity. Christiansen (2004) suggests that when

individuals perceive social approval with respect to their chosen occupations they create a sense of positive identity. Moving beyond social approval, social theorists from other disciplines contend that while social approval is significant in shaping identities, social dimensions and relationships may actually go on to *form, shape* or even *produce* identities (Berger & Luckman, 1966; Burr, 2003; Gergen, 1994, 2000, 2003; Phelan & Kinsella, 2009).

The findings revealed many socio-cultural factors that influence how occupation and identity are shaped, and potentially formed and produced by family identity, relational identity, family tradition and culture. Family and relational aspects of identity were predominant in the findings. Children's occupations and identities were frequently shaped by parents, siblings, relatives, peers, best friends, pets, and popular culture. For instance Teresa took up horseback riding to "be more like her dad" and Elissa was influenced to use the elliptical because of her sister.

Interestingly, Gergen (2000) asserts that the emergence of technology has enabled society to form more relationships beyond those traditionally formed by face-to-face encounters. Such relationships not only include people who surround a person in daily life, but also include relationships formed between the self and characters or 'stars' from the entertainment world, who appear to be important in children's lives. Gergen (2000) proposes the notion of a *relational self*, "in which the self is replaced by the reality of relatedness—or the transformation of 'you' and 'I' to 'us'" (p.156). From this perspective, as one becomes socially saturated, one begins to realize that the notion of an autonomous self does not exist (Gergen, 2000). Instead, one becomes conscious of the

interdependence on others, understanding that relationships are central to constructing the self (Gergen, 1994, 2000). In this light:

One's potentials are only realized because there are others to support and sustain them; one has an identity only because it is permitted by the social rituals of which one is part; one is allowed to be a certain kind of person because this sort of person is essential to the broader games of society. (Gergen, 2000, p. 157)

The findings point to ways in which children negotiated occupation, identity and disability within the socio-cultural context. Beth, for example, expressed not caring what people think of her disability. Her mother described her as, "She's always just been Beth". Burr (2003) contends that identity is socially produced, however there is also an element of human agency evident when one represents oneself by choosing from the discourses available and resisting others. In this case, Beth appears to be resisting particular discourses surrounding disability. This speaks to the dialectic relationship between the individual and social dimensions of identity and occupation; an area that merits further scholarship in occupational science.

6.9.4 Identity as Dynamic

An overarching theme throughout this study was the dynamic nature of both occupation and identity. Occupation and identity were described in the past, in the moment, and in the future. Age played a role in awareness of one's identity and the notion of growing up was seen to shape opportunities for choice and for negotiating independence. Children's interests were seemingly shaped and reshaped by family, friends, popular culture, leading to frequent changes in occupational participation and

perhaps how children see themselves from day-to-day. This coincides with emerging perspectives from scholars in the field, suggesting that identity for adults and older adults is potentially dynamic, multiple, day-to-day, and emerging from social interactions (Asaba & Jackson, 2011; Lalberte-Rudman, 2002; Finlay, 2004).

At the outset of the study, it was thought that this research would lead to a deeper understanding of occupational identity as an emerging construct in occupation-based discourse. The findings however raise more questions than answers concerning conceptualizations of occupational identity, and open avenues for further investigation. Current conceptualizations of OI appear to render a more static than dynamic picture; occupational identity is conceptualized as a unitary thing that can be named and discovered. The concept of “we are what we do” can amplify such an impression when taken at face value. The findings of this study reveal the dynamic nature of occupational identity and suggest that many socio-cultural dimensions play a role in shaping one’s occupations and identities. Perhaps *part* of who we are is what we do, *and* also what we don’t do, can’t do, will do, won’t do, like to do, don’t like to do, want to do, have access to do, are allowed to do, are forbidden to do, do now, did before, virtually do, and so on. This also raises questions about occupational identity as its own construct; whether or not it should stand as a construct on its own or whether the unique and dynamic relationship between occupation and identity should be explored further. It is clear that more research is needed to further understand what factors shape, reshape, and are shaped by occupation and the implications for identities and the relationship between the two.

6.10 Conclusion and Implications for Occupational Science

With respect to childhood identities, deeper considerations about the ways in which occupational identities may be socially constructed raise immense moral and practical concerns about how societies are organized and develop. The significance of the occupations we value and enable children to participate in, and the moral commitments reflected through communities and societies, highlight significant collective responsibilities for how future identities are potentially shaped and produced.

This study raises issues for conceptualizations of occupational identity, and for considerations about how collective dimensions of occupational engagement shape identity formation, particularly in children. For instance, both *collective* and *individual* occupations appear to shape occupational identities in childhood. In addition, social and cultural discourses about the value of occupations shape expectations and actions with respect to which occupations children engage in, and have implications for how identities are shaped.

There are a number of pertinent critiques emerging within identity theory and within occupational science that raise promise with respect to generative avenues for further scholarship. In particular, future scholarship that explores socially, discursively, collectively, culturally, and relationally oriented conceptions of identity hold much promise. In addition, an examination of the implications of such for advancing conceptions of occupational identity, particularly in childhood, where children's primary occupations frequently occur in collaboration with others, and where the influence of powerful others has implications for shaping occupational engagement is an area of pressing concern.

6.11 References

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7. Picture this...Safety, Dignity, and Voice

Ethical research with children:

Practical considerations for the reflexive researcher⁵

7.1 Introduction

Upon commencing this research project we aimed to do what many consider to be ‘the impossible’, to conduct qualitative research with children. To our surprise, this seemed to be a task that others would not dare to do. Not only did we want to interview children, we wanted them to take pictures. Many skeptical colleagues encouraged us to think practically, telling stories of others who were not able to get their projects through the institutional research board (IRB), who were not able to recruit many children to participate, and who were unable to get children to ‘talk enough’ to garner ‘rich’ data. You want to finish this project right? Have you considered the ethical issues? I wouldn’t if I were you...

As researchers with backgrounds in occupational therapy, the first author having worked primarily with children in schools, our clinical experiences revealed another possibility. Children have stories, they tell stories, and they tell stories in many different ways. Eliciting those stories was one challenge, but the real challenge was to conduct research with children that was ethically sound. Discerning what that might look like and staying true to our ethical commitment required a great deal of researcher reflexivity, well beyond the parameters of what was required for the IRB. In particular we became

⁵ A version of this chapter is in press: Phelan, S. K. & Kinsella, E. A. (In Press). Picture this...safety, dignity, and voice. Ethical research with children: Practical considerations for the reflexive researcher. *Qualitative Inquiry*.

aware of the ethical importance of reflexivity that attends to safety, dignity and voice as ethical ideals in research with children, and of how easy it might be to unintentionally neglect these dimensions.

This paper draws on ethical considerations negotiated while conducting research with children. The research project investigates children's activities, how they are implicated in the shaping of identity with school-aged children with physical disabilities, and how socio-cultural factors shape children's participation in childhood activities. The research uses several methods including: photoelicitation interviews (children take photographs of their daily activities, and use these photographs in interviews) and semi-structured interviews within a case study methodological design.

We discovered that there are many ethical considerations when conducting research with children. Some of these considerations are important with respect to research with children in general, while others arise more particularly when using visual methods. In this paper, we propose that the aim of conducting ethical research with children involves an ongoing commitment to researcher reflexivity, and that the tenets of enabling safety, dignity and voice for children can prove helpful in assisting researchers to navigate the complex ethical issues that transpire when working with children.

Drawing on the above, as well as examples from our research, the following discussion is framed around two broad categories: procedural ethics and ethics in practice (Guillemin & Gillam, 2004). In particular, five areas of ethical concern are considered (a) Assent or willingness to participate, (b) Informed consent and assent using visual methods, (c) Issues of disclosure, (d) Power imbalances, and (e) Representations of the child.

Procedural ethics and *ethics in practice* are considered by Guillemin and Gillam (2004) as two necessary and interactive dimensions of research ethics. ‘Procedural ethics’ involves seeking approval from ethics committees and review boards. Ethical considerations pertaining to preparation of informed consent and assent procedures will be discussed as examples of procedural ethics, recognizing that there are overlaps with the ‘ethics in practice’ dimension when implemented in the field. ‘Ethics in practice’ refers to the everyday ethical issues that arise while conducting research (Guillemin & Gillam, 2004). For instance, the researcher must decide how to respond or act in the moment, and these issues or dilemmas are often unpredictable. Guillemin and Gillman refer to “ethically important moments” (p. 262), which may include moments when participants indicate discomfort with their responses, reveal their vulnerability or moments when a researcher must decide how far to probe a participant about a distressing experience. This paper considers ethical issues pertaining to disclosure, power imbalances, and representation as examples of ethics in practice, and discusses some of the researchers’ experiences of negotiating “ethically important moments” (Guillemin & Gillman, p. 262).

7.2 Procedural Ethics

7.2.1 Assent or Willingness to Participate

In order to uphold respect for a child participant’s dignity the child’s assent or willingness to participate is sought in addition to informed consent by the parents (Dockett, Einarsdottir, & Perry, 2009; Dockett & Perry, 2011; Mishna, Antle, & Regehr,

2004). Assent is sought after written consent from a parent or legal guardian is obtained. This occurs by explaining to the child the purpose of the research project and the child's role in the process (Dockett et al., 2009; Dockett & Perry, 2011; Mishna et al., 2004). A number of scholars point out that the purpose of the study and the process of assent is to be explained in a way that a child can understand, and that using pictures and/or age appropriate language is helpful to foster the child's comprehension (Helseth & Slettebø, 2004; Lambert & Glacken, 2011; Mishna et al.). Acquiring assent reinforces the child's right to refuse to participate or to dissent, even though consent by the parent has already been given (Dockett & Perry, 2011; Mishna et al.).

Most IRBs will require a written assent form to be used in studies involving school-aged child participants. Some of the questions that informed the design of our assent process are as follows: Why are you [the research participant] here?, Why are we [the researchers] doing this study?, Will there be any tests?, What will happen to you?, Will this study help you?, What will happen to your pictures?, What if you have any questions?, and Do you have to be in the study? It was helpful to read the assent form with the child, or when feasible to have the child read the question and the researcher read the answer back to them. Creating opportunities for children to ask many questions is another consideration in obtaining assent (Lambert & Glacken, 2011). We discovered that when working with children with disabilities, this frequently required additional time and patience especially when children were using augmentative communication devices, and suggest that this is worthy of consideration in the research design process. Most importantly, for purposes of assent, the researcher must be clear that the child is not required to participate in the research project if she or he does not want to, that the child

is not expected to participate by the researchers or anyone else (including parents, teachers, etc.), and that the child will not face negative consequences if she or he withdraws from the study at any point (which can be a child's biggest fear) (Bruzzese & Fisher, 2003; Dockett & Perry, 2011; Lambert & Glacken, 2011).

Assent forms are also signed by the child, which can potentially be a fun activity, particularly if children enjoy printing their names or "signing autographs". Helseth and Slettebø (2004) contend that written assent "can often give children a feeling of significance in the situation and empowers the feeling that their consent to participation really counts" (p. 303). However in our experience, for some children the act of written consent may feel like a school task, and be time consuming, especially if printing is not easy for them (which was often the case when working with children with physical disabilities). For example, in our research a child with cerebral palsy wished to sign her name on the assent form. She was able to sign her own name, however it was somewhat difficult for her. She was determined to complete the task to show what she could do, as this was something she was proud of. It seemed important to allow her to do so, however completing her signature took approximately 45 minutes, which was almost the length of the planned session. This not only took a lot of time, but a lot of the child's attention, which from a research perspective may have been better utilized for the actual interview. In such cases, it may be beneficial to work into the ethics protocol the option to obtain recorded verbal assent, along with assent by marking an "X" or placing a sticker on the signature box. Another possibility may be to ensure that the option for additional visits to complete data collection is built into the research design, should delays of this nature arise.

An additional caution is to consider whether children are signing their names simply to show they can, or to please their parents or the researcher, without truly understanding why they are signing and what it entails. For example, in our study some children became anxious to sign or print their names to show their skills with respect to this task, or to get started quickly without going through the assent information and questions which were perceived as “boring”. Reflexivity in this regard may help the researcher stay attuned to the situation and ensure the assent process is enacted and revisited without moving on prematurely.

Obtaining assent can be easier said than done. It requires patience on the part of the researcher, and sensitivity to ensure that the child truly understands what they are about to participate in and why, not only when completing the formalities of the assent form but throughout the research process. Although the completion of a formal assent document is in most cases required by the IRB, it does not mean assent is finite and should not be revisited throughout the research process (Dockett & Perry, 2011; Fine, Weis, Weseen, & Wong, 2011; Helseth & Slettebø, 2004). Cocks (2006) recommends that researchers make a conscious effort to remain vigilant to the child’s responses throughout the entire research process, becoming attuned to children’s ways of communicating in order to recognize moments when children are uncomfortable with their participation. Children can assent in different ways, including inviting you, as the adult/researcher, into their worlds (Cocks, 2006). In this study, the researcher began each session with time for “rapport building”. Spending time simply talking about the child’s day created opportunities for them to ask questions such as: “Why are you asking kids questions?”, “What is your project for” and, “When is your project going to be done?”.

Often in this time children invited the researcher to see their pets, bedrooms, poster collections, latest craft project or computer game. All of which, could be interpreted as accepting the presence of the researcher in their activities (Cocks, 2006).

Cocks (2006) contends:

It is the beliefs of the researcher that influence the ethical nature of a piece of work and impact the final product. Therefore, flowing through each of the core issues of the ethical framework, particularly through the application of 'assent', is the reflexivity of the researcher. (p. 261)

We propose that one reflexive practice of an ethical researcher is to ask yourself if you believe the child has understood and truly assented to participation in the study. This requires sensitivity, awareness, and acute observational skills. At times, the child's expression or body language may reveal that she or he is uncomfortable or not sure of what is going on (Dockett, Einarsdottir, & Perry, 2009). We observed that often children just want to move on to the 'doing' of the research, the 'fun stuff'. If you sense this might be the case, one option is to reiterate some of the information in a playful way, while also offering opportunities for children to ask questions and potentially stop participation if they no longer are interested. Consent and assent with children is better approached as a process versus a single event (Renold, Holland, Ross, & Hillman, 2008; Warin, 2011). Revisiting a child's choice to participate at each stage of the research process is critical (Etherington, 2007; Warin, 2011). Such attention to the child during the research process requires ongoing researcher reflexivity and ethical mindfulness (Cocks, 2006; Etherington, 2007; Warin, 2011).

7.2.2 Informed Consent and Assent using Visual Methods

When using visual methods with children, there is another level of informed consent required, and additional informed consent and assent procedures take place. Informed consent is also required from others who may appear in the pictures taken by the participants (Wang & Redwood-Jones, 2001). This can be challenging for the participants to manage, especially if a child wants to take a picture of another child, as informed consent must be obtained from the other child's parents and assent must be obtained from the child appearing in the picture. For example, in our study the following questions were used to design the assent process for children: Why are you being asked to be in a picture?, What will happen to you?, and, What will happen to the pictures?

In addition to all consent documents, Wang & Redwood-Jones (2001) contend that it is beneficial to offer the option for participants to choose if they would like their pictures to appear in research publications, presentations, or other appropriate venues in order to protect their privacy and ensure their confidentiality. Although participants may consent and assent for their pictures to be displayed in different media arenas or texts, there are a number of ethical implications that arise surrounding representation of the child. These are discussed in more depth later in this paper.

When approaching others who may be photographed by participants, the consent and assent procedures are out of the researchers' hands. We found it necessary to provide really clear and detailed instructions; it was helpful to provide participants with a folder, clearly marking the documents and highlighting places for signatures. When it is out of the researchers' hands, it is difficult to know how the procedures took place, and if other participants were clearly informed; therefore we suggest emphasizing the importance of

the consent and assent information and procedures with participants and their legal guardians.

This raises another question about the demands of the research that some may view as ethical: Is this process too much to ask of participants? Certainly reflexivity about the pros and cons of the demands on participants of consent and assent, especially when others may be involved, is a consideration worthy of attention during the design of the research.

7.3 Ethics in Practice: Ethics in the Moment

7.3.1 Issues of Disclosure

Given that children may not have the capacity to anticipate the information they may be asked to disclose, children may not understand the potential risks and benefits to participation in research. Visual methods can be particularly problematic in connection with anticipating potential risks associated with disclosure, as images allow the researcher access to dimensions of an individual's experience, in more delicate and intimate ways than are possible when the researcher is physically present (Clark-Ibáñez, 2004). Given the potential of the images to reveal aspects of the individual's experience beyond their conscious control, we found that researcher reflexivity was helpful in negotiating the potential risks of unintentional disclosure. Some scholars contend that these risks may be more pertinent in research with children (Mishna et al., 2004; Punch, 2002).

We suggest that researchers attempt to anticipate potential risks and explain them in a way that is meaningful to the child, recognizing that we can never anticipate them all. Reflexivity may increase researchers' awareness of their own preconceived assumptions about children and childhood (Davis, 1998; Finlay & Gough, 2003), and heighten sensitivity to potentially harmful situations when anticipating ethical challenges and when actually faced with "ethically important moments" (Guillemin & Gillam, 2004, p. 262).

Based on the experience of interviewing children, we have found it best to let the child direct the interview to the extent possible, thus offering the child a chance to choose what she/he feels comfortable sharing. The PEI method is helpful, as children can choose the pictures they would like to discuss (or choose not to discuss), and share these in any order they wish (Dell Clark, 1999; Dockett et al., 2009). Letting the child direct the interview can also help the researcher be more sensitive to moments where the child may feel vulnerable after a response, influencing the researchers' decisions whether or not to probe difficult topics. For example, an excerpt from one of the transcripts, illustrates a moment where Shanon felt that the child began to reveal more than she initially intended. Shanon trusted her gut feeling and did not probe the issue, letting the child direct the next step.

Shanon: Do you think there is anything else that I would need to know about you?

Sarah: Yeah.

Shanon: Like what.

Sarah: I don't hang out with other kids a lot.

Shanon: No?

Sarah: No. I am kind of shy.

Shanon: Kind of shy?

Sarah: Yup. I don't...can't really...can't really...can't really open up to other kids. Let's just say that.

Shanon: Ok.

Sarah: Oh, I've been to Respite [Community Organization]... [continues to discuss this experience]

In text alone, it may be hard to imagine the moment in context. However, in this moment there was definitely some tension and discomfort experienced by both the child and the researcher. This discomfort was observed in Sarah's nonverbal cues; Sarah avoided eye contact, looked away from the researcher and focused her gaze on the ground, her voice became low and quiet, and she began to speak quickly with hesitation at the end of each sentence.

Following this event we (the researchers) engaged in reflexive dialogue to explore if Shanon's decision not to probe further was the 'right' thing to do. This was an 'ethically important moment' for both researchers, as the tension between collecting important data and respecting the child's body language regarding her discomfort with disclosure came to a point of tension. This was the first time the child had talked about her peers, which was something the researcher was looking to explore. The question of pursuing the collection of additional data was weighed in light of the ethical cost at hand. Glenn (2004) suggests that in many instances silence can be just as powerful as speech. We recognized that interpretive insight into Sarah's experience could be gained by observing the silences, not necessarily requiring a probe for more data that could be

‘heard’. According to Macklin and Whiteford (2012), although informed consent meets the demands of IRBs, researchers may still face a moral conundrum in the field: “Clarity versus care; which to choose”? (p. 97). In this case, Shanon opted for care. This is not to say that care supersedes clarity in all cases, but we suggest that reflexivity on the part of the researcher may help to negotiate the moral conundrums researchers face.

In such situations the environment may play an important role. Mishna et al. (2004) suggest that creating an environment that is too comfortable might impact the ability of the child to protect him or herself, leading to the unintentional disclosure of information. Jokinen, Lappalainen, Meriläinen and Pelkonen (2002) contend that over time the participant-researcher relationship can transform from stranger to friend, “making it easier to acquire knowledge from the informants’ point of view” (p. 166). This can be beneficial from a research point of view, however if a child sees a researcher as a friend, they could in turn become increasingly vulnerable. Reflexivity may assist researchers in treading these very fine lines.

7.3.2 Power Imbalances

Issues of power and power imbalances in relationships with researchers are also of concern when conducting research with children (Phelan & Kinsella, 2011). Although a relationship that creates a false sense of ‘friendship’ may raise ethical issues, so does a relationship that minimizes the child’s agency, creating another fine line that researchers may find it helpful to negotiate through reflexivity.

The way in which a researcher presents oneself, the language used, the clothes worn, the body language adopted, how one interacts with the child, and the context of the

interview, can each influence the balance of power in both negative and positive ways (Phelan & Kinsella, 2011). For example, dressing casually, using fun ‘child friendly’ language, and conducting interviews on the playroom floor may work to decrease power imbalances. Whereas wearing formal attire, conducting interviews at the dining room table where the child usually completes his or her homework, using language that the child may not understand or language that sounds like something a teacher might say, may act to create power imbalances. Such approaches might favour the researcher as the powerful adult, and the child as less powerful and expected to comply with whatever the adult asks or expects of them. The child’s perception of the adult researcher as unduly powerful is potentially dangerous. Ethical researchers are called to be reflexive about how to create conditions where children have agency and share power to the extent possible (Punch, 2002). We deliberated about how to present ourselves as researchers, not only on the first visit to the home but also the following visits. Questions considered included (a) how the parents might perceive the researcher dressed professionally or casually, (b) how comfortable the parent would be inviting the researcher into their home based upon first impressions, (c) how the children might perceive the researcher, (d) how important it was to appear approachable upon first impression from a child’s perspective, and (e) how to talk to both parents and children in ways they could understand, even if that meant explaining things two different ways. In the end, the choice was made to wear clothes that were plain, casual, and comfortable in order to facilitate getting down on the floor if the children wanted to work in different places. Each child was asked where they would like to work that day, and typical places like kitchen tables were not assumed. Interestingly, most children chose the kitchen table on the first session, however second

and third sessions were often conducted in different places like the playroom, bedroom, or a place that was less frequented by other family members (we assume for privacy).

One challenge is that children may fall into the familiar teacher-student role, where they feel they must perform to their best, be on their best behaviour, and provide information that the ‘teacher’ wants to hear (Burke, 2005; Cappello, 2005). Therefore the establishment of a relationship that is distinct from the teacher-student relationship, and one that elicits the child’s own perspectives is critical (Phelan & Kinsella, 2011). During this research, some children assumed that Shanon was meeting with them in their home as a ‘helper’ (support staff) who would be coming to visit them on a regular basis like other care workers who come for respite or therapy. This positioned Shanon in a particular role with a significant degree of power, despite efforts to avoid a situation such as this.

Another issue related to power is the importance of ensuring that the child understands that he or she can choose to participate or withdraw at any time. Often children do not understand that they have a right to withdraw from the research project unless asked directly and reassured that this is okay (Mishna et al., 2004). For this reason it is beneficial to create a safe and reassuring environment from the beginning, and to offer the child opportunities to withdraw in ways that she/he feel it is safe to do so. One strategy that we adopted was to begin each session with an overview of what we were going to do that day, followed by asking the child if that sounded okay, if he or she had any other questions and still wanted to participate. In one instance, on the third session, one child participant asked if she *had* to have her pictures shown in magazines, books,

and presentations (assent and consent was formally obtained in the first session prior to taking the pictures).

Teresa: Oh and plus I wanted to tell you, [you] know that thing that says its fine if I go in a textbook or stuff? I don't want to go in a textbook.

Shanon: Okay, that's okay, we can take it off, no problem. I'll show you. So it says here, your pictures in articles, book chapters, or presentations that I would do...

Teresa: Not presentations.

Shanon: Not presentations. No. [crossed out on the form]

Teresa: Or textbooks.

Shanon: Or text books, okay. [crossed out on the form]

Teresa: I don't really want to be in any.

Shanon: That's perfectly fine. So I crossed those out.

Teresa: Okay. Maybe articles are fine I guess. Oh its, never mind.

Shanon: You know what? It is totally okay, we don't have to use your pictures for anything.

This afforded the opportunity to go over the assent form again and clearly let her know that she did not *have to* say yes, even if her mother did say yes. In this case the child decided she would rather not have her pictures published. Her mother overheard our conversation and came over to ask why, in a way that would be encouraging the child to change her mind. This provided an opportunity to reiterate that it was the child's choice and that it was okay not to use the pictures. Warin (2011) encourages researchers working with children to be ethically mindful of the potential disparities between child

and parent consent and assent, recognizing that often there can be a mismatch, explicit or implicit.

Nutbrown (2010) contends “children’s words, drawings, and images as well as the children themselves can become the objects of research if dynamics of power are not recognized, acknowledged, and addressed” (p. 7). Reflexivity has been noted as a vehicle for helping researchers to bring their awareness to power dynamics that might arise in the research process (Barker & Weller, 2003). This includes reflexivity about the power dynamics between parents and their children as these may also influence the research project with respect to data collection and fear of withdrawal (Barker & Weller, 2003). Balancing concerns about safety and protection of the child with issues of dignity and voice are an ongoing challenge for reflexive researchers working with children (Danby & Farrell, 2004).

The choice of research methods may also help to minimize power imbalances. An overarching assumption of the PEI method is that it has the potential to minimize power imbalances between the researcher (adult) and the researched (child) (Dell Clark, 1999; Phelan & Kinsella, 2011). Power may be shared with the child by asking the child to direct and take his or her own photographs making it possible for the child to have a sense of control over the research process (Dell Clark, 1999; Epstein, Stevens, McKeever, & Baruchel, 2006; Frohmann, 2005). However, despite the best intentions, this method can still be influenced by authority figures (i.e. parents or caregivers), which may limit the child’s control and level of participation in the research (Barker & Weller, 2003; Clark-Ibáñez, 2004). The study design and researcher’s decision regarding who will take the photographs inherently influences the distribution of power. For example,

although it is possible to use researcher-produced photographs when conducting theory-driven research, one shortcoming is that this process reduces the child's influence in the research process (Clark-Ibáñez, 2004). In more inductive research, photoelicitation “autodriven” interviews (Dell Clark, 1999) allow participants to take their own pictures. This approach enables the child to “drive” the interview process so that what is discussed is more likely to be pertinent and relevant to the child and the child maintains a certain sense of shared control and power (Dell Clark, 1999). ‘Who’ is generating the photographs, and the rationale for anyone other than the child generating the photographs, become significant considerations in photoelicitation research (Burke, 2005; Clark-Ibáñez, 2004, Dell Clark, 1999; Phelan & Kinsella, 2011). Such issues may have implications for determining whether or to what extent the ‘voice’ of the child is represented, and for contributing to contextualized interpretations of the data.

On one hand the choice of methods, such as PEI, can help to balance power in the research process, however one may argue that this too can be potentially harmful. Methods that are considered “fun”, novel, and more attuned to children's competencies or interests may create an environment where the child is more comfortable or “at ease” with the adult researcher (Punch, 2002). This can be seen as an advantage, but also as a danger in the sense that the child may become *too comfortable*, rendering them vulnerable to unintentional disclosure, among other risks. Punch (2002) suggests using both traditional and innovative research methods to balance and address both ethical and methodological issues associated with research with children.

7.3.3 Representations of the Child

Closely related to issues of power, the ethical implications of how the voices and images of children are represented in research are significant ethical issues. Wang and Redwood-Jones (2001) raise the issue of participants being “placed in a false light by images and by words” (p. 566). The ethical imperative is on the researcher to be sensitive to how participants are being represented in both dimensions. Attending to one’s own reflexivity in the writing and dissemination phases of research reporting, recognizing the ethical imperative to represent the child with dignity, and acknowledging that researcher interpretations and representations of a particular child are only one of many possible representations would seem to be ethically important.

When deciding whether to use photographs in publications or presentations, researchers might consider ways to hide the identity of the child, such as pixilation, blurring the face or image, or perhaps consider not to use the photographs but rather to use only text in representation of the findings (Nutbrown, 2010). This raises another ethical debate about voice - by deciding to blur faces or not use photographs, even though you may have consent and assent, might researchers be silencing children in attempts to protect them? Nutbrown (2010) challenges decisions to distort images of children or not to include images of children in research despite consent, suggesting that such decisions contribute to the “Othering” of children in research. Nutbrown wrestles with the notion of presenting distorted pictures to represent the experiences of participants, and what the act of distortion might imply with respect to identity, voice, being true to participants, and integrity in research and as a researcher. She suggests that conducting research with an ethic of respect for persons, knowledge, democratic values, and quality of research might

not be possible if researchers choose to manipulate images even though they have full consent to use them. This debate contributes to the representation conundrum. Barron (2000) (as cited in Nutbrown, 2010) cautions researchers to consider moments when children potentially become “vulnerable to representations that others impose on them” (p. 33).

In our work, we have wrestled with the tensions that have emerged surrounding decisions to use photographs in publications and presentations. In a recent publication we considered using a photograph and corresponding text to illustrate an example of photoelicitation and its ability to tap into social dimensions that may otherwise remain silent. The photograph depicted a very powerful image of disability, which could be interpreted as an example of resistance to dominant discourses of disability. However, it could also be interpreted to display a more negative view of a child’s experience. We considered the importance of including this representation, yet at the same time were unsure of how the child or parent might feel five or ten years later, knowing that this picture was published in a book, where the child’s identity was clearly visible and potentially construed as vulnerable through the corresponding text. As we could not come to a decision we were comfortable with at the time, we decided not to use that particular picture as an example, nor to distort the image or add pixilation to hide the child’s identity. We are still wrestling with this tension, considering the arguments and counter arguments, drawing upon our own reflexivity, and engaging in reflexive dialogue to consider representation of this in future work. We recognize that the child has a right to her voice being heard (Lundy, 2007), however that it takes time and reflexivity to consider how to represent her voice while attending to her privacy, safety and dignity.

In addition, with methods such as PEI the risks of invasion of privacy become amplified (Wang & Redwood-Jones, 2001). Invasion of privacy may occur when photographs of others are taken without their knowledge. Researchers can attempt to address this concern through the use of written consent forms and assent forms for participants to use with others appearing in their photographs. However, as previously discussed, these forms and procedures have limitations.

Representation that maintains the voice, safety and dignity of the child is a fine line, and reflexivity on the part of the researcher may help to work through some of these ethical issues. Guillemin & Gillam (2004) suggest that reflexivity on the knowledge produced and how the knowledge is generated is also important. Asking questions such as “How do I know?” and “How do I know what I know?” (Hertz, 1997) may help researchers to better discern how to represent findings in an ethical manner. Considering how children or parents might feel about their photographs appearing in print five or ten years from now, and considering any nagging gut feelings lingering with the researcher, may also assist in discerning issues of representation. Furthermore, researchers might consider what the images add to the discussion: Are they necessary?, Do they supplement the text to provide a richer picture? or, Are they just an added novelty?.

Using photographs and text together can be more revealing and identifying by nature. If photographic images and text are to be used together in a larger document such as a book or thesis dissertation, the implications of all of these details in one place may raise additional ethical concerns. Despite pseudonyms used, the clear use of photographs together with detailed text from interview transcripts can allow for identification of the child and has the potential to compromise the child’s privacy and confidentiality. This

may be dangerous for the child, especially if what is represented is of a sensitive nature. Researcher reflexivity may assist in determining where, when and how the data is used together.

7.4 Becoming a Reflexive Researcher:

Guiding Questions for Research with Children

Discussing reflexivity in relation to ethics and research is one thing, however, enacting reflexivity in our everyday research practice is far more challenging, or shall we say, easier said than done. Guillemin and Gillam (2004) contend that “reflexivity does not prescribe specific types of responses to research situations; rather it is a sensitizing notion that can enable ethical practice to occur in the complexity and richness of social research” (p. 278). Although we agree with this statement, we are also aware that being a reflexive researcher may appear to be a daunting and unattainable task for some. The question “why be reflexive” turns into “how can I be reflexive”, and it is our hope that the questioning does not stop there. Recently, several publications have proposed considerations and guidelines to assist researchers in being reflexive throughout the research process. Nutbrown (2010) suggests deeply considering: a) the need for “guardians” of child participants, not “gatekeepers”, and the researchers’ responsibility in ensuring that the guardians have the information necessary to act in the interest of their children (p. 10), b) looking beyond the traditional notion of “protection” of research participants, to “a culture of caring, vigilance, sensitivity, and fidelity” (p.11), and c) the importance of self-reflexivity in order to see children not as Othered but as “*Otherwise*—having a different way of knowing” (p. 11). Warin (2011) suggests a set of

guidelines for the practice of reflexivity and ethical mindfulness, particularly for conducting research with children, where she elaborates and adds to the considerations raised by Nutbrown. Warin suggests practical ways to address Nutbrown's considerations, and challenges researchers to be explicit about their ethical practice in their published work, to commit to framing "consent as an ongoing and relational concept rather than a one-off activity" (p. 813), and to enhance their capacity for reflexivity by working the hyphen between self and others.

In addition to these considerations, we propose the following reflexive questions that may help to guide researchers as they begin to consider reflexive approaches in their research with children, see Table 5. These questions are by no means an exhaustive list, and are intended to prompt reflexive conversations in the hope of revealing ethical moments and points of consideration that may otherwise go unnoticed. Beginning with questions such as these, has the potential to generate additional questions specific to the research, and to encourage reflexivity to permeate through the work.

Table 5: Reflexive Research with Children: Guiding Questions

Ethical Issue	Reflexive Questions
Obtaining Assent	<ul style="list-style-type: none"> • In addition to consent from the parents, has assent from the child been solicited? <ul style="list-style-type: none"> ○ If images/photographs are being used, have the child and parent been consulted about potential uses/dissemination? • Has the child truly assented to participation? <ul style="list-style-type: none"> ○ How have I made the conscious effort to revisit assent throughout the research process? ○ What have I observed (or not) that leads me to believe the child has assented/dissented? Can I provide examples? Have I noticed any verbal/nonverbal cues? ○ How might I/others have influenced the child's decision to assent?
Disclosure	<ul style="list-style-type: none"> • Reflecting on the interview guide, context, and/or images used, what are the potential risks of unintentional disclosure? How have I ensured that the child and parent/guardian understands such risks? <ul style="list-style-type: none"> ○ How can I increase my own awareness/sensitivity to such risks? ○ Have I considered clarity versus care? ○ Is the child's dignity being upheld in all dimensions of the research process? ○ Is the child's emotional, psychological, physical, and spiritual safety being preserved in the research process? ○ Have I allowed the child to direct what he/she feels comfortable sharing?

Ethical Issue	Reflexive Questions
Power	<ul style="list-style-type: none"> • How have I presented myself to the child? How does the child perceive my role? <ul style="list-style-type: none"> ○ In what ways have I created a safe space? ○ What aspects of the research relationship are making me feel uncomfortable? ○ What aspects of the research relationship are flourishing? • How have I continued to offer opportunities for the child to withdraw? Ask questions? • How do the methods used contribute to balancing power dynamics and allowing for the child’s influence on the research? <ul style="list-style-type: none"> ○ Have I considered the benefits and risks to each method? ○ In what ways am I sharing power with the child in the research process? ○ Is the child’s right to share power with the researcher being upheld?
Representation	<ul style="list-style-type: none"> • Have I considered safety, dignity, and voice throughout the research and dissemination process? <ul style="list-style-type: none"> ○ What are my preconceived assumptions about children/childhood? ○ What are my intentions? Have I identified my “self” in the research? ○ Whose voice is represented in the text/images? ○ How might I be silencing participants’ voices?

7.5 Conclusion: A Call for Reflexivity

Reflexivity is often used to demonstrate rigour in qualitative research (Finlay, 2002; Finlay & Gough, 2003; Jootun, McGhee, & Marland, 2009); however, reflexivity can be used as a tool to enact ethical research practice (Etherington, 2007; Guillemin & Gillam, 2004; Nutbrown, 2010) at every stage of the research project (Punch, 2002, Warin, 2011).

As Guillemin & Gillman suggest: “Adopting a reflexive research process means a continuous process of critical scrutiny and interpretation, not just in relation to the research methods and the data, but also to the researcher, participants, and the research context” (Guillemin & Gillman, 2004, p. 275). They go on to state:

Being reflexive in an ethical sense means acknowledging and being sensitized to the microethical dimensions of research practice and in doing so, being alert to and prepared for ways of dealing with the ethical tensions that arise... reflexivity does not prescribe specific types of responses to research situations; rather, it is a sensitizing notion that can enable ethical practice to occur in the complexity and richness of social research. (p. 278)

Reflexivity begins before the research design. Nutbrown (2010) calls for reflexivity on the part of the researcher to examine “our own positionality, what brings us to the project, and what we really think about children” (p. 11). She also asserts, “we have to be clear about our values, the importance we give to children’s actions and views, how we value their perceptions, and how useful their view of the world is” (p.11). Reflexivity in relation to these issues and perceptions leads to the shaping of the research

design, process, implementation, analysis and dissemination. Ethical research practice is an overarching concern throughout this process.

Reflexivity as ethical research practice does not stop once data collection and analysis is complete. Holding one's decisions up to scrutiny until the last paper is written or the last image is revealed holds ethical significance. Not only is there an imperative to be cognizant of the way children are represented in the present but also in the near and distant future.

As Nutbrown (2010) contends:

Though it is probably never possible wholly to protect all young children—no research, however interesting, however important, should knowingly put children at risk and researchers who involve children in their enquiry must remain aware that they carry a constant duty of care to their young participants. (p. 8)

In this paper, we have highlighted particular ethical issues that researchers may face in research with children. Groundwater-Smith (2011) proposes the notion of *living ethical practice in qualitative research*, she calls for researchers to “put ourselves and our academic egos to one side and think instead of the well-being of those who are often vulnerable and lacking in power” (p. 209). Extending the discussion started by Guillemin and Gillam (2004), Ellis (2007), Etherington (2007), Nutbrown (2010), and Warin (2011) in *Qualitative Inquiry* (among others), we propose that a call for greater attention to reflexivity in qualitative research lies at the heart of *living ethical practice* in qualitative research and that the ideals of enabling child safety, dignity and voice serve as useful guides in the quest for ethical practices in research with children.

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8. Discussion and Conclusions

8.1 Introduction

This work concludes with a discussion of the implications of this work for occupational science, occupational therapists and health care professionals, social inclusion policies, and children and their parents, in light of the findings of the research and the dissertation as a whole. I discuss reflexive insights on the research process, including methodological insights, considerations, and my journey as a researcher. This is followed by a discussion of strengths and limitations, and directions for a future research agenda. Finally, I discuss the quality criteria used to evaluate this work, ending with concluding remarks.

8.2 Integrated Manuscripts: Telling a Story

I chose to complete this dissertation using an integrated manuscript approach. The manuscripts, together, tell a story of the work and how I have grown throughout the PhD process as a scholar and a researcher. The first manuscript (chapter two, entitled *Occupational Identity: Engaging Socio-Cultural Perspectives*) was inspired after completing a review of current literature on occupational identity and identifying a gap in socio-cultural dimensions in relation to the emerging construct. This led to an examination of identity theory from socio-cultural perspectives and to a proposal for the integration of such perspectives to notions of occupation and identity in occupational science.

The second manuscript (chapter three, entitled *Constructions of disability: A call for critical reflexivity in occupational therapy*) arose from critical conversations about my personal experiences in practice and essentially why I chose to pursue a doctoral degree and explore disability and identity in childhood at a deeper level. Upon reviewing critical disability studies literature, and engaging in reflexivity to interrogate my own assumptions and clinical practice experiences, I knew this was a new lens that would contribute to the design and analysis of my work. This manuscript speaks to my assumptions and new understandings pertaining to disability and how I view disability in this work. It also speaks to the implications of reflexivity for further conceptualizing disability in theory, practice and education, and enhancing occupational therapy's mandate as a socially responsible discipline.

The third manuscript (chapter five, entitled *Photoelicitation Interview Methods and Research with Children: Possibilities, Pitfalls, and Ethical Considerations*) discusses the photoelicitation interview methods used to engage children as active participants in the research. This manuscript contributes theoretical and practical knowledge pertaining to the use of photoelicitation methods with children, and illustrates it as a method worth considering when researching children's occupations from a child's perspective.

The fourth manuscript (chapter six, entitled *Childhood, identity, and occupation: Perspectives of children with disabilities and their parents*) presents the empirical contributions of this dissertation. The previous three manuscripts play a significant role in providing the foundation for this work and shaping this manuscript, in its theoretical frameworks, and consequently in its methodological design, analytic perspective, and the direction of the discussion.

The fifth and final manuscript (chapter seven, entitled *Picture this...Safety, dignity, and voice, Ethical research with children: Practical considerations for the reflexive researcher*) returns to the notion of reflexivity, which inspired the work from the beginning, and continues to play a prevalent role in thinking back about the ethical conduct of research on a broader scale. Ethical research practice was something that I was sensitive to in both theoretical and empirical research pursuits. During the conduct of this research, and as ethical issues arose, I became acutely aware that little is written about the ethical conduct of research with children, yet numerous ethical issues are at play. My interest in ethical clinical practice also contributed to this manuscript, as I see it is an integral component of holistic practice in occupational therapy and professional practice in general. This sensitivity contributed to my awareness of the potential for ethical issues to arise in research, and my desire to contribute to a conversation that might help to improve research practices with children, by contributing to researcher reflexivity in the field.

8.3 Implications for Occupational Science

8.3.1 Enacting Occupation and Identity...Occupation “as” Identity,

Occupational Identity, or Occupation “and” Identity

This research contributes to the scholarly conversation concerning occupational identity as a construct in the field of occupational science, particularly by advancing socio-cultural perspectives on occupational identity and by contributing to knowledge about the ways in which children enact identity through participation in occupation. In

chapter six (Childhood, Identity, and Occupation: Perspectives of Children and their parents) I discuss the complexities of “occupational identity” in light of the findings presented from this research. I discuss three dimensions arising from the study that contribute to further conceptualizations of how occupation is implicated in the shaping of identity for children with disabilities: identity and disability, identity as social, and identity as dynamic (see chapter six for a detailed discussion). Here I contend that this research raises questions about current conceptualizations about occupational identity, calling for further investigation that explores socially, discursively, collectively, culturally, and relationally oriented conceptions of occupation and its role in shaping identities in the dynamic sense. This work extends boundaries about conceptions of occupational identity to consider the socio-cultural dimensions (both visible and invisible, conscious and unconscious) that play a role in shaping what occupations children participate in, and also how, when, where, why and with whom. In just beginning to understand the relationship between occupation, socio-cultural dimensions, and identity, I question whether that the notion of *occupational identity* may be too static to encompass the dynamic nature of this relationship. For this reason, I am choosing to see occupation and identity as related, overlapping, but also as mutually exclusive, and I recognize that more research and scholarly work is required to examine and advance understanding of the complexities of this relationship. In addition to referring to the term *occupational identity* in my writing, I also use the phrase *occupation ‘and’ identity*, to represent how I see both *occupation* and *identity* as more complicated and larger than the sum of its parts.

8.3.2 Informing Occupational Constructs

8.3.2.1 Occupational Development

In general, there is limited research in OS and OT literature with respect to the understanding of children's occupations and identities. I propose that such research has potential to contribute to another emerging construct, *occupational development*, which is being studied from both a childhood and lifespan perspective (Case-Smith, 2005; Davis & Polatajko, 2004; Humphry, 2002). The construct of occupational development is in an early stage of conceptualization, and can be defined as "the gradual change in occupational behaviours over time, resulting from the growth and maturation of the individual in interaction with the environment" (Law, Polatajko, Baptiste, & Townsend, 2002). As scholarship on this topic continues to evolve, I suggest that interrelationships with aspects of occupational identity are a promising area for future elaboration and thinking.

In writing about occupational development, Wiseman, Davis, and Polatajko (2005) found that engagement in occupation was dependent on available opportunities, which were in turn influenced by resources such as time, transportation, finances, and the necessary physical materials. This coincides with the findings and beliefs of other researchers in the OS and OT fields (Case-Smith, 2005; Davis & Polatajko, 2004; Humphry, 2002), and also with the findings of this research, particularly the parents' perspectives. Wiseman et al. (2005) demonstrated that children have different motivators for engaging or not engaging in occupations: enjoyment, sense of flow, to receive praise or rewards, appropriate fit between abilities and demands, desire to try something new, opportunity to help others, and absence or presence of competition. Children indicated

that they engaged in occupations for the purpose of self-improvement, and thus occupational competence became a key motivator evident in Wiseman et al.'s (2005) account. It has been suggested in the literature that competence and self-efficacy are highly related to the creation of meaning and identity (Christiansen, 1999; Kielhofner, 2008). Children in this study described some of the same motivators for participation in occupations contributing to their identities. However children talked about occupations they perceived themselves as competent in, and others they perceived themselves as not competent in, as both contributing to their identities.

Humphry (2005) raises broader issues such as society's role in shaping the development of occupation and occupations that are co-constructed with others, as having implications for children's meaningful engagement and performance. The findings of this study support this perspective, and demonstrate the potential link between occupational development and occupational identity from a socio-cultural perspective. A socio-cultural approach to research and theory development has the potential to reveal understandings of the influence of the social world on constructions of childhood, children's occupations, development, and identities. Further research in this area may contribute to the understanding of childhood occupations in general; such research is much needed in occupational science.

8.3.2.2 Occupational Justice

I also see great potential for future research that links the construct of occupational identity with the occupational science construct of *occupational justice*. Such a link can promote attention to broader social issues and further enhance the relevance of OI research. Considering that the vision for occupational science is to

become more socially responsible and socio-politically relevant (Asaba, Blanche, Jonsson, Laliberte Rudman, & Wicks, 2007; Laliberte Rudman et al., 2008), connections to constructs need to be made at a broader and more global level. *Occupational justice* refers to opportunities and resources necessary for participation, inclusion, and full citizenship (Townsend & Wilcock, 2004). Considering the connection between occupation, socio-cultural (and I would expect socio-political) dimensions, and identities—occupational justice issues may be seen as having a significant role in shaping (occupational) identities. Townsend and Wilcock (2004) contend that diversity, inclusion, and shared advantage are connected to the concept of occupational justice. They assert, “in an occupationally just society no one would be denied participation in occupations that he or she needed or wanted to do to build their individual lives or their communities” (Townsend & Wilcock, 2004, p. 261). From an OI perspective, one might add: *and to build their individual, social, relational, discursive and cultural identities*. Considering my proposal (refer to chapter six, the empirical findings of this research) that what we are is not only what we do, but also what we don’t do, can’t do, will do, won’t do, like to do, don’t like to do, want to do, have access to do, are allowed to do, are forbidden to do, do now, did before, virtually do, etc.—constructs like occupational justice challenge occupational scientists to think more broadly about choice, sanction, access and inclusion and how these notions shape (occupational) identity. I believe this to be a generative area for future research and scholarship.

8.4 Implications for Occupational Therapists and other Health Care Professionals

“No genetic code, no chemical intervention, and no microsurgical technology will be invented to repair broken identities and the assault on meaning that accompanies them. Because of this, the new millennium will realize the health-enabling, restorative potential of occupation” (Christiansen, 1999, p. 556).

Drawing on both my clinical experience working in pediatrics and research experiences with children, I have begun to understand the significance for children with disabilities of having opportunities to participate in occupations, and how such opportunities can shape and reshape a child’s identity. Based on the findings of this study and observations made in practice, it appears that there are frequent gaps in social experiences, and these gaps often grow as children with disabilities progress through school. For some children, there are also physical and developmental gaps that become apparent, making it harder for children with disabilities to “keep up” with their peers. Eventually awareness of such gaps may threaten and/or shape children’s identities and influence the occupations they choose to participate in. Elaine alluded to this when talking about Laura’s experiences:

...and now she has become more aware of her identity. Things get harder too, and I think that is part of the reason. Like the social things, the academic part as you go into further grades, it gets a lot harder...to keep up, so...that has become a struggle and she is quite aware of that.

Similar ideas were depicted in a study conducted by Heah, Case, McGuire and Law (2007) that researched parents’ perspectives of their children with disabilities’ successful

participation. One parent described electing to switch the child from an integrated school, to a segregated school: “She was starting to really compare herself last year. Not so much in appearance, but definitely intellectually. She was noticing a big gap.” (Heah et al., p. 44).

In practice, I have witnessed both “positive” constructions of identity and damage to identity, as children transition through the school system. This ultimately appears to impact their success with respect to school-related activities, sense of self, and well-being. I propose that occupational therapists, other health care professionals and education professionals working in the school health sector could potentially play a role in facilitating generative occupational engagement by: promoting the discovery and maintenance of meaningful occupation; advocating for inclusion and full participation in both school and community environments; advocating for more social opportunities both inside and outside of the classroom; and generating awareness (with education staff, health professionals, policy makers, and parents) of the implications of opportunities to participate in childhood occupations, and what this might mean not only in terms of development, but for children’s identities. Knowledge and awareness of the various socio-cultural factors that shape occupation and identity (see chapter six) may help sensitize professionals to children’s experiences (past, present, and future), which in turn may provide opportunities for implementing proactive measures to foster accessible and inclusive environments (physical and social) that contribute to positive identities.

Reflexivity has played a significant role in this work shaping my theoretical perspective, raising questions for clinical practice, informing my approach to ethical research practices, and to considerations about rigour and quality in scholarly work. In

addition to having implications for research practice (see chapter seven, discussing reflexivity as a tool for enacting ethical research with children), I propose that reflexivity has implications for professional practice for occupational therapists and other health care professionals (see chapter three, manuscript entitled *Constructions of disability: A call for critical reflexivity in occupational therapy*). Based on my experience completing this dissertation, and my experience in clinical practice with children, I propose that in addition to critical reflexivity informing notions of disability in practice, that critical reflexivity may be applied to interrogate social structures, and policies and procedures that shape how professionals enact their practice. Used in this way, critical reflexivity may assist professionals in recognizing locations where children's identities and opportunities to participate in occupations may be threatened at a systemic level. Such dimensions may be overlooked with demands from institutional structures to produce quantifiable clinical outcomes with an emphasis on productivity (Stein, 2002).

8.5 Implications for Social Inclusion Policies

Further data emerged beyond what was included in the manuscripts. I intend to develop these findings into several manuscripts in the future. These data are significant and responds to the research question: How are socio-cultural factors implicated in children with disabilities' opportunities to participate in childhood occupations? A second cross case analysis, using the same analysis process as outlined in the methodology section, and focused on the above question was undertaken. Six major conceptual categories that represent the many socio-cultural factors implicated in shaping children's opportunities to participate in childhood occupations were identified: 1) Barriers and

Enablers to Participation (with sub categories: cost, geography, accessibility, policy, awareness of resources, availability of resources and supports, impairment and education, getting creative), 2) Being Included, 3) Risk, Safety and Protection, 4) Because “Its good for you...”, 5) Disability versus Ability , and 6) Negotiating Independence and Dependence. These findings have implications for social inclusion/exclusion and participation for children with physical disabilities in home, school and community environments. As an example, Elaine described the following vignette about Sarah’s experience at school:

I think that socially, that is a social time right she doesn’t have lunch with her friends because they have lunch in the developmental room. I mean she makes friends in there but it’s not her classmates so she doesn’t get that lunch social time, she doesn’t often get the recess social time, you know the social time will all be in classroom time. When you talk to your friends and hang out with your friends it’s usually on your lunch break right and she doesn’t do that, she doesn’t get that. Because they put all the developmental kids in, most of them are in the lunchroom, they get one lunchroom with a couple of supervisors for the staffing right. So they have their lunch in there and she socializes a bit with those kids but it’s not the same as having your lunch and then running outside for recess with your friend’s right. So that social time yeah is lacking in a way, and I don’t know about the rest of the time but how do you get around that right.

In addition, across cases children and parents described participation in a variety of different activities and sports in the community. However, the majority of the time

children's participation consisted of private lessons, very small groups, and limited team sport participation. Several examples illustrate this:

Shanon: And do you ride horses with anyone else, I know you go with Laura but is there anyone else, do you have a group or is it just you girls?

Sarah: It's just us and another girl.

Shanon: And how many people are in your class? [swimming lessons]

Laura: Well, actually it is not a class. It is just me and Jordan.

Shanon: So you have a ski class or is it just you and a teacher?

Beth: Just me and a teacher.

Shanon: Yeah. Does anyone else go riding with you at the same time?

Teresa: No, we have private lessons.

Shanon: Have you ever done it with a class?

Teresa: No.

Teresa even went as far as expressing her experience with a class, explaining her preference for private lessons in other activities, "I'd rather...have like a private lesson for crafts because, and cooking, especially cooking, because its kind of, I never get to do anything and its kind of annoying that I don't get to do everything and everybody gets to do a whole lot of stuff."

Social inclusion “can be described as being centrally concerned with people and populations having opportunities to participate in society and to enact their rights of citizenship in everyday life” (Whiteford & Pereira, 2012). Social exclusion is becoming a pressing issue in Canada at this time, particularly with respect to children with disabilities being excluded from public policy frameworks, definitions of ‘healthy’ child development, and community living (Luxton, 2002). Hertzman (2002) argues that “If our physical and social environments, and the institutions that govern them, systematically limit the chances of some groups of children to develop as fully as others, then this too is a form of social exclusion” (p. 1). The findings presented in this dissertation speak to some of these limited chances, particularly from the social environment in relation to others’ perceptions of disability and children seeking a sense of belonging at school and in the community. Considering that dimensions of identity may be shaped by opportunities to participate in childhood activities, work that investigates socio-cultural factors may lend itself to support social inclusion initiatives and promote greater participation, contribution, and citizenship for children with disabilities. An occupational perspective of identity may offer generative possibilities, addressing not only concerns regarding children’s development, but also addressing taken for granted dimensions such as children’s identities and perceptions of self, which can be shaped by opportunities to *do*.

8.6 Implications for Children and their Parents

This work may also have implications for children and their parents, as it raises many issues in the home, school and community environments. A better understanding of how socio-cultural factors shape opportunities to participate in occupations, and in turn shape identities, can alert parents to situations or environments that may not be meeting their children's needs—not just physically but socially. In addition, the findings may alert parents that they are “not alone” in terms of the socio-cultural barriers they encounter in trying to facilitate their child's participation in everyday activities. This knowledge may give parents the confidence to advocate for their children in school and community settings, to create more opportunities for participation, social experiences, and identity exploration in inclusive environments. In addition, being aware of how various socio-cultural factors shape occupation and identity may alert parents to opportunities for participation they might consider fostering in the home environment, in light of the potential occupations have in shaping who the child is becoming.

8.7 Reflexive Insights on the Research Process

8.7.1 Methodological Insights

8.7.1.1 Reflexivity and the Research Context

The context of the research is important to consider when interpreting the data, and thinking about implications and directions for future research. This work was conducted and situated in the Canadian context. The Canadian context is generally

comprised of Western values, prioritizing an individualistic perspective that values the promotion of choice and independence. In addition, it is also shaped by particular seasons, holidays, traditions, governing bodies, etc. Each participant also brings his or her own experiences, cultures, beliefs, traditions, etc. to the research, again situated within the broader Canadian context. And finally, I bring to the research my own experiences, cultures, beliefs, traditions, etc. situated within the broader Canadian context. Many of these preunderstandings have shaped the design of the study, the questions asked, the photographs taken, the comics created, the interpretation of the data, and the conclusions drawn. In this light, I am not able to illustrate or capture all of the socio-culture factors that shape identity and opportunities to participate in occupation. I can only represent what has come to light in this particular study. Many of the unique attributes of each individual case do not get full exposure in a cross case analysis, even though I believe they deserve merit and contribute to the work as a whole. Overall, It is not my intention to generalize the findings of this study, but to present them as one interpretation of the data I have gathered.

Although I did not collect demographic data, which looked at ethnicity or socioeconomic status, I cannot help but question how such dimensions may have contributed to this work. It is my guess that the majority of families were of “middle class”. I assume that this played a significant role in children’s opportunities to participate in occupations, especially leisure occupations and paid programs. I initially expected that some children would have very few leisure or extra-curricular opportunities because of costs associated with them, and potentially because parents might have to spend more time at work versus at home with their children to cover day-to-day expenses

of having a child with a disability. Although cost was discussed as a barrier to participation, it was not as much of a concern as I anticipated. Perhaps if my sample included families with a variety of different socioeconomic statuses, my findings would look much different.

Children and their parents were recruited through a local children's rehabilitation center, which offers many resources, programs, and recreational programs. So essentially I recruited from a population who was already accessing services, which might assist these families in finding opportunities to participate. Recruitment was very difficult in general (14 months to recruit six children and parents), and I could imagine it being even more difficult without the help of a children's centre in accessing this particular population. But again, I could imagine the findings being much different if I were to be able to locate families who were not already connected with supports and resources in their communities.

The majority of the cases represented white middle class families, with only one family being from a Middle Eastern country. This particular case, the case of Simah and Amar was unique in many ways, and may not be fully represented alongside the others. Cultural nuances played a role in opportunities to participate in occupations, shaping of multiple identities, and even in the research process in general. My experiences with this family were unique. I was treated not as a researcher, or support worker, but as an honoured guest. In each visit time was spent just chatting, sharing food and drink, and meeting all members of the family. The notion of 'family' permeated all sessions, interviews, and photographs. Interviews took place as a family. To my surprise, the family decided on their own that instead of taking photographs, they wanted to use

photographs that they had taken as a family to represent “who Amar is”. Together, the family decided upon 72 photographs. When finding this out after developing the photographs and arriving to the second session with Amar, I felt a sense of panic and anxiety, as this was not the protocol I had designed and followed up until this last and final case. However, it really was the only way that made sense to them, and it worked. I learned a lot from this experience and garnered insight on how I would approach using photographs in the future to represent identity. I feel that this cultural piece was lost on the cross-case analysis, and it is my intention to develop a manuscript based on this case alone to pay it due diligence.

Finally, I also recognize that gender was not addressed in this work, yet I do think it is something that I would like to explore more deeply. First, five of the six children were females, and all of the parent participants were mothers. I suspect if more male perspectives were brought into this work the findings may potentially reveal some gender-related dimensions. Interestingly, two of the five female child participants expressed identifying more with boys than girls. One of whom went as far as expressing that she preferred to wear a boy’s bathing suit versus a girl’s bathing suit, which was one of the reasons she quit competitive swimming. Although this finding was not prominent enough to result in its own theme, perhaps a secondary analysis of the data may reveal more to this regard. I wonder if these children identified more with boys at this time in their identity development secondary to many of the added pressures on girls to meet certain expectations of image, body, and persona permeating in popular culture. I cannot say for sure based on the data, however can not help but question and raise this as a question for future research.

8.7.1.2 A Picture is (not) worth a thousand words...

One of the reasons I chose photoelicitation as a method was based upon the notion that ‘a picture is worth a thousand words’. As discussed in chapter five, it has been well documented in the literature that visual methods, including photoelicitation methods, have proven to be successful in eliciting children’s perspectives in research (Burke, 2005; Cappello, 2005; Epstein, Stevens, McKeever, & Baruchel, 2006). After completing this research, I agree with this sentiment to a certain extent, however I contend that such methods are only successful if you are able to recognize their limitations and work with these limitations to reveal what is beyond the borders of the image.

The use of photographs, technology, computer software and the creation of the comic was a gateway into children’s experiences, perspectives, and trust. Interview sessions with children averaged one hour to one hour and 15 minutes (with some interviews approaching the two hour mark). Based upon my experience working with children as an occupational therapist, I was shocked at the length of time children were engaged in each session. Even their parents appeared to be shocked. I do not believe I would have elicited the amount of data I have if I had not used the photographs and comics.

That being said, the use of the photographs did not come without its disadvantages. Although I had built in questions in my interview guides that probed beyond the ‘frames’, it was very difficult to get children to think outside of the pictures we had in front of us, even after I had put the pictures away. This became a challenge, and perhaps without the photographs placing boundaries on our discussions, children may have told very different stories; past, present and future. Mitchel (2008) alerts us to

consider the partial reality of the photograph. Emmison and Smith (2000, p. 40, as cited in Mitchel, 2008) contend a photograph “must be considered a selective account of reality”. Much like the partial reality of identity, the partial realities in the photographs may have shaped identity during the interview sessions. Perhaps this is not necessarily a limitation, but more an aspect to recognize and help situate the data.

Interestingly, aesthetics became a factor in decision making for children, especially when choosing pictures to include in the comics. This was not something I initially considered, but something I could sense happening during some of the sessions. Some children appeared to be fixated on what the overall image looked like, not necessarily the “meaning” or intended representation of the meaning. For example, Laura was attempting to select pictures for her comic and the following is an excerpt of our conversation:

Laura: Sorry, I am just...

Shanon: That’s ok.

Laura: Um...um, this one. [choosing photographs]

Shanon: That one and then...

Laura: It is still blurry. I thought it wouldn’t be blurry if I did that...

When her comic was developed and we were about to start to discuss some of the questions during session three, Laura remarked:

Laura: What are we going to do if we don’t like it, like...

Shanon: Like if you don’t like the picture, or if you don’t like the activity?

Laura: No, if I don’t like the picture.

Shanon: You don’t like that picture?

Laura: No, if I don't like a bunch of these pictures.

Shanon: What would we do?

Laura: Yeah if I didn't, just say if I didn't like one of these pictures I could like, what would you do if I didn't like this?

Shanon: Well we could just talk about what you would rather have there instead...is it the pictures that you don't like, or the activities that you don't like?

Laura: The picture's a little bit dark.

Shanon: They are a little bit dark.

Laura: It's a little bit red.

Shanon: It is a little bit red.

Laura: Why's it so red?

Shanon: I think because it just didn't turn out very well on the camera.

Laura: My face looks all red like I'm angry.

As you may be able to tell, I was surprised by her response in the moment, and did not really know how to respond, especially since Laura was only the second child I was interviewing. I was trying to buy some time, think of what to say or do. In reflecting on it however, I am not surprised that she would be concerned with how the pictures turned out. Perhaps I would too. I think about myself, choosing pictures to frame and hang on the wall, I choose the ones that are aesthetically pleasing even if they are not necessarily representative of the most meaningful moments. This made me realize that the aesthetics of the pictures may be playing a more significant role in representation of children's identity than I had originally thought. Although recognizing it at first, I did not

really see how it might play out as a whole. In this moment I tried to redirect Laura to the occupations themselves, and in future sessions tried to reiterate that it doesn't matter what the pictures look like, the meaning behind the pictures was more important. I am not really sure if children really understood or accepted that. I question whether or not it was possible for them to separate aesthetics from meaning, especially living in a society that really values aesthetics and success. It may run far deeper than mere "choice".

In addition to these thoughts, a more thorough discussion of reflexivity and visual methods is presented in chapter seven. To revisit the proverbial phrase, *a picture is worth a thousand words*, I now see it more as *a picture may not be worth a thousand words, but it might help to start a 'particular' conversation...choose wisely!*

8.7.1.3 You may be wondering...where are all the pictures?

Ethical issues concerning representations of the child through images were discussed in-depth in chapter seven. Revisiting this topic here, I still do not have answers as to how one might go about representing the child through photographs while attending to the child's safety, dignity, and voice. I wrestle with not including photographs, wondering if I am silencing children and their perspectives. I also question why I really want to include the photographs, is it because of the meaning or the aesthetics (as previously discussed). At the same time it is much more complicated than that. I am concerned about how they may be interpreted by others, and concerned about making a decision that might harm a child and that I might regret in the future. For now, I feel it might be safer for the children if I continue to be critically reflexive before deciding how to use the images in the future. Complications also arise with consent. In particular, one child clearly chose not to have any images included in publications or presentations. In

addition, some people who appeared in photographs or comics chose not to consent to publications and/or presentations. If I only include a select few photographs or comics, how might this represent the data as a whole? I question, do I really need the images to convey the thoughts, ideas and perspectives represented in this work. And finally, do they really need to be all in one place alongside many quotes, findings, reflections, and contextual factors? Perhaps in a dissertation, the images with the text could be too identifying.

After many sessions of debate, Anne and I decided to leave the images out of this document. This decision was not easy, and is still unsettling, but we contend it is better than blurring faces and distorting images (Nutbrown, 2010) and better than only representing a select few images, considering that too may shape the data in ways we might not intend. We have however chosen to include images in presentations if they add to the purpose of the presentation and are necessary to tell the story of the research. Since presentations are not permanent published documents, and do not include many identifiers, I feel that this is a good compromise. Everyone will have a different opinion on this choice. I too may change my mind in the future. Recognizing that we have jumped sides on this debate many times, even within the same conversation, a choice had to be made, and we chose the option that we felt best represented the interests of the child and that we were most comfortable with.

8.7.2 Almost five years later...Rediscovering the Self

As I sit here writing this last chapter, in this all too familiar room, at this all too familiar desk, sitting on this very worn down, well-used desk chair, I can't help but reflect upon the last four years and eight months. Beginning this journey I bought a piece of art at a local art shop, for my home office, for some inspiration. A painting with the following words:

Find your space...

There is a space

Where you discover yourself

Where your core is inspired and nourished

And creativity knows no boundaries

A space where your dreams merge with your passion

And drive to make them happen

A space where your spirit and imagination begin to harmonize

A space where you feel free [author unknown]

These words really spoke to me. I came back to university in pursuit of such space, as I felt constrained in the environment I was working in as a therapist. I had high hopes that I would find this space, and find it quickly. Little did I know that it would be such a journey, emotionally and physically. In writing the words of this poem, I can't help but feel emotional, and at the same time realize how lucky I am to have found such a space—in my research and in my writing.

I think the pivotal moment for me was discovering a more critical perspective.

Thank you to Anne Kinsella, Sandy Deluca, and Lilian Magalhães for reminding me to

“put it up to question”. So many lingering tensions and discomforts stemming from practice were finally named. My whole reality was flipped upside down, turned inside out, and perhaps in its new contorted state, set ‘right’ again for the time being. I have a new lens, a new way to examine the world, and it looks upon a space where I feel free. Reflexivity became a comfort and a curse. As I became more aware of my self, I was not sure how comfortable I was in my own skin. But working through these tensions on my own, with Anne during hour long meetings that quickly turned into three or four, and with critical companions (friends, mentors, and family), I began to reconcile some of my previous assumptions, forgive myself for thoughts or actions beyond my consciousness, and finally gave myself permission to just be thankful for the opportunity I have had to rediscover a new emerging, dynamic self in the “messiness” of it all.

Studying identity is no easy task. It is not something you can hold, touch, capture, see, or predict. In fact, at times I remember telling others, “every time I think about it for too long, it hurts my head!” Attempting to research identity can be frustrating, confusing, and at times I felt like my mind was in complete overload trying to make sense of it all. Think about how you would answer the question “How would you describe your identity?”. Could you do it? Are you comfortable doing it? Do you start, and then stop not knowing what to say? Does it make you uncomfortable? Does it depend on who is asking you? At first I thought it was an easy question, and now I realize that perhaps the answer I would give is shaped by so many factors, conscious and unconscious. A partial reality. One truth of many. How do I want to be represented? What would I leave out, perhaps by choice? How would you know? How do I want you to see me?

I can tell you that I have learned so much in this process, more than I can put into words. The children have taught me how dynamic, fleeting, multiple, relational, complex and ‘in the moment’ identities really are. It isn’t possible to “prove” it, name it, or fully explain it. The best I can do is share with you my perspective on how I saw it if only for a moment.

8.8 Strengths and Limitations

Some of the strengths and limitations of this work have been previously discussed in chapter five, where strengths and limitations of the method and practical considerations generated from this experience are discussed. Also, some additional strengths and limitations have been discussed above in section 8.6 through a reflexive lens. The following summarizes the most pertinent strengths and limitations.

8.8.1 Strengths

There were several strengths to this study. In particular, the use of photoelicitation appeared to break down barriers between the researcher and the child, giving the child more power and choice with respect to how they represent themselves and their occupations. This method also allowed the children to express themselves through images, which appeared to overcome some language and expressive barriers (Dell Clark, 1999; Harper, 2002; Phelan & Kinsella 2011; Prosser & Burke 2008), particularly for children whose disability affected verbal communication.

Interviewing parents elicited diverse perspectives, which allowed for comparison between individual and social perspectives with respect to identity and occupation. The

combination of perspectives: child, parent, individual and social, brings new knowledge to the field and advances conceptions of occupation and identity in childhood. Multiple interview sessions with each child was also an advantage for the development of rapport and for understanding the dynamic nature of children's identities and occupations.

Case study methodology allowed for indepth exploration of occupation and identity from multiple perspectives and using multiple methods. The opportunity to analyze each case as a whole, and then complete a cross-case analysis attending to the common and unique attributes of each case, speaks to the capacity of case study methodology to attend to the complexities of phenomena such as occupation and identity and to advance knowledge about emerging constructs. The findings from the cross-case analysis are presented in this dissertation, however I also intend to develop the individual case findings in the future. This work has practical utility for the education of clinicians and students through conferences, workshops, seminars, courses, and publications as it presents indepth exemplars of how occupation and identity are enacted and embedded in socio-cultural dimensions from the perspectives of children and their parents.

Another strength of the study was the adoption of a socio-cultural lens to study occupational identity and the generation of new theoretical work to advance such a perspective in the field. The majority of existing research has discussed occupation and identity from an individualistic perspective, however this dissertation contributes to a broader conceptualization of occupation and identity as entrenched in socio-cultural structures (Phelan & Kinsella, 2009). This perspective adds to the current body of literature, and highlights how a dialectic between the individual and the social plays a role in opportunities to participate in occupation and in the shaping of identities.

Another strength is the use and promotion of researcher reflexivity, and concern for ethical issues such as the safety, dignity, and voice of the children throughout the process. In wrestling with difficult decisions about the use of photographs and the interviews with children, the ethical conduct of the research was a strong point of the process.

My previous background as an occupational therapist working in school health with children with disabilities may also be seen as a strength of the study. This background allowed for increased sensitivity to issues arising within the interviews, a capacity to communicate with the children, and an ability to adapt to children's needs with respect to their attention spans and engagement with the process. My experiences in clinical practice also allowed for an indepth consideration about what a critically reflexive lens might bring to work with children (as discussed in chapter three) and to the research project in general (as discussed in chapter seven).

Finally, both children and parents appeared to enjoy participating in the study. Children were engaged for long periods of time (average interview session was one hour to one hour and 15 minutes). For instance at the end of our third session Elissa said "Aww. I could do this all day!", and after the parent session Leslie stated: "It was a blast!".

8.8.2 Limitations

In addition to some of the limitations discussed in section 8.7, there were several additional limitations to this study. Children were given only two weeks to take photographs, which provided only a snap shot of the child's occupations over a short

time, and children's occupations evolve frequently. Some parents reported that their child took all of the photographs at the end of the two-week period in a rush to complete the project; perhaps more time may have alleviated the need to rush. For Amar, he and his mother decided to use photographs that they already had on his computer, despite the original instructions. This offered him a wider range of occupations with which to represent himself. Incorporating both new and previously taken photographs may be a consideration for future research. In relation to the comic, each comic included 10 photographs (based on space, limiting the comic to one page). This decision was made for practical reasons. However, children were limited in what pictures they could choose to represent themselves. For example, Beth expressed: "I found it [comic] a little small...like maybe I could write you one more line of squares." and "I can't relax with it...just ten pictures that have nothing to do with each other except for me and my life." Perhaps an opportunity to create an additional page would have been helpful, although it would likely mean creating another session, which could be difficult for families to commit to in terms of time.

The participants of the study were also predominantly female, limited in number, and the children had a wide range of abilities. This was satisfactory given that the study was exploratory. Nonetheless, to attend to the subtle nuances of identity, disability, and gender (among other factors) a more focussed sample may be fruitful for future research. Finally, only mothers of the children agreed to participate in this study, leaving the father's perspectives absent. Future research that includes the father's perspective is encouraged.

Another limitation was the amount of time required of families for participation in the study. Recruitment was extremely difficult, which may in part be attributed to the amount of time and commitment required to participate in the study. While the time spent with the families was a considerable strength for rapport building, and for generating a significant depth of rich data, it may also have contributed to challenges with recruitment. In retrospect, I wonder if recruiting from multiple sites may have assisted in increasing the size and diversity of the sample.

8.9 Directions for Future Research

8.9.1 A Program of Research: Children, Occupation and Identity

This work is just the beginning of a discussion around children's occupations and identities. First, I chose to interview school-age children (considered 8-12, however the children who participated were between 10-12). I made this decision based upon the premise that at this age children were beginning to discover more occupations and occupational choices, however not quite at the stage where they were negotiating what Erikson (1963) would deem *Identity Confusion and Crises*. Although there are limitations to Erikson's stage theory of child development, it proved helpful in considering the sample for the study. Erikson (1963) describes late childhood as a period of time where children focus more on industry, or being productive (*Stage 4: Industry vs. Inferiority, 5-12 yrs*). Children begin to learn that one can win recognition by producing things, from which they develop a sense of industry. School life takes greater precedence over other activities, driven by the desire to be industrious. During this stage, children become ready

to apply the self to skills and tasks beyond playful exploration. Erikson (1963) proposes that the “*fundamentals of technology* are developed, as the child becomes ready to handle the utensils, the tools, and the weapons used by the big people” (p. 259). This stage is also the beginning of the first sense of a division of labour and of differential opportunity. During this stage, society becomes significant in shaping what is accepted as meaningful roles. All of these changes lend to the development of identity. I saw this age as a good opportunity to begin exploration of childhood occupations and identities, as I suspected children would be more engaged in a diverse range of self-care, productivity and leisure occupations. I recognize that Erikson’s theory is situated in a North American context that often values productivity and individualistic perspectives. Such values are implicit in Erikson’s notions of childhood and they shape understandings of childhood and development in a particular way. Nonetheless, this perspective was helpful in that it helps to make apparent the socio-cultural factors that appear to shape identity in contrast. Knowledge about both perspectives is also key to understanding the dialectic between the individual and the social dimensions. Future research, exploring children’s identities, occupations and participation, both younger (early childhood) and older (youth and teen), from a perspective that recognizes the dialectic between individual and socially oriented dimensions, is needed to garner a better understanding of how identity is shaped over time and under multiple socio-cultural factors and circumstances.

In this study I chose to interview children with physical disabilities, without specifying a specific diagnoses, as the study was exploratory in nature and represented novel research in the field. Future research is needed to address perspectives of children

with a variety of disabilities (physical, intellectual, mental, dual diagnoses), and also children without disabilities.

This study was limited to perspectives of children and their parents, however there are many other influences in children's lives. Integrating perspectives of teachers, educational assistants, support workers, therapists, coaches, peers, siblings, relatives and mentors would generate prolific discussion about how identity is shaped from a broader socio-cultural perspective.

In addition, future research may adopt different methodologies in order to garner findings from different angles and perspectives. I have found case study to be a helpful methodology to conduct exploratory and flexible research, while still being able to look at multiple perspectives and integrate a variety of data sources, while analyzing them as a whole. I also suggest the consideration of narrative and grounded theory methodologies for future studies.

Narrative inquiry is a popular method used in social science disciplines to gain access to one's identity (Boydell, Goering, & Morrell-Bellai, 2000; Chase, 2005; Kraus, 2006). This methodology is becoming more popular in occupational science as a means to explore occupation and its constructs, specifically occupational identity (Braveman & Helfrich, 2001; Goldstein, Kielhofner, & Paul-Ward, 2004; Howie, Coulter, & Feldman, 2004; Segal, 2005). Narrative analysis allows the researcher to explore the relationship between participants' dynamic construction of the self, and obtain valuable insights with respect to social, cultural, and historical circumstances that permit or limit construction, which in turn creates depth in research (Chase, 2005).

Charmaz (2004) suggests that grounded theory methods are suitable for “studying individual processes, inter-personal relations, and the reciprocal effects between individuals and larger social processes”, including identity (Charmaz, 2004, p.498). Charmaz has successfully used grounded theory from a constructivist perspective to study processes of identity reconstruction and adaptation in the face of chronic illness (Charmaz, 1994; Charmaz, 1995). In OS research, the use of grounded theory methodologies and methods are gaining popularity (Britton & Moore, 2002; Farber, 2000; Isaksson, Lexell, & Skar, 2007; Jackman & Stagnitti, 2007; Segal, 2000). However, its use in investigating identity and occupation or occupational identity is very limited (Reynolds, 2003). Stanley and Cheek (2003) validate the lack of attention to grounded theory in occupation based literature, and draws attention to the promise of such a methodology, given the early stages of research related to generating theory.

Future possibilities are virtually endless in this area of research, as there is much work to be done to further conceptualize occupation “as” identity, occupational identity, or how I am currently coming to see it—occupation “and” identity in relation to children. It is an exciting time for both occupational scientists and therapists interested in this area of work, as it presents an opportunity to generate new ideas at a time when children’s occupations are gaining more recognition in government agendas (Active Healthy Kids Canada, 2011).

8.9.2 Where will I go from here?: Proposing my next steps

Secondary findings from my doctoral research have raised questions that inform my future program of research. First, I plan to *critically examine current social inclusion policies in community and education settings to examine the ways in which they promote or create barriers to inclusion and participation for children with disabilities*. Social inclusion became an underlying theme in my doctoral work, both in relation to children's everyday activities and their experiences within the education system. As an occupational therapist working in schools, I witnessed tensions within the system with respect to the facilitation of inclusive social and physical environments. It is with both of these experiences that I have developed an interest and passion for social inclusion policy development.

Second, I plan to expand upon my research by further examining the *socio-cultural dimensions that shape participation in everyday activities for children with a variety of disabilities, and explore how such participation contributes to perceptions of identity, health, and well-being*. This objective is timely and relevant considering participation in childhood activities have recently been highlighted in proactive efforts to foster health and well being in Canadian youth (Active Healthy Kids Canada, 2011). I am also interested in how occupational therapists can implement intervention strategies to foster participation, positive identity, health and well-being, and how they can advocate for children with disabilities at the broader population health level.

Third, I plan to examine the *ethical issues occupational therapists face when working with children and families to enable inclusion and participation in childhood activities*. As an occupational therapist working in school health, I experienced ethical

tensions on a daily basis while navigating the health care system, education system, and working with team members, children and their families. Research on ethical issues in occupational therapy practice has primarily focused on generalized issues, issues concerning adult/older adult populations, or issues experienced by student therapists (Foye, Kirschner, Brady Wagner, Stocking, & Siegler, 2002; Kinsella, Park, Appiagyei, Chang, & Chow, 2008). Understanding the unique ethical issues encountered by occupational therapists in pediatric rehabilitation settings is an area of research worth exploring to assist therapists in meeting best practice standards, to inform occupational therapy curricula, and to contribute to health care policy development.

8.10 Quality Criteria

In case study research, there are few resources pertaining to quality of the work. Stake (1995) outlined a critique checklist for a case study report. Creswell (2007) lists his own six criteria for evaluating a “good” case study. Such guidelines appeared to be vague and did not fit well with this research, considering I did not approach case study methodology in a traditional way, nor did I complete a traditional case study report. Yin (2009) suggests the use of construct validity, internal validity, external validity, and reliability—which do not align with a constructivist-constructionist paradigmatic position. Merriam (2009) also suggests using Lincoln and Guba’s (1985) quality criteria (credibility, consistency/dependability, and transferability), however, they appear to have inherent post-positivist underpinnings (Morrow, 2005). To evaluate the quality of this work, I have drawn on a bricolage approach, combining various criteria from various scholars to fit the nature of this study. I have combined elements of Charmaz’s (2006)

criteria to align with my approach to analysis, as well as Morrow's (2005) criteria for trustworthiness, and a combination of Finlay (2002), Hesse-Biber and Piatelli (2007), Morrow (2005) Warin (2011), and Phelan and Kinsella (In Press) for attention to subjectivity and reflexivity in relation to rigor.

8.10.1 Adequacy of the Data

Morrow (2005) suggests that the researcher assess the *adequacy of the data* as a means of quality assurance. Adequacy of the data goes beyond number of participants or interview transcripts, and is more concerned with "information-richness of the cases selected and the observational/analytical capabilities of the researcher" (Patton, 1990, p. 185). Purposeful sampling was used based on particular inclusion and exclusion criteria to select cases that would provide rich data pertaining to the research questions (Morrow, 2005).

Data collection was an iterative process, sensitive to the emergent data. Literature on occupation, identity, disability and participation interpreted through a socio-cultural perspective informed the interview guide. In addition, observations during the interview sessions, text from log books, and time spent with the families continued to inform the interviews leading to spontaneous questions about what was observed and what was absent. Polkinghorne (2005) advocates for multiple interviews with each participant to ensure depth and richness of data. Three sessions were conducted with each child to build rapport and garner rich data. One session was conducted with each parent formally, however, parents were consulted or often a part of additional sessions with the child.

Morrow (2005) recommends the use of multiple data sources to achieve “*adequate variety in kinds of evidence*” (p. 255). Morrow (2005) contends, “the more variety in the data sources one is able to obtain, the greater will be the richness, breadth, and depth of the data gathered” (p.256). In this study multiple data sources were used: PACS assessment, photoelicitation interviews, photographs, comics, photograph logs, semi-structured interviews, and reflexive journals/dialogues.

Finally, Morrow (2005) suggests seeking disconfirming instances in the data to compare with confirming instances in order to understand the complexities of the phenomena and develop categories that reflect participants’ experiences as best as possible. By completing analysis of each case separately before conducting a cross case analysis, both confirming and disconfirming instances were sought by attending to the complexities of each case, and the commonalities and unique features across cases. Constant comparative analysis techniques (Charmaz, 2006) assisted with understanding the complexities and comparing and collapsing categories and sub-categories.

8.10.2 Adequacy of Interpretation

Morrow (2005) advocates for adequacy of interpretation during data analysis, interpretation, and dissemination. She asserts, “immersion in the data is essential” (p. 256). I attempted to immerse myself in the data beginning with data collection and transcription. Transcripts, photographs, comics, assessments, logs, and reflexive notes were repeatedly read and revisited. In reading each transcript I found it necessary to listen to the audio (or watch the video for participants who were video recorded), in order to contextualize the text and “re-live the moment”. I found this extremely effective for

analysis and interpretation. This technique often invoked embodied responses that signaled the need for: reflexivity, transparency, acknowledgement of my own assumptions and preunderstandings, and further analysis. Park Lala and Kinsella (2011) contend that witnessing and attending to our own embodied responses in research, “we may begin to better understand the phenomenon at hand and how our bodies serve as a means of perception itself” (p. 85).

Morrow (2005) asserts that an analytic framework should be utilized and articulated to interpret the data. This process was detailed in chapter two (theoretical perspective), chapter three (theoretical lens), and chapter four (data analysis procedures and techniques).

Finally, Morrow (2005) contends that an adequate and balanced amount of supporting quotes and researcher’s interpretations should be presented in dissemination efforts. Chapter six (empirical manuscript) has been submitted to the Journal of Occupational Science in this form, and I have attempted to include a significant amount and variety of participant quotations, including both parent and child perspectives. I have also provided my own interpretations and have been reflexive throughout the research process in attempts to be transparent in terms of my epistemological stance, my involvement as the researcher, and the lenses through which I have interpreted the data. I have also attempted to be cognizant of including adequate and balanced supporting quotes in recent conference presentations and public presentations; including a variety of quotes, letting the quotes speak for themselves, and being as explicit as possible about my position as the researcher and my interpretations of the research. Adopting a reflexive methodology (see chapter four for a deeper discussion on reflexive methodologies) has

also assisted with this approach, in that I view reflexive methodology as an approach to research in which the researcher explicitly adopts a reflexive gaze with respect to the conduct of research and its interpretation (Alvesson & Sköldbberg, 2009).

8.10.3 Credibility

Charmaz (2006) lists questions for the researcher to help determine the *credibility* of the work. These questions attend to the adequacy of data and interpretation (described above). In addition, Charmaz asks, “Has your research provided enough evidence for your claims to allow the reader to form an independent assessment –and *agree* with your claims?” (p. 182). I have remained sensitive to the design and purpose of the study, ensuring that I contextualize this work and not claim it has generalizability. This work contributes to conceptualizations of constructs in occupational science and occupational therapy disciplines, and potentially has practical implications for different groups as discussed earlier in this chapter. As mentioned above, I have made every effort to include as many participant quotes as possible in the manuscripts, being mindful of the space allotted for the journal. As is, chapter six, the empirical manuscript on childhood, identity and occupation, exceeds the length specified by the journal. However, after a request to the editor for the journal to consider a longer manuscript and brief review of the paper by the journal editor, it was invited at this length for submission.

8.10.4 Originality

Charmaz (2006) suggests *originality* as a criterion for quality research, advocating for research that: offers new insights, explicates social and theoretical significance, and considers how the work refines, extends and/or challenges current concepts. Considering no empirical research directly examining occupation and identity for children with physical disabilities has been conducted as of yet in occupational science or occupational therapy, this work offers new insights and generative possibilities. Contributions of this work inform emerging theories on occupation and identity, particularly through a socio-cultural perspective, which up until recently has been limited in occupational disciplines. It challenges current conceptualizations of occupational identity, which typically are rooted in an individual perspective (Phelan & Kinsella, 2009), and extends this work across the lifespan (where the majority of the focus has been on adults and older adults).

8.10.5 Resonance

Resonance asks the researcher if they have revealed both liminal and taken-for-granted meanings, drawn links between larger collectives and individuals, and if it offers deeper insights about participants' lives and worlds (Charmaz, 2006). By employing both a socio-cultural and critical disability lens to the work, I have sought out liminal and taken-for-granted meanings by: (1) seeking an understanding of the often unnoticed socio-cultural factors shaping identity and opportunities to participate in childhood occupations, and (2) seeking an understanding of social constructions of disability in relation to identity and opportunities to participate in childhood occupations. A socio-cultural perspective and my intent to understand the dialectic between the individual and

the social in relation to occupation and identity, has assisted me in drawing links between the larger collective and the individual. The multiple data sources and perspectives elicited (including the child perspective, parent perspective, and my own perspective as the researcher) have garnered deep and unique insights about children's occupations, identities, and experiences in a variety of contexts. The published and in press manuscripts held resonance with the journal editors and peer reviewers who agreed to publish the work, the participants expressed resonance with the process through their authentic participation and positive feedback about the process, I experienced resonance with participant responses in light of my past experience as an occupational therapist, and my dissertation supervisor Anne Kinsella expressed her sense of resonance with the insights garnered in the research presented here.

8.10.6 Usefulness

Charmaz (2006) advocates for interpretations that people can use in daily life, that ignite areas of future research, and that contribute to knowledge. I have suggested practical implications of this work for occupational science, occupational therapists and other health care professionals, social inclusion policy initiatives, and parents and their children. I have outlined directions for future research, suggesting avenues to refine, extend, and challenge existing knowledge. I have also outlined how this work has contributed to knowledge, in this chapter and also through dissemination of manuscripts integrated within this dissertation.

8.10.7 Subjectivity and Reflexivity

Reflexivity allows researchers to analyze how subjective and intersubjective dimensions shape their research (Finlay, 2002). Morrow (2005) asks researchers to be transparent about their perception of subjectivity in the research. In chapter one and chapter four, I situate myself as a researcher, describe my epistemological journey and am upfront about my beliefs about research being constructed between the participants, the researcher, and the reader. In chapter three I go deeper into an analysis of my assumptions and preunderstandings, drawing upon reflexivity and my clinical practice experiences. I have embraced this position and have been reflexive throughout not only the research process, but also the dissertation as a whole. As previously discussed, I have kept reflexive notes and have participated in many reflexive dialogue sessions with my doctoral supervisor exploring alternative interpretations and perspectives.

Chapter seven provides an indepth discussion about reflexivity and ethical research practices, listing a set of guiding questions that I relied on and revisited throughout this work. In addition, Hesse-Biber and Piatelli (2007) list a series of questions to provoke reflexive thinking. I have reflected upon these particular questions/points to consider throughout the research process and used them as a tool to help me critically reflect during data collection and analysis: (1) What particular biases do you bring to your research?, (2) How does your epistemology affect the types of questions you ask?, (3) How often did you answer a question from the participants or share a piece of your social biography? (4) Are you feeling personal discomfort—why?, and (5) How did you respond emotionally and intellectually to the data?

Finally, Warin (2011) recommends paying close attention to “me too” moments in the data, as they serve to develop self-awareness and reveal our blind spots—considering the similarities and dissimilarities to better understand the phenomena and context. Specifically, Warin (2011) offers the following guidelines: (i) recognize self in research, (ii) look for self in participants’ perceptions, and (iii) recognize similarities and dissimilarities with participants and “me too moments” (p. 812). She also advises “when our research participants are children this may sometimes entail a revisit to our own childhood” (Warin, 2011, p. 812). I was attuned to this throughout the research, both during interview sessions and when analyzing data. For example, when Sandra spoke about Teresa’s horseback riding,

She [Teresa] would just fight you tooth and nail, every time we went [Horseback Riding], and it’s like, no, you don’t quit, you know, you see it through to the end, and then you re-evaluate it. So we saw it through to the end of May.

I could not help recalling a similar experience in my childhood, begging my parents to enroll me in Girl Guides. I absolutely hated it! However, I can vividly recall phrases like “you don’t quit”, “see it through”, and “we bought the uniform, you are doing it until you finish”. Unlike Teresa, I had to remain in Girl Guides for four years, until I ‘graduated’. I really resented that. At the same time it was important for me to recognize this “me too moment” and interrogate why I recognized myself in the data and how these experiences were quite different. Another example came from an interview with Beth’s mother Judith. Judith was speaking about how Beth really identified with boys and did not have many girl friends. I too experienced this growing up. I couldn’t help thinking about it, and was trying to consciously resist the temptation to share my own story even though for some

reason I really wanted to. For a moment I let my guard down as a researcher and this transpired:

Judith: Like she says she really likes hockey cards. But [laughs] I don't know if that's really true or if that's just I want to fit in with the guys kind of thing. Yeah. So she's done her own kind of tradeoffs that way, I think. You know. She might not be wearing pink but she's collecting hockey cards. But not, I don't think, necessarily because she has a real interest in it.

Shanon: Yeah. That's funny, because I was like that too. And I had like the hugest hockey card collection. And I probably didn't really know, like, I think I probably liked putting them in the plastic sheets and stuff, more than anything.

Here I recall remembering recognizing this as a “me too moment” in the moment, being attuned to the fact that I was sharing a piece of my own social biography (Hesse-Biber & Piatelli, 2007) and was cautious of that and the dangers of creating blind spots. I recognized it as something I needed to further reflect on to reveal blind spots and consider how it might have shaped the remainder of the interview. Overall, I do believe that recognizing moments like these were also grounding, in the sense that I was always looking for constructions of disability, and how such constructions may have played a role in shaping occupations and identities from a social perspective, and the “me too moments” reminded me that it's not always about disability, sometimes it is simply just kids being kids.

8.11 Concluding Remarks

In conclusion, I contend that there are many generative possibilities for future research examining how occupation is implicated in the shaping of identity from a socio-cultural perspective. For me, the next step in this journey will involve not only taking a socio-cultural perspective, but a socio-political perspective in the hopes of working toward a more occupationally just and inclusive society for children with and without disabilities. I do believe in the potential of this work to influence policy makers to commit to collective responsibility for how future identities are shaped and produced in societies and communities. In coming to the end, I would like to revisit a quote that inspired this journey, and also one I believe I must not forget. Sorell and Montgomery (2001) remind us,

We must remember that not everyone has the opportunity to compose a personal sense of identity. Many groups and individuals, even in this new century, spend entire lifetimes in regions of extreme political chaos, severe personal restriction, or dire economic circumstances where survival demands adherence to a limited range of roles, activities and beliefs. For these people the story of ideal personal and social identity, composed in a society that is itself trustworthy, autonomous and generative—may be a bitter parody of their lived experience (p. 123).

8.12 References

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Appendices

Appendix A: The University of Western Ontario Non-Medical Research Ethics Board Approval



Office of Research Ethics
The University of Western Ontario

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. E.A. Kinsella
Review Number: 17099S
Review Date: May 07, 2010
Protocol Title: Examining Occupational Identity: Perspectives of Children and their Parents
Department and Institution: Occupational Therapy, University of Western Ontario
Sponsor:
Ethics Approval Date: June 14, 2010

Review Level: Full Board
Approved Local # of Participants: 40

Documents Reviewed and Approved: UWO Protocol, Letter of Information and Consent, Letter of Information and Consent (those being photographed), Assent, Assent (those being photographed), Poster.

Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Non-Medical Research Involving Human Subjects (NMREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the applicable laws and regulations of Ontario has granted approval to the above named research study on the approval date noted above.

This approval shall remain valid until the expiry date noted above assuming timely and acceptable responses to the NMREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the study or consent form may be initiated without prior written approval from the NMREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the NMREB:

- changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- all adverse and unexpected experiences or events that are both serious and unexpected;
- new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the NMREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the NMREB.

Chair of NMREB: Dr. Jerry Paquette
FDA Ref. #: IRB 00009941

Ethics Officer to Contact for Further Information

<input checked="" type="checkbox"/> Grace Kelly	<input type="checkbox"/> Janice Sutherland	<input type="checkbox"/> Elizabeth Wambolt	<input type="checkbox"/> Denise Grafton
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UWO NMREB Ethics Approval - Initial
V.2007-10-12 (pptApprovalNoticeNMREB_initial)
17099S
Page 1 of 1



Office of Research Ethics
The University of Western Ontario

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. E.A. Kinsella
 Review Number: 17099S
 Review Date: January 20, 2011

Revision Number: 1
 Approved Local # of Participants: 40
 Review Level: Expedited

Protocol Title: Examining Occupational Identity: Perspectives of Children and their Parents
 Department and Institution: Occupational Therapy, University of Western Ontario

Sponsor:
 Ethics Approval Date: January 20, 2011
 Expiry Date: June 30, 2012

Documents Reviewed and Approved: Revised participant recruitment and study team. Poster.

Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Non-Medical Research Involving Human Subjects (NMREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the applicable laws and regulations of Ontario has granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above.

This approval shall remain valid until the expiry date noted above assuming timely and acceptable responses to the NMREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the study or consent form may be initiated without prior written approval from the NMREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the NMREB:

- changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- all adverse and unexpected experiences or events that are both serious and unexpected;
- new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the NMREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the NMREB.

Chair of NMREB: Dr. Riley Hinson
 FDA Ref. #: IRB 00000941

Ethics Officer to Contact for Further Information		
<input checked="" type="checkbox"/> Grace Kelly	<input type="checkbox"/> Janice Sutherland	<input type="checkbox"/> Elizabeth Wambolt

This is an official document. Please retain the original in your files.

UWO NMREB Ethics Approval - Revision
 V.2007-10-12 (pptApprovalNoticeNMREB_REV) 17099S Page 1 of 1

cc: ORE File



Use of Human Participants - Ethics Approval Notice

Principal Investigator: Dr. Anne Kinsella
Review Number: 170995
Review Level: Delegated
Approved Local Adult Participants: 40
Approved Local Minor Participants: 0
Protocol Title: Examining Occupational Identity: Perspectives of Children and their Parents
Department & Institution: Occupational Therapy, University of Western Ontario
Sponsor:
Ethics Approval Date: April 15, 2011 **Expiry Date:** June 30, 2012

Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Revised UWO Protocol	Revised recruitment and age range eligibility (8-12).	

This is to notify you that The University of Western Ontario Research Ethics Board for Non-Medical Research Involving Human Subjects (NMREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the applicable laws and regulations of Ontario has granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above.

This approval shall remain valid until the expiry date noted above assuming timely and acceptable responses to the NMREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

The Chair of the NMREB is Dr. Riley Hinson. The UWO NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

Ethics Officer to Contact for Further Information

<input checked="" type="checkbox"/> Grace Kelly	<input type="checkbox"/> Elizabeth Wambolt	<input type="checkbox"/> Janice Sutherland
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This is an official document. Please retain the original in your files.



Use of Human Participants - Ethics Approval Notice

Principal Investigator: Dr. Anne Kinsella
Review Number: 170995
Review Level: Delegated
Approved Local Adult Participants: 40
Approved Local Minor Participants: 0
Protocol Title: Examining Occupational Identity: Perspectives of Children and their Parents
Department & Institution: Occupational Therapy, University of Western Ontario
Sponsor:
Ethics Approval Date: August 18, 2011 **Expiry Date:** June 30, 2012

Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Revised UWO Protocol	For those participants who have communication challenges, video recordings will also be taken to ensure accuracy of their speech for data collection and analysis.	
Revised Letter of Information & Consent		

This is to notify you that The University of Western Ontario Research Ethics Board for Non-Medical Research Involving Human Subjects (NMREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the applicable laws and regulations of Ontario has granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above.

This approval shall remain valid until the expiry date noted above assuming timely and acceptable responses to the NMREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

Members of the NMREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussions related to, nor vote on, such studies when they are presented to the NMREB.

The Chair of the NMREB is Dr. Riley Hinson. The UWO NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

Ethics Officer to Contact for Further Information

Grace Kelly	Janice Sutherland
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This is an official document. Please retain the original in your files.

Appendix B: Thames Valley Children Centre Ethics Approval

15 June 2010

Dr. Elizabeth Anne Kinsella
Assistant Professor, School of Occupational Therapy
The University of Western Ontario



Re: Examining Occupational Identity: Perspectives of Children and their Parents

Dear Dr. Kinsella,

As you know, on 14 June 2010, Thames Valley Children's Centre's (TVCC) Research Advisory Committee (RAC) reviewed and approved your above-named project. Congratulations! The Committee felt that the project was a well-designed qualitative study that could help identify the social and cultural factors that shape children's engagement in occupations. **Once the Research Program has received a copy of an ethics approval letter for your study from the University of Western Ontario, you may contact Linda Bolack and begin recruitment of study participants.**

The Committee has provided some feedback for your consideration as you conduct your project.

There are two other qualitative studies that will be getting underway at TVCC at about the same time as your study. The Committee requests that you inquire if clients are already participating in another qualitative study prior to their acceptance to be involved in your study. It is not a requirement that they only participate in one study at a time, but the Committee feels that it is important to let clients know that, should they choose to be involved in two qualitative studies simultaneously, they could perhaps find this somewhat onerous.

The Committee suggested that you revisit your inclusion/exclusion criteria and clarify what is meant by "born with a disability" and "dual diagnosis affecting cognition". As the Committee members pointed out, most children with Cerebral Palsy experience the injury that leads to their diagnosis after birth. Therefore, this criterion, as stated, would exclude many clients from your study. In addition, the Committee wondered if "dual diagnosis" referred to IQ and/or learning disability. The criterion of no cognitive impairment at all would also decrease the number of potential participants in the required age range substantially.

Members of the RAC also would like to point out that if the study eventually includes teachers, you would need to seek approval for your study from the relevant Boards of Education.

The Committee extends their best wishes for a successful project!

Jnette McDougall, PhD
Researcher, Research Program
Chair, Research Advisory Committee
Thames Valley Children's Centre

Cc: Karen Lowry, Director, CCIR, Privacy Officer
Brent Duncan, Director, CATSS
Linda Bolack, Physiotherapist, Clinic

Beyond disability

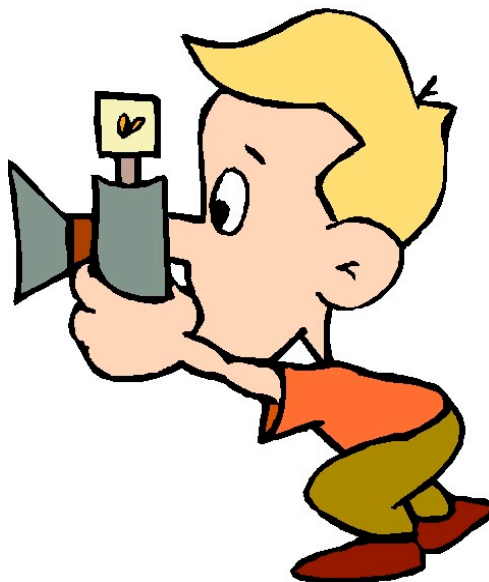
Appendix C: Recruitment Flyer**The University of Western Ontario****Invitation to Participate in a Research Study**

The purpose of this study is to examine and begin to develop theory about how childhood occupations (daily activities) influence the formation of identity in children 8-12 years of age with physical disabilities. The researchers are interested in the perspectives of children and their parents.

What is involved?

Participation in this study involves three interview/activity sessions with the child participant, and one interview session with the parent participant.

Children will be given digital cameras to take pictures of their daily activities, and these pictures will be used during the interview sessions.

**Who is eligible?**

To participate in this study as a child, you must be 8-12 years of age, living with a physical disability. One parent or guardian/primary caregiver will be asked to participate in the study with their child.

For further details about this study or to sign-up, please contact

Shanon Phelan

Appendix D: Letter of Information



Letter of Information

Examining Occupational Identity: Perspectives of Children and their Parents

Researchers

Shanon Phelan, PhD (Candidate), MSc OT, OT Reg. (Ont.), Doctoral Student
Investigator
Health and Rehabilitation Sciences, Field of Occupational Science,
University of Western Ontario

Dr. Anne Kinsella, PhD, OT Reg. (Ont.), Principal Investigator
School of Occupational Therapy
University of Western Ontario

Advisory Committee:
Dr. Angela Mandich, PhD, OT Reg. (Ont.), and Dr. Lilian Magalhães, PhD
School of Occupational Therapy
University of Western Ontario

Dr. Doreen Bartlett, PhD
School of Physical Therapy
University of Western Ontario

Researcher Background:

I am a PhD student in the Department of Health and Rehabilitation Sciences, field of Occupational Science at The University of Western Ontario and the information I am collecting will be used in my thesis. My clinical background is in occupational therapy, specifically working with children in school and home environments.

Description of the Research

Occupational Science is an interdisciplinary field dedicated to the study of human occupations. Here, the term ‘*occupations*’ is defined as “groups of activities and tasks of everyday life, named, organized, and given value and meaning by individuals and a

culture” (Townsend & Polatajko, 2007, p. 369). The purpose of this study is to examine and begin to develop theory about how childhood occupations (daily activities) influence identity in children with physical disabilities. This research will have implications for occupational therapists, other health care professionals working in therapeutic contexts, and families with children with disabilities.

Invitation to Participate

You are being invited to participate in a research study that aims to examine how occupations influence the construction of identities with children ages 8-12 years with physical disabilities. The purpose of this letter is to provide you with the information you require to make an informed decision about your participation in this research. Your participation along with the participation of your child will make a unique contribution to understanding children’s occupations and identities. This study is being conducted as part of a requirement in the Doctor of Philosophy (Occupational Science) program at the University of Western Ontario.

We are looking for families where both parents and child are willing to participate. Children will be asked to take photographs of their daily activities, and these photographs will be used to guide the interview process. Interviews will involve asking questions about the activities the child participates in (i.e. Why? Where? With who? What makes participation easy? What makes participation hard?) Parent(s)/guardian(s) will be asked to participate in one interview that seeks information about their child’s participation in childhood activities and their perceptions on how this might influence their child’s identity. Children will be asked to participate in 3 sessions over a six week period of time. The sessions will include participation in an assessment looking at the child’s daily activities, a take home photography project, and two interviews.

The sessions will be conducted in your current place of residence at your convenience over a six week period. If you prefer, the sessions can be conducted at the University of Western Ontario at Elborn College. All interviews will be audio-taped, transcribed, and analyzed to explore ideas that emerge from the interviews. If your child has a disability that impacts his/her ability to communicate verbally, the interview sessions will be video-taped to accurately understand what your child is saying. The video and audio recordings will be destroyed upon completion of the study and will not be used for any other purpose besides transcription. The photographs will also be included in the data set to be analyzed. A copy of this letter and a copy of the consent form will be provided for you to keep for your own reference if you choose to take part in this study.

Eligibility

To participate in this study, your child must be 8-12 years of age, living with a physical disability since birth, living in the community with at least one family member, speak and comprehend English, and be without any other medical condition that might inhibit the ability to participate in the interview process and sorting and categorizing activities. At least one parent/guardian must be willing to participate in an interview and speak and comprehend English. Please let the researcher know if you or your child are involved in any other study at this time.

Privacy and Confidentiality

Your participation in this study is voluntary. You may refuse to participate, or withdraw from the study at any time. Should you choose to withdraw, your data set will be removed from the study. The results of this study may be used in scholarly publications or presentations, however a pseudonym will be used in place of your name to protect your privacy and confidentiality. Photographs may also be used in publications and presentations, therefore consent forms will be provided for anyone appearing in the photograph. No information that discloses your identity will be released or published without your specific consent. Research materials will be accessible only to the primary and secondary researchers. Research materials will be stored in a locked filing cabinet at the University of Western Ontario, and destroyed after a period of ten years. The transcripts may be taken off of University premises to the student researcher's home during the analysis process. Personal identifiers will be removed from any research material taken off site, and will be stored on a password protected computer and any hard copies will be stored in a locked filing cabinet in a locked home office. All information will be strictly anonymous. Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

Potential Risks and Benefits

There are no serious risks attributed to participating in the proposed research. There is a minor potential for emotional and/or psychological stress due to the nature of the interview process. Participants may discuss stories that could potentially elicit negative feelings or memories with respect to their experience with disability as a child or parent. There are no direct benefits associated with your participation in this study, however participants will be able to share their stories about their experiences with disability, and how such experiences shape identities. In addition, these stories will increase awareness with respect to some of the socio-cultural factors that shape opportunities to participate in childhood occupations, which may in turn shape identity, health and well-being. Sharing such insights can potentially lead to social change in the future that may benefit children with disabilities, their parents, and society at large. Findings from this study may also inform future occupational therapy theory and may contribute to a model that shapes therapeutic practice.

If you have questions about the conduct of this study or your rights as a research subject you may contact the Office of Research Ethics, University of Western Ontario, at 1-519-661-3036 or email at: ethics@uwo.ca. If you wish further information about this study you may contact Shanon Phelan or Dr. Anne Kinsella.

Shanon Phelan, PhD Candidate
Department of Health and Rehabilitation Sciences
University of Western Ontario

Dr. Elizabeth Anne Kinsella, PhD
School of Occupational Therapy
University of Western Ontario

Appendix E: Consent Forms for Parents and Children**Child Participant Consent Form****Examining Occupational Identity: Perspectives of Children and their Parents****Investigators: Dr. E. Anne Kinsella & Shanon Phelan**

I have read the Letter of Information, have had the nature of the study explained to me, I understand my role as a research participant and I agree to participate. All questions have been answered to my satisfaction.

I also agree that any pictures of me and my environment and property may be used for the following purposes:

- 1) In articles: ____ Yes ____ No
- 2) In book chapters: ____ Yes ____ No
- 3) In presentations, slide or print form: ____ Yes ____ No

Signature of Research Participant (Child): _____

Print Name: _____

Date: _____

Signature of Parent/Guardian: _____

Print Name: _____

Date: _____

Signature of Person Obtaining Consent: _____

Print Name: _____

Date: _____

Parent Participant Consent Form**Examining Occupational Identity: Perspectives of Children and their Parents****Investigators: Dr. E. Anne Kinsella & Shanon Phelan**

I have read the Letter of Information, have had the nature of the study explained to me, I understand my role as a research participant and I agree to participate. All questions have been answered to my satisfaction.

Signature of Research Participant: _____

Print Name: _____

Date: _____

Signature of Person Obtaining Consent: _____

Print Name: _____

Date: _____

Appendix F: Child Assent**Assent for Children**

Examining Occupational Identity: Perspectives of Children and their Parents

Researchers:

Shanon Phelan, PhD (Candidate), MSc OT, OT Reg. (Ont.), Doctoral Student Investigator
Health and Rehabilitation Sciences, Field of Occupational Science,
University of Western Ontario

Dr. Anne Kinsella, PhD, OT Reg. (Ont.), Principal Investigator
School of Occupational Therapy
University of Western Ontario

Advisory Committee:

Dr. Angela Mandich, PhD, OT Reg. (Ont.), &
Dr. Lilian Magalhaes, PhD
School of Occupational Therapy, University of Western Ontario

Dr. Doreen Bartlett, PhD
School of Physical Therapy, University of Western Ontario

Why you are here:

The researchers want to tell you about a research project on children's daily activities and how these activities help children tell others about "who they really are". They want to see if you would like to be in the study. Shanon Phelan, Anne Kinsella and some other researchers are doing this study.

Why are they doing this study?

They want to see what you do and how this makes you who you are.

Will there be any tests?

No there will not be any tests. None of these activities will be on your report card for school.

What will happen to you?

If you want to be in this study 4 things will happen:

1. You will do a card sorting activity that will tell the researchers about what you do everyday. This will not be a test and you will not get a grade or mark.
2. You will get a digital camera to use, so you can take pictures of all of the things that you do.
3. You will meet with Shanon to talk about your pictures and make a comic strip using your pictures.
4. You will meet with Shanon again to talk a little more about your pictures and about what you do.

Will this study help you?

No, this study will not help you directly but in the future it might help others understand what children do and why these things are important.

What will happen to your pictures?

The researchers will keep a copy of your pictures. You will get to keep a copy of the comic strip you make using your pictures. The researchers might use your pictures in academic articles (magazines for adults and researchers), academic books (text books for adults and older students in university or college), and academic presentations (presentations for parents,

teachers, therapists and researchers) if that is okay with you.

What if you have any questions?

You can ask questions any time, now or later. You can talk to Shanon, your parents, teachers, or anyone else.

Do you have to be in the study?

No, you do not have to be in the study if you do not want to. No one will be mad at you if you don't want to be in the study, just say no. Even if you say yes, you can change your mind later. It's up to you.

Yes, I want to participate in this study

Print name of Child

Signature of Child

Age

Date

Signature of Person Obtaining Assent

Date

Appendix G: Session One Interview Guide

Phase One: Children's Perspectives Session One: Demographic Information/Pediatric Activity Card Sort/Camera Orientation Semi-structured Interview Guide

Children

Demographic Information

1. What is your name?
2. How old are you?
3. What grade are you in at school?
4. Who do you live with?
5. Do you have any brothers or sisters? How old are they?
6. Do you have any pets?

Pediatric Activity Card Sort (PACS)

The next thing I am going to ask you to do, is an activity that will help me understand the types of things you like to do, need to do, want to do, and what people might expect you to do. Does that sound okay with you?

(See appendix for a copy of the “Steps in Using the PACS”)

Camera Orientation

I would first like to thank you both again for agreeing to participate in my research study. I am going to go over some of the camera use instructions and also your roles in this phase of the project.

1. I am going to give you this digital camera and log book to use for the next two weeks. I would like you to take approximately 30 photos on this camera to show me the activities that you participate in on a daily basis. If you take a photo and would like to discard it, feel free to do so and choose another one instead. [explain and demonstrate how to use the camera at this point].
2. I would like for [Name of Child] to take pictures of his/her daily activities, think about it as an opportunity to tell others “who you really are”. If [Name of Child] is not able to take the picture his/herself or if he/she wants to be in the picture, it is okay for you or another adult to take the picture for him/her. If this happens, I would like you record the picture number, a brief description of the photo, and reason why the child was not able to take the photo in the log book. If the child does not take the picture, it is important that the child see the picture in the viewer before accepting it. Most importantly, all pictures must be initiated by [Name of Child], keeping in mind it is entirely their choice with respect to what activities they want to take pictures of. Pictures may be taken in any environment [Name of Child] chooses.

3. The log book can also be used to record details of the picture taken, in the child's words. [Name of Child] can write in the book themselves, or with assistance. Sample questions will be provided, but the child is not limited to, or required to answer all of the questions. For example: Why is this activity/picture important? Who do I do this activity with? Who helps me with this activity? Where do I do this activity? When do I do this activity? What do I like/dislike about this activity? What would I feel like if I couldn't do this activity? Why did I choose to take this picture?
4. If another person appears in the picture with [Name of Child], they must complete a consent form. I will give you multiple copies to use if needed. If a child appears in the picture with [Name of Child], both you (participant's parent) and the child appearing in the picture's parent must be present in order for the parent to sign the consent form on behalf of their child. At this time the child appearing in the photograph must complete the assent form.
5. I will collect the cameras when you are finished and I will develop the photographs before the next session, to be used in the interview. Photographs will be downloaded onto the computer to access in the Comic Life program on the next session.

Appendix H: Letter of Information for Person Having His/Her Picture Taken**Letter of Information for Person Having His/Her Picture Taken****Study Title:**

Examining Occupational Identity: Perspectives of Children and their Parents

Researchers:

Shanon Phelan, PhD (Candidate), MSc OT, OT Reg. (Ont.),
Doctoral Student Investigator
Health and Rehabilitation Sciences, Field of Occupational Science,
University of Western Ontario

Dr. Anne Kinsella, PhD, OT Reg. (Ont.), Principal Investigator
School of Occupational Therapy
University of Western Ontario

Advisory Committee:

Dr. Angela Mandich, PhD, OT Reg. (Ont.), and Dr. Lilian Magalhaes, PhD
School of Occupational Therapy
University of Western Ontario

Dr. Doreen Bartlett, PhD
School of Physical Therapy
University of Western Ontario

You are being invited to take part in a study being conducted by researchers from The University of Western Ontario who are studying childhood occupations (activities) and their relations to identity for children with physical disabilities. In this study, the person who will take your picture has received a digital camera, and instructions about its use, from the researchers. The photographer has been asked to take pictures of his/her daily activities. Some of these pictures might be taken at the photographer's home, school, and/or community setting, and may include other people in the setting including those who participate in such activities with them. Prior to having your picture taken, you have received written information about the study, and you must also sign a Consent Form

giving permission for your picture to be taken. Your photographer will have the Consent Form for you to sign. If you are a child, your parent/guardian must be present to consent on your behalf, and you must complete an Assent for Child Having His/Her Picture Taken Form. All pictures that your photographer takes will be collected and developed by the researcher.

Your photographer will then participate in a series of interviews with a researcher, and the photographer will be asked about his or her daily activities. Your photographer will be asked to discuss the importance of the activities in the pictures they have selected and the meanings that are significant to them.

Are there any risks or discomforts?

There are no known or expected risks to participating in this research.

Are there any benefits of taking part?

By allowing your picture to be taken, you are assisting others to better understand how activities play a role in shaping identity.

What happens to the pictures?

To protect your identity, only numbers will be used to identify pictures, and the pictures will be locked in a secure filing cabinet in the university. Any identifying information about you, such as your name or location, will be kept in a secure separate location from your picture. Your picture will be kept indefinitely to help us better understand how identity is shaped through engaging in activities, particularly for children with physical disabilities, in this and future research. If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your permission.

Other information about this study:

You do not have to permit your picture to be taken if you do not wish this. If you have any questions or require additional information please contact Shanon Phelan or Dr. Anne Kinsella.

If you have questions about the conduct of this study or your rights as a research subject you may contact the Office of Research Ethics, University of Western Ontario.

Shanon Phelan, PhD Candidate
Department of Health and Rehabilitation Sciences
University of Western Ontario

Dr. Anne Kinsella, PhD
School of Occupational Therapy
University of Western Ontario

Appendix I: Consent forms for Children and Adults Having His/Her Pictures Taken**Participant Consent Form: Child****Examining Occupational Identity: Perspectives of Children and their Parents****Investigators: Dr. E. Anne Kinsella & Shanon Phelan**

I have read the Letter of Information, have had the nature of the study explained to me, I understand my role as a research participant and I agree to participate. All questions have been answered to my satisfaction. I also agree that any pictures of me and my environment and property may be used for the following purposes:

- 1) In articles: ____ Yes ____ No
- 2) In book chapters: ____ Yes ____ No
- 3) In presentations, slide or print form: ____ Yes ____ No

Signature of Research Participant (Child): _____

Print Name: _____

Date: _____

Signature of Parent/Guardian: _____

Print Name: _____

Date: _____

Signature of Person Obtaining Consent: _____

Print Name: _____

Date: _____

Participant Consent Form: Adult**Examining Occupational Identity: Perspectives of Children and their Parents****Investigators: Dr. E. Anne Kinsella & Shanon Phelan**

I have read the Letter of Information, have had the nature of the study explained to me, I understand my role as a research participant and I agree to participate. All questions have been answered to my satisfaction. I also agree that any pictures of me and my environment and property may be used for the following purposes:

- 4) In articles: _____ Yes _____ No
- 5) In book chapters: _____ Yes _____ No
- 6) In presentations, slide or print form: _____ Yes _____ No

Signature of Research Participant: _____

Print Name: _____

Date: _____

Signature of Person Obtaining Consent: _____

Print Name: _____

Date: _____

Appendix J: Child Assent for Having His/Her Picture Taken**Assent for Child Having His/Her Picture Taken****Study Title:**

Examining Occupational Identity: Perspectives of Children and their Parents

Researchers:

Shanon Phelan, PhD (Candidate), MSc OT, OT Reg. (Ont.),
Doctoral Student Investigator
Health and Rehabilitation Sciences, Field of Occupational Science,
University of Western Ontario

Dr. Anne Kinsella, PhD, OT Reg. (Ont.), Principal Investigator
School of Occupational Therapy
University of Western Ontario

Advisory Committee:

Dr. Angela Mandich, PhD, OT Reg. (Ont.) and
Dr. Lilian Magalhaes, PhD
School of Occupational Therapy
University of Western Ontario

Dr. Doreen Bartlett, PhD
School of Physical Therapy
University of Western Ontario

Why are you being asked to be in a picture?

Your photographer has been asked to take pictures of the activities he/she does and who he/she does these activities with. These pictures will be used in a research project about what children do, and how these activities make them “who they really are”. Shanon Phelan and Anne Kinsella and some other researchers are doing this project.

What will happen to you?

You will have your picture taken. The researchers will ask your photographer questions about the activities in the picture and what they mean to them.

What will happen to the pictures?

The researchers will keep a copy of the pictures. The researchers might use your pictures in academic articles (magazines for adults and researchers), academic books (text books for adults and older students in university or college), and academic presentations (presentations for parents, teachers, therapists and researchers) if that is okay with you.

Will this study help you?

No, this study will not help you directly but in the future it might help others understand what children do and why these things are important.

What if you have any questions?

You can ask questions any time, now or later. You can talk to Shanon, your parents, teachers, or anyone else.

Do you have to be in the study?

No, you do not have to be in the study if you do not want to. No one will be mad at you if you don't want to be in the study, just say no. Even if you say yes, you can change your mind later. It's up to you.

Yes, I want to participate in this study

Print name of Child

Signature of Child

Age

Date

Signature of Person Obtaining Assent

Date

Appendix K: Session Two Photoelicitation Interview Guide

Phase One: Children's Perspectives Session Two: Photoelicitation Interview Semi-structured Interview Guide

Interview Guide:

1. Tell me about yourself and what you like to do? What do you do on a typical day?
2. Lets look at your pictures. I would like you to sort them into three piles:
 - A) I do not like to do.
 - B) I sort of like to do.
 - C) I really like to do.

Probes: Tell me about this picture? Tell me why you picked this picture? Is this picture really important to you-why?

3. Are there any activities that are missing that you would like to tell me about?
4. Are there any activities that you don't do, and you would really like to do?
 - a) Why?
5. Are there any activities that you do, and wish you didn't have to do? Can you tell me about them?
6. Are there any activities that others expect you to do? Can you tell me about them?
7. Are there any activities you do in the fall/winter/spring/summer?
8. Lets look at this pile, "I really like to do". Can you pick the top ten pictures? The ones most important to you? /The ones that represent who you are?
 - a) Are there any pictures missing?
 - b) Are there any pictures not in your top ten that you wish were in your top ten? Why?
9. Lets look at your top ten pictures more closely. You can pick a picture to start with, and I am going to ask you a few questions about each one.
 - a) What is happening in this picture?
 - b) Who do you do this with?
 - c) When do you do this activity?
 - d) Where do you do this activity?
 - e) Why do you like this activity?
 - f) Why is it important for you?

- g) What makes it easy to participate in _____?
- h) What makes it hard to participate in _____?
- i) Who helps you do _____?
- j) How special is _____ to you?
- k) How do you feel when you are doing _____?
- l) How do you think you might feel if you couldn't do _____?
- m) What do others think about you doing _____?
- n) Is there anything missing in this picture?

After the semi-structured interview, these pictures will be used in the Comic Life program to tell a story "All about Me".

10. Lets take your top ten pictures and we will use them in this computer program to make a comic strip "who I really am" [occupational portrait]. The pictures can be arranged in any order you like.

11. We can add titles to your pictures. Is there any picture you would like to add a title to? Which ones?

12. We can add "thought bubbles" [phrases] to your pictures. Is there any picture you would like to add a "thought bubble" to? Which ones? What would you like to say?

13. I would like to ask for your permission to show your comic strip [occupational portrait] to your [Mom/Dad/Guardian's name] when I meet with them next. Would this be okay with you? It is okay if you do not want me to show them.

Thank you very much for your participation and for helping me out today!

Appendix L: Session Three Interview Guide

Phase One: Children's Perspectives Session Three: Follow-up Interview Semi-structured Interview Guide

Interview Guide:

Lets look at your comic strip [occupational portrait] for a moment, and we will use it as a guide to answer some questions I would like to ask you.

1. Have you always liked these activities?
 - a. Have you been doing them for a long time? Short time? How long?
2. Are there activities here that you have done all of your life?
3. Do you think you will do some of these things in the future? Which ones?
4. Are there any new activities that you would like to try in the future? Can you tell me about them?
5. Are there any activities that you used to do a lot, but don't do anymore? Why?
6. Do you like to do some of these activities by yourself? Which ones?
 - a. Why?
7. Do you like to do some of these activities in a group? Which ones?
 - a. Why?
 - b. With who? (Family? Friends? Brother/Sister? Teacher? Etc.)
8. What do others think about what you do [be specific if possible]?
 - a. Parents?
 - b. Teachers?
 - c. Friends?
 - d. Relatives?
9. Are there activities that you do that make you "who you are"? Can you tell me about them?
10. What activities make you feel "more like yourself" when you are doing them?
11. What activities make you feel "not like yourself" when you are doing them?

Thank you very much for your participation and for helping me out today!

Appendix M: Parent Session Interview Guide

Phase Two: Parents' Perspectives Semi-structured Interview Guide

Parents

Demographic Information

1. What is your name?
2. What is your age?
3. What is your relation to the child (mother, father, guardian)?
4. What is your current living situation?
 1. Do you live with your child?
 2. One or two parent household?
 3. Do you have any other children? Do they live with you/your child?
5. What do you understand about [Name of Child]'s disability? How would you describe your child's disability?
6. Does [Name of Child] attend school? Home schooled?
7. Is [Name of Child] integrated into a classroom full day/part day? With peers the same age?
8. Does [Name of Child] receive support at school/community? Ex. Educational Assistant? Nurse? Therapists?
9. Has [Name of Child] ever received treatment from an occupational therapist? Past? Present?

Interview Guide:

1. Could you tell me about [Name of Child]?
 - a. What activities does he/she do?
 - b. What does he/she like to do? Enjoy doing?
 - c. What does he/she not like to do?
 - d. What activities are meaningful to him/her?
 - e. What activities does he/she do that are meaningful to you?
2. Are there any activities that [Name of Child] does not do, but you wish they did? Could you tell me about them?
3. Are there any activities that [Name of Child] does, that you wish they did not do? Could you tell me about them?
4. Are there any activities that [Name of Child] does not do, but they wish they did? Could you tell me about them?
5. Are there any activities that [Name of Child] does, that they wish they did not do? Could you tell me about them?

6. What activities does [Name of Child] do on a daily basis?
 - a. Personal care? i.e. dressing, bathing, making lunch
 - b. School/productivity? i.e. homework, chores, volunteer work
 - c. Leisure? i.e. hobbies, social activities, sports, play, movies, reading
 - d. What activities does [Name of Child] do apart from you? With you? With the assistance of others? Independently?
7. In your opinion how would you describe [Name of Child]'s sense of identity?
 - a. Has it changed significantly for any reason? For example:
 - i. Age? Over time?
 - ii. School?
 - iii. Extra-curricular involvement?
 - iv. Developmental milestones?
 - v. Relationships? i.e. friends, relatives, mentors
 - vi. Challenges?
 - vii. Accomplishments?
8. In your opinion, what activities play a major role in creating [Name of Child]'s identity?
9. How might [Name of Child]'s sense of identity differ from peers his/her own age?
10. In your opinion, how might you influence the activities [Name of Child] engages in?
 - a. Choices?
 - b. How might this influence his/her sense of identity?
11. What does the notion of "disability" mean to you?
12. What do you think "disability" means to [Name of Child]?
13. How does [Name of Child]'s disability play a role in what activities he/she participates in?
 - a. How do others perceive [Name of Child]'s disability?
 - i. Family members?
 - ii. Friends?
 - iii. Teachers?
 - iv. Therapists?
 - v. Community supports?
 - vi. Work related peers? Boss? Co-workers?
14. Can you describe any barriers to participation in [Name of Child]'s activities?
 - a. Can you give me an example?
 - b. What resources are missing?
 - c. What makes participation hard?

15. Can you describe any facilitators to participation in [Name of Child]'s activities?
 - a. Can you give me an example?
 - b. What resources are necessary?
 - c. What makes participation easy?

16. Are there any activities that [Name of Child] can do at home with assistance, but is not able to do at school/community?
 - a. Personal care? i.e. dressing, bathing, making lunch
 - b. School/productivity? i.e. homework, chores, volunteer work
 - c. Leisure? i.e. hobbies, social activities, sports, play, movies, reading

17. Are there any activities that [Name of Child] can do at home independently, but is not able to do at school/community?
 - a. Personal care? i.e. dressing, bathing, making lunch
 - b. School/productivity? i.e. homework, chores, volunteer work
 - c. Leisure? i.e. hobbies, social activities, sports, play, movies, reading

18. If so, how do you think this might impact [Name of Child]'s identity in these environments (School/Community)? (In response to question 11 and 12)

19. Who does [Name of Child] do most of his/her activities with?
 - a. In your opinion, how might this person(s) influence his/her identity?

20. Some parents say that they are protective of their children with disabilities when it comes to participating in different activities. What is your view?
 - a. Are there activities that you would prefer [Name of Child] does not participate in? Can you tell me about them? Why?
 - b. Are there activities that you encourage [Name of Child] to participate in? Even though you might feel they are "risky"?

21. Can you think of any activities that [Name of Child] would like to do and can't do? Why?

22. With the consent of [Name of Child], I am going to show you the pictures that he/she took to describe who he/was and what he/she likes to do. What do you think about this?
 - a. Is there anything here that surprises you?
 - b. What pictures might be missing? Describe...

23. Is there anything else about _____ that you would like to tell me that we have not discussed already?
 - a. Anything else about your perspective of _____ identity?

Thank you very much for your participation!

Probes: What would be an example? Describe that in more detail. Tell me more about that.

Appendix O: Copyright Permission for Chapter Two

Confirmation for Permission to Include Copyrighted Material in a
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Shanon Phelan 9:26 AM (4 minutes ago)

From: **Clare Hocking**
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To: Shanon Phelan

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in her Doctoral thesis entitled "Enacting Occupation: Perspectives of Children and their Parents" provided that print and electronic copies of her thesis include a full citation to the published version.

Clare Hocking

Professor
Department of Occupational Science and Occupational Therapy
School of Rehabilitation and Occupation Studies
Faculty of Health and Environmental Sciences

Appendix P: Copyright Permission for Chapter Three



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Chapter Three Permission to Use Copyrighted Material in a Doctoral Thesis

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To: Shanon Phelan [redacted]

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Cc: cjotqualeditor [redacted], Sueann Rogers [redacted]

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Phelan, S. K. (2011). Constructions of disability: A call for critical reflexivity in occupational therapy. Canadian Journal of Occupational Therapy, 78, 164-172

in her

Doctoral thesis entitled "Enacting Occupation: Perspectives of Children and their Parents"

provided that print and electronic copies of her thesis include a full citation to the published version.

Janet M. Craik, MSc., OT (C), OT. Reg. (Ont.)

Director of Professional Practice/ Directrice de la pratique professionnelle

Canadian Association of Occupational Therapists/ Association canadienne des ergothérapeutes

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Appendix Q: Copyright Permission for Chapter Five



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RE: Enquiry from SensePublishers bookstore

Peter de Liefde [mailto:Peter.deLiefde@SensePublishers.com] Tue, May 1, 2012 at 8:38 AM
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 Van: Edwin Bakker
 Verzonden: dinsdag 1 mei 2012 14:18
 Aan: Peter de Liefde
 Onderwerp: FW: Enquiry from SensePublishers bookstore

Your call

-----Oorspronkelijk bericht-----
 Van: Shanon Phelan [mailto:shanon.phelan@westernu.ca]
 Verzonden: dinsdag 1 mei 2012 13:54
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Dear Sense Publishers,

I am writing to request permission to include a copyrighted chapter in my doctoral thesis (co-authored with my doctoral supervisor). I am a University of Western Ontario graduate student completing my Doctoral thesis entitled "Enacting Occupation: Perspectives of Children and their Parents". My thesis will be available in full-text on the internet for reference, study and / or copy. Except in situations where a thesis is under embargo or restriction, the electronic version will be accessible through the Western Libraries web pages, the Library's web catalogue, and also through web search engines. I will also be granting Library and Archives Canada and ProQuest/UMI a non-exclusive license to reproduce, loan, distribute, or sell single copies of my thesis by any means and in any form or format. These rights will in no way restrict republication of the material in any other form by you or by others authorized by you.

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The material will be attributed through a citation.

Appendix R: Copyright Permission for Chapter Seven

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[Norman K. Denzin](#)
Co-editor, Qualitative Inquiry

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Curriculum Vitae

EDUCATION

Doctor of Philosophy 2007-Present

Occupational Science Field

Health and Rehabilitation Sciences Program

Faculty of Health Sciences, The University of Western Ontario

Title: *Enacting Occupation and Identity: Perspectives of Children and their Parents* (Defense June 29, 2012)

Supervisor: Dr. Elizabeth Anne Kinsella

Advisors: Dr. Lilian Magalhães, Dr. Angela Mandich, Dr. Doreen Bartlett

Master of Science 2003-2005

Occupational Therapy

School of Occupational Therapy

Faculty of Health Sciences, The University of Western Ontario

Research Project: *Exploring a cognitive intervention for children with Pervasive Developmental Disorder*

Research Supervisor: Dr. Angela Mandich

Kinesiology 2002-2003

Faculty of Health Sciences, The University of Western Ontario

Bachelor of Science 1998-2002

Honours Human Kinetics Program

Faculty of Biological Science, University of Guelph

AWARDS, GRANTS, AND SCHOLARSHIPS

Faculty of Health Sciences Recognition of Excellence Awarded for excellent contribution to teaching in the Faculty of Health Sciences, The University of Western Ontario 2011-2012

Ontario Graduate Scholarship, \$15,000 2011-2012

Social Sciences and Humanities Research Council of Canada Doctoral Fellowship, \$20,000 2010-2011

Canadian Foundation of Occupational Therapy Doctoral Award, \$3,000 2010-2011

Ontario Graduate Scholarship, \$15,000 (declined) 2010-2011

Faculty of Health Sciences Recognition of Excellence Awarded for excellent contribution to teaching in the Faculty of Health Sciences, The University of Western Ontario 2010-2011

Nomination, Excellence in Teaching Award, Student Council, School of Occupational Therapy, Faculty of Health Sciences 2010-2011

Graduate Thesis Research Award, \$795	2011
Faculty of Health Sciences Graduate Student Travel Award, \$600	2011
Health and Rehabilitation Sciences Graduate Student Travel Award	2011
Faculty of Health Sciences Graduate Student Travel Award, \$600	2010
Health and Rehabilitation Sciences Graduate Student Travel Award, \$500	2010
Young Scholar Award, Engaging Reflection in Health Professional Education and Practice Conference, London, Ontario	2009
CAOT Student Award Awarded for highest academic standing in the MSc OT program	2005

RESEARCH CONTRIBUTIONS

SUMMARY

	Published	In Press	Accepted	Submitted
Refereed Papers	3	1		1
Peer-Reviewed Book Chapters	2	1		
Refereed Conference Presentations and Abstracts in Peer-Reviewed Conference Proceedings	13		2	
Refereed Conference Poster Presentations	3			

PUBLICATIONS

i) Refereed Papers

Phelan, S. K., & Kinsella, E. A. (In Press). Picture this... Safety, Dignity, and Voice. Ethical research with children: Practical considerations for the reflexive researcher. *Qualitative Inquiry*.

Phelan, S. K. (2011). Constructions of disability: A call for critical reflexivity in occupational therapy. *Canadian Journal of Occupational Therapy, 78*, 164-172.

Phelan, S., & Kinsella, E. A. (2009). Occupational identity: Engaging socio-cultural perspectives. *Journal of Occupational Science, 16*(2), 85-91.

Phelan, S., Steinke, L., & Mandich, A. (2009). Exploring a cognitive intervention for children with Pervasive Developmental Disorder. *Canadian Journal of Occupational Therapy, 76*, 23-28.

Phelan, S., & Kinsella, E. A. (Submitted). Childhood, identity, and occupation: Perspectives of children with disabilities and their parents. *Journal of Occupational Science*.

ii) Peer-Reviewed Book Chapters

Phelan, S., & Kinsella, E. A. (2011, Invited Book Chapter). Photoelicitation interview methods and research with children: Possibilities, pitfalls and ethical considerations. In J. Higgs, A. Titchen, D. Horsfall & D. Bridges (Eds.). *Creative spaces for qualitative researching. Living research* (pp. 125-134). Rotterdam, The Netherlands: Sense.

Kinsella, E. A., **Phelan, S.**, DiMuzio, T. & Kwong, J. (2008). Moral Imagination: Three Portraits. In J. Nisker (Ed.) *From the Other Side of the Fence. Stories from Health Care Professionals* (pp. 83-95). Halifax, NS: Pottersfield Press.

Kinsella, E. A., & **Phelan, S.** (In Press). "I am not the same person I was in September": Eliciting occupational narratives through an arts-based approach to ethics education. In M. Molineux (Ed.). *Occupational narratives: Narrative research in human occupation and health*. Blackwell Press.

PRESENTATIONS

i) Refereed Conference Presentations and Abstracts in Peer-Reviewed Conference Proceedings

Phelan, S., & Kinsella, E. A. (June 2012). Examining occupation and identity in childhood: A case study approach. *Occupations and practice through time. Canadian Association of Occupational Therapists Conference 2012*. Quebec City, QC.

Phelan, S., & Kinsella, E. A. (June 2012). Photoelicitation: An innovative and occupation-based method for researching children's occupations. *Occupations and practice through time. Canadian Association of Occupational Therapists Conference 2012*. Quebec City, QC.

Phelan, S., & Kinsella, E. A. (May 2012). Occupation, Identity, and Disability: Case studies with Children. *2012 Canadian Society of Occupational Scientists Conference. Fostering Interdisciplinarity & Interprofessional Excellence in Occupation*. Edmonton, AB.

Phelan, S., & Kinsella, E. A. (May 2012). Safety, dignity, and voice: Ethical considerations in researching occupation with children. *2012 Canadian Society of Occupational Scientists Conference. Fostering Interdisciplinarity & Interprofessional Excellence in Occupation*. Edmonton, AB.

Phelan, S., & Kinsella, E. A. (October 2011). Ethical considerations in qualitative research with children: The quest for safety, dignity, and voice in the research process. *17th Annual Qualitative Health Research Conference*. University of Alberta, International Institute for Qualitative Methodology. Vancouver, BC.

Phelan, S., & Kinsella, E. A. (October 2011). Photoelicitation interviews and research with children: Practical considerations from the field. *17th Annual Qualitative Health Research Conference*. University of Alberta, International Institute for Qualitative Methodology. Vancouver, BC.

Phelan, S., & Kinsella, E. A. (October 2011). Using photoelicitation interviews as a method to study occupation with children: Reflections from the field. *2011 Annual Research Conference 'Mountaintop Reflections. Learning from Ten Years as a Scholarly Community'.* Society for the Study of Occupation: USA. Park City, Utah.

Phelan, S. (December 2010). Embodiment and the disabled body: A critically reflexive examination. *Body/Practice-A symposium*. Charles Sturt University, Wagga Wagga, NSW, Australia.

Phelan, S. (October 2010). Occupational Identity in Childhood: What do we know and what does this mean for occupational science? *1st Joint Conference of the CSOS and SSO: USA – 'Redefining Boundaries and Bridges in Occupational Science'*. London, ON.

Phelan, S., & Dennhardt, S. (October 2010). "If I am what I do, what can I do?" Exploring constructions of childhood and risk: Shaping occupations and identities. *1st Joint Conference of the CSOS and SSO: USA – 'Redefining Boundaries and Bridges in Occupational Science'*. London, ON.

Phelan, S., & Kinsella, E. A. (May 2009). A Critically Reflexive Look at Occupational Identity: A Call for Social Perspectives. *1st International Conference on Engaging Reflection in Health Professional Education and Practice*. University of Western Ontario, London, ON.

Phelan, S., Azevedo, A., Bardell, A., Polley, S., Wubben, D., Kinsella, E. A., & Gibson, L. (June 2009). Narratives of Professional Practice: Meaningful moments in therapists' lives. *Engaging in Healthy Occupation: Partners for Change. Canadian Association of Occupational Therapists Conference 2009*. Ottawa, ON.

Phelan, S., & Kinsella, E. A. (June 2009). An examination of socially oriented perspectives: Implications for conceptualizing occupational identity. *Engaging in Healthy Occupation: Partners for Change. Canadian Association of Occupational Therapists Conference 2009*. Ottawa, ON.

Phelan, S., & Kinsella, E. A. (Accepted, October 2012). Ethical research on occupation with children: A call for reflexivity. *Occupation and place: Sustainability, balance, and occupation. 11th annual research conference of the Society for the Study of Occupation (SSO): USA*. Portland, Oregon.

Phelan, S., & Kinsella, E. A. (Accepted, October 2012). Occupation, identity, participation, and social inclusion: Case studies of children with disabilities. *Occupation and place: Sustainability, balance, and occupation. 11th annual research conference of the Society for the Study of Occupation (SSO): USA*. Portland, Oregon.

ii) Refereed Conference Poster Presentations

Kinsella, E. A. & **Phelan, S.** (June 2012). Mapping the terrain: Reflection in occupational therapy. *Occupations and practice through time. Canadian Association of Occupational Therapists Conference 2012*. Quebec City, QC.

Kinsella, E. A., & **Phelan, S.** (May 2010). 'I'm not the same person I was in September': Engaging occupational narratives through an arts-based approach to ethics education. *15th World Federation of Occupational Therapists (WFOT) Congress*. Santiago, Chile.

Phelan, S., Wubben, D., Polley, S., Bardell, A., Azevedo, A., Kinsella, E.A., & Gibson, L. (May 2009). Narratives of professional practice: Reflecting on meaningful moments in therapists' lives. *1st International Conference on Engaging Reflection in Health Professional Education and Practice*. University of Western Ontario. London, ON.

TEACHING EXPERIENCE

Instructor , School of Occupational Therapy,	2011-2012
The University of Western Ontario, MSc OT Year 2 Course,	2010-2011
OT9612y Ethics and Professional Practice in Context	

Teaching Assistant , School of Occupational Therapy,	2009-2010
The University of Western Ontario, MSc OT Year 2 Course,	2008-2009
OT9612 Ethics and Professional Practice in Context	
Instructor: Dr. Elizabeth Anne Kinsella	

Co-supervisor, MSc OT Student Research Project 2008-2009
 School of Occupational Therapy, The University of Western Ontario
Research Project: Narratives of Professional Practice
 Students: Andria Azevedo, Ashlee Bardell, Sarah Polley, Dana Wubben
 (Conferred 2009)

Teaching Assistant, School of Occupational Therapy, 2008
 The University of Western Ontario, MSc OT Year 1 Course,
**OT532 Assessment of Personal Resources and Barriers for Occupational
 Performance**
 Instructors: Dr Sandi Spaulding, Donna Dennis

RESEARCH EXPERIENCE

Research Assistant 2012-Present
 Supervisor: Ann Bossers
 Department: School of Occupational Therapy, The University of Western
 Ontario
**Research Project: Preceptor Education Program (PEP) For Health
 Professionals and Students, Case Study on the Learning Identified by
 Participants in an online Interprofessional Preceptor Education Program**
 –Funded by The Ministry of Health and Long-Term Care

Research Assistant 2007-2010
 Supervisor: Dr. Elizabeth Anne Kinsella
 Department: School of Occupational Therapy, The University of Western
 Ontario
**Research Project: An Analysis of an Arts-Based approach to Ethics
 Education in Occupational Therapy** -SSHRC Funded

PROFESSIONAL EXPERIENCE

Occupational Therapist 2005-2007
 Comcare Health Services, School Health Support Services Program
 St. Catharines, Ontario (Service for the Niagara Region)
 Clientele: Children 4-21 years of age, with a variety of physical disabilities and
 mental health diagnoses (ex. Cerebral Palsy, Spina Bifida, Developmental
 Delay, Down's syndrome, Asperger's syndrome), and their families, in a
 school-based/community setting.

Occupational Therapist 2005-2007
 Comcare Health Services, Adult/Pediatric Community Program
 St. Catharines, Ontario (Service for the Niagara Region)
 Clientele: Children, adults and older adults with a variety of physical
 disabilities, and their families, in a community setting.

SERVICE AND COMMITTEE WORK

Column Editor, Occupational Therapy Now, Sense of Doing Column 2012-Present
 Canadian Association of Occupational Therapists Practice Magazine

Executive Member (elected), Canadian Society of Occupational Scientists, 2012-2014
 Board of Directors, 2-year Term