2019

# Interpreting Belonging in People with Developmental Disabilities: A Case Study, Photovoice Exploration

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Abstract

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Dissertation Submitted in Partial Fulfillment

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Doctor of Philosophy

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August 2019

# Abstract

In this qualitative study, the social construct of community citizenship as perceived in the worldviews of adults with developmental disabilities living in a large eastern city was explored. While authors report government-sponsored institutionalization and custodial care is no longer as common, the voices of people with developmental disabilities are still to be heard on what they think about being participating members of their communities rather than segregated as they once were. This study provided a group of adults with developmental disabilities an opportunity to help others better understand their thoughts about belonging. A combined case study and photovoice research approach was used in the study. Five adult participants were supplied with cameras with which to take photographs of what they felt best represented their interpretation of belonging and community citizenship. Each was later interviewed to provide descriptions of their pictures. The data were then evaluated with the assistance of qualitative analysis software to determine themes. The findings indicated the participants placed high personal value on gainful employment and expressions of respect from others. In keeping with Maslow's hierarchy of needs thesis as well as the self-actualization and self-determination theories, a sense of belonging is vital to emotional health and well-being. The results of this study contribute to social change by affirming what participants communicated – an inclusive community is one that promotes and provides equitable opportunities for employment, respect, decision-making, and participation.

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# Acknowledgments

There are many people I need to thank for standing with me on this life-altering academic journey. What started as a mere bucket-list fantasy slowly morphed into a real event. I could not have done this without the encouragement and support of the following whose contributions were often substantial, sometimes minor, but always real. First, Dr. Barbara Benoliel, Chair of my Dissertation Committee. I thank you for your witty humor and patience you showed for the times I questioned why I was doing this. Your steadfast guidance got me over the finish line. It has been an honor working with and learning from you. Dr. Analeah Green, Member of my Dissertation Committee. Your astute attention to detail and suggestions made me a better researcher and academic. Thank you for being part of my team. I thank my immediate family; my partner in life, Antonet, and our daughter, Diana Marie, for enduring the past few years with patience and understanding frequently with the added cost of my missing family gatherings. For your unlimited support in helping me achieve what I desperately wanted, I am eternally indebted. To the best friend a man could ever have, Toby, my cotton-poo companion, who stayed up very late at night and into the early morning by my side or at my feet, his presence was silent encouragement to push on to this moment. I want to thank my older sibling, Frank, who sadly did not live to see my achievement. I can truly say, "I've reached the moon," my brother (you alone will appreciate what I mean). To my other sibling, Sergio, and mom, Elvira, thank you for the pride you have shown me with every accomplishment, big or small. This is one of the biggest. In conclusion, I thank the men and women with developmental disabilities I have had the good fortune to work with and known throughout my social work career. The opportunities to learn from you were never in short supply. This Ph.D. dissertation was driven by your stories, pictures, and passion for life – an experience I will forever treasure.

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# Chapter 1: Introduction to the Study

## Introduction

The institutional era for people with developmental disabilities (DDs) in Ontario, Canada spanned 133 years from 1876 to 2009 (Brown, 2015; Ontario Ministry of Community and Social Services, 2012). At the peak of Ontario's institutional model in the late 1970s, more than 10,000 people with DD were residents of such facilities (Ontario Ministry of Community and Social Services, 2012). These facilities no longer exist, but their growth and demise played a significant role in how disability has been theorized and conjectured (Brown, 2015).

According to the current Canadian Survey on Disability (2012), there are 3,775,900 (13.7% of) Canadians aged 15 years and older who self-identified as having some type of disability and 160,500 (0.6% of Canadian adults) were identified as having a DD (Statistics Canada, 2015). Furthermore, the occurrence of DD was highest among those between the ages of 15 and 24 at 1.2% and decreased with age to 0.4% among those 65 and older (Statistics Canada, 2015). DD are often concurrent with other types of disabilities; more than 9 in 10 of those with a DD also report at least one other disability (Statistics Canada, 2015).

Despite a shift from segregated to community care settings (Ontario Ministry of Community and Social Services, 2012), adults with DD continue to be viewed as people seen but not heard (McCauley & Matheson, 2016). The transference of people with DD from institutions to noninstitutional supportive settings did not mean automatic acceptance by the general population. Moreover, it did not signal people with DD are included with their non-DD peers in the full range of citizenship activities that would enhance quality of life (Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014).

The term DD is used to describe a broad spectrum of conditions and associated challenges some people face in learning and often, with communication (AAIDD, 2010; American Psychiatric Association, 2013). Developmental disorders encompass disorders such as mental retardation, chromosomal anomalies (including Down's, Patau's, and Edward's syndromes); fetal alcohol spectrum disorders; autism spectrum disorders; and some forms of dual diagnoses, which include mental illness (Chartier et al., 2016). These challenges can be mild or severe and typically present at birth or before 18 years of age (Developmental Services Ontario, 2016).

These statistics, however, reference only the population living in private households and not those still living in smaller scale institution-like settings. Central to the ongoing narrative is the treatment of people with DD and how they see themselves through the lens of a more inclusion-aware society. They also must deal with the lingering, disparaging vestiges of the past whereas people with DD were intentionally sheltered, insular congregations (Brown, 2015; McCauley & Matheson, 2016).

An examination of the transition from a medical model, institutional support system to an individualized, self-determined, and person-directed service delivery framework in Ontario is best informed by the people most affected. The use of photographs and conceptualizations of belonging to a community can help close gaps in understanding the level of citizenship experienced by people with DD (Select Committee on Developmental Disabilities, 2014). Furthermore, investigating lived experiences can provide new appreciation of the world views of people with DD. Although legal obligations to people with disabilities have been addressed with legislation and social policy advancements (Canadian Government Charter of Rights and Freedoms, 1982; Select Committee on Developmental Disabilities, 2014), people with DD remain among the most marginalized groups in Western society (Overmars-Marx et al., 2014).

Individualized, or person-directed planning; self-determination; and participation in decision-making have been established modalities of encouraging social inclusion (Holburn, Jacobson, Schwartz, Flory, & Vietze, 2004). However, researchers have found the availability of community living options do not necessarily result in positive outcomes insofar as belonging (Brown, 2015; McCauley & Matheson, 2016; Owen, Griffiths, & Condillac, 2015a, 2015b, Seth, Slark, Boulanger, & Dolmage, 2015). Mansell (2006) reported the current community-support system although generally positive, presented a “mixed picture” (p. 70). Data indicated most individuals participated in the community, but the frequency and degree of that involvement or social inclusion remained problematic for many (Brown, 2015; McCauley & Matheson, 2016). Similar findings led Griffiths, Owen, and Condillac (2015) to conclude “community integration has been largely superficial and infrequent” (p. 45).

The case study approach I used in this study reflected awareness of self-images held by people with DD insofar as belonging to a community. This is a research feature I have not found in the literature. Service providers in studies such as Griffiths et al. (2015) reported transitions and adjustments from institutional to community settings were generally successful. Noteworthy was the level of ongoing support once required in the facilities was not needed when people moved to the community (Griffiths et al., 2015). Significant regressions in abilities were not realized in these new settings (Griffiths et al., 2015). One explanation is that perhaps beneficial changes transpired once they began making community connections and developing their sense of belonging.

This case study represented respondents' ideas of community membership and participation and was framed as follows: The research was predicated upon providing an opportunity for adults with DD to express their views about belonging in contrast to an exploration of the attitudes, beliefs, and perceptions of the general Canadian public on disability issues. Most Canadians hold positive views of their personal outlook of interactions with people with disabilities and believe advancements have ensued in the inclusion of people with disabilities; however, Canadians also contemporaneously believe discriminatory attitudes and actions toward people with disabilities continue to have a strong social presence (Prince, 2014). The overarching objective was achieving an understanding of the ideas held by people with DD of belonging in community life and available pathways to social inclusion. The current status of this inclusion is better understood by looking into contending attitudes and progressive public thinking surrounding this distinctive social issue.

The analysis proceeds as follows: a historical overview of the social position of people with DD in Canada (Ontario in particular) highlighting significant public and political milestones involving the inclusion of people with DD. Second, I will provide the interview responses of adults with DD under the premise of exploring their photographs (i.e., what they mean in terms of how these might explain or describe conveyance of belonging). Finally, I will summarize the research findings and what they could mean for present and future social policy impacting people with DD in achieving the inclusion and full citizenship of Canadians with DD. Given the ongoing ambiguity of public attitudes and beliefs regarding DD and the individuals themselves, some cultural work may benefit the understanding of disability concerns and advancing interest in the well-being of people with DD (Prince, 2014).

## Background of the Problem

An emergent turning point in societal attitudes concerning DD in Ontario can be traced to the proclamation of the Developmental Services Act of 1974 (Government of the Province of Ontario, 1974; Ontario Ministry of Community and Social Services, 2012). This legislation signaled a mind shift in services and supports designs; one that highlighted independence, social inclusion, and self-determination (Ontario Ministry of Community and Social Services, 2012). The second, and perhaps most significant turning point, is found in the systematic closing of what were known as Schedule 1 Facilities, owned and operated by the Ontario Ministry of Community and Social Services (Brown, 2015). As I will explain in more detail Chapter 2, the closing of these institutions, which housed thousands of individuals with varying functional levels of DD, began in the late 1980s and resulted in the moving of former residents to communities across Ontario (Brown, 2015).

Understanding the cultural shift away from the central role of facilities in the lives of people with DD to their abandonment as support systems is one of the underpinnings of this study. Deinstitutionalization was well underway throughout the 1990s as the public exerted more pressure on the Ontario government to move away from institution-based, paternalistic models of care to those embracing the enhancement of quality of life and self-determination (Brown, 2015). This pressure intensified when allegations of long-standing abuse and neglect in these facilities were proven, forcing their accelerated closure in 2009 (Select Committee on Developmental Disabilities, 2014).

The emergent question was how people would respond to a new need for redefining what it meant to belong (McCauley & Matheson, 2016; Select Committee on Developmental Disabilities, 2014). Social inclusion, personal choice, and independence became the objectives for supporting people with DD in a marked deviation from the past (Select Committee on Developmental Disabilities, 2014). This transition signaled "a new way of providing services and supports … the closure of these institutions and the government's for how people with DD were treated in the past were important steps but apology we must not stop there" (Select Committee on Developmental Disabilities, 2014, p. 4).

Past researchers have found quality of life generally improved when people transition from large group living to small or independent living (Bock & Joiner, 1982; Doody, 2011; Emerson & Hatton, 1994; Lemay, 2009; Mansell, 2006). During the evolution of deinstitutionalization processes, systems planning focused on placing individuals in community support settings whenever and wherever vacancies presented with little input from families or individuals (Ontario Ministry of Community and Social Services, 2012). At the apex of the systematic institutional era (circa 1970), Ontario had 20 facilities, about half the national total (Radford, 2011). However, in 2009, the last three remaining government-operated institutions were closed in Ontario (Ontario Ministry of Community and Social Services, 2012). The long-established journey from an institution-based service system for people with DD to a community-based framework promoting independence, inclusion, and choice came to an end (Mackie & Philip, 2004).

Service providers have rated quality of life in the context of the transition from institution to community of the majority (i.e., 91%) of individuals as being good (53%) to excellent (38%; Griffiths et al., 2015). Only 1% of respondents considered the quality of life for individuals as being poor Griffiths et al., 2015). The excellent ratings referenced improved skills, health, community engagement, and renewed opportunities to connect with family (Griffiths et al., 2015). The good ratings were attributed to positive life changes and promotion of personal choice (Griffiths et al., 2015). The most common changes reported in this study were in the areas of choice-making, independence, and community connections (Griffiths et al., 2015). Service providers responded that 66% of the people who moved to community settings from segregated facilities were more independent, and 89% were able to make decisions about their daily living routines (Griffiths et al., 2015). Eighty-five percent of the respondents reported an increase in choice-making since leaving the institutions (Griffiths et al., 2015).

With a strengthened movement underway for the repatriation of individuals to communities, the provincial government was shaping a new disability supports narrative. The intended outcome was to strongly acknowledge the right of people with DD to live and belong in open communities available to us all (Brown, 2015). Brown (2015) provided evidence that institution-to-community adjustment was easily and quickly attained, with former institution residents experiencing a higher quality of life in the community. Moreover, these outcomes lent assurance to the idea that the best decision was taken to close these facilities (Brown, 2015). However, little evidence exists to demonstrate what the former residents themselves consider of their sense of belonging and citizenship.

An understanding of institutional lived experiences can provide a contrast to the conceptualizations of acceptance and belonging expressed by the respondents with DD in this study. Despite social progress, some researchers have suggested many of the controlling, discriminatory, and service-centered institutional practices are still in use in community settings (Brown, 2015; McCauley & Matheson, 2016). Perhaps this is indicative of policy and supports that are not in sync with the current social climate experienced by people with DD described in academic literature (Schalock & Verdugo, 2012; Schippers, Zuna, & Brown, 2015). Moreover, the Select Committee on Developmental Disabilities (2014) concluded that doing away with outdated institution-based models of care and the provincial government's apology for the neglect and abuse suffered there were important first steps.

This investigation of how supports for people with DD to build relationships with their communities through person-directed planning and self-determination of personal choices can lead to their empowerment and belonging is useful. As important is looking at this subject without a pathological and medical overlay, which are typically used to define DD. Corrigan and Bink (2015) found service providers are often seen by individuals and their families as perpetuating stigma, medical diagnoses, and pathologies as defining their clientele. The perceptions complainants expressed were of service providers focusing on medical diagnoses and ignoring the person (Corrigan & Bink, 2015). In this study, individuals with DD are seen as differently abled with diverse needs, wants, and aspirations.

## Problem Statement

The call for social inclusion and creating a sense of community belonging for people with DD has been established (Brown, 2015; McCauley & Matheson, 2016) but for some, more remains to be accomplished (Select Committee on Developmental Disabilities, 2014). Many argue progress has been slow or misguided in ensuring service provider mandates reflect an enrichment and entrenchment of citizenship, self-determination, and personal choice as essential components of the rethinking of developmental services social policy (Duffy, 2010; Martin, Ashworth, & Ouellette-Kuntz, 2012; McCauley & Matheson, 2016; McCormack & Farrell, 2009; Ontario Ombudsman, 2016). I have found the extant literature to be unclear or omitting altogether the notions and conceptualizations of people with DD about their world views of actively belonging to their community. What people with DD think about inclusionary social practices requires renewed and increased awareness (Brown, 2015; McCauley & Matheson, 2016).

According to some, the developmental services landscape in Ontario has morphed to one of crisis management rather than being proactive in responding to basic needs, like accessibility to support resources promoting self-reliance and direction (Ontario Ombudsman, 2016). The argument posits the changeover has not been seamless from long-standing institutional models of care to inclusionary community supports that promote building strong relationships and bonds with community identities (i.e., citizenship) and belonging (Brown, 2015). McCauley and Matheson (2016) opined there are several unmet promises made by the provincial government and community advocates when the deinstitutionalization process began. These pledges focused on the Ontario government fulfilling its objectives for a society that includes people with DD as complete citizens (McCauley & Matheson, 2016). The implications of these shortcomings make Canadian society less inclusive, according to some (Brown, 2015; Martin et al., 2012; McCauley & Matheson, 2016; Ontario Ombudsman, 2016). The Select Committee on Developmental Disabilities (2014), a bipartisan political entity mandated to investigate and assess the quality of DD services in Ontario, concluded government policy to provide robust, person-directed care encouraging and supporting self-determination and community inclusion has failed, and many people with DD continue to be marginalized (Ontario Ombudsman, 2016).

These omissions appear to be ongoing and are reflected by the Ontario Ministry of Community and Social Services (2017) strategic plan for 2017–2020. The plan contains no detailed descriptions of upcoming initiatives for addressing a sense of belonging and independence of people with DD, although there is acknowledgement "people's needs have evolved, as have their expectations" (Ontario Ministry of Community and Social Services, 2017, p. 6). This is indicative of a lack of clarity regarding government policy and committing to solving the perceived crisis in the province's developmental services sector (Ontario Ombudsman, 2016).

People with DD want to be more independent and included in plans affecting their future (McCauley & Matheson, 2016; Overmars-Marx et al., 2014). In this study, I investigated the complexities of government and social policy and the ambiguity of Canadians' stance on the issue of inclusion and belonging (see Prince, 2014). Moreover, I provided research participants with DD a vehicle for making their thoughts and perspectives known via photographic art form (see Mitchell, 2011; Rose, 2016).

## The Purpose of this Study

The purpose of this qualitative study was to understand the lived experiences of five people with DD as they described and explored their interpretations of belonging. I have not found the literature to be reflective of the thoughts and feelings expressed by people with DD about personal connections with their community. Although traditional methods of talk therapy and surveys can also provide insight, in this qualitative study I used photovoice (see Mitchell, 2011; Rose, 2016) as the means of data collection through personal photography to help elicit perceptions and worldviews through follow-up interviews as well as review and analysis of background history and documentation relevant to the individuals. With this investigation, I intended to help understand how the interpretations of adults with DD help shape their understanding of their social world and their place in it.

The case study approach is increasingly popular among qualitative investigators (Creswell, 2013; Hyett, Kenny, & Dickson-Swift, 2014). Current qualitative case study designs are shaped by study approaches and methodologies creating variety for the researcher to pursue (Hyett et al., 2014). Denzin and Lincoln (2011) maintained experienced qualitative researchers identify case study analyses as stand-alone qualitative approaches. Case study designs maintains a level of flexibility not readily available in other qualitative approaches, such as grounded theory or phenomenology (Hyett et al., 2014).

## Research Questions

The following central research question and subquestions guided this study

Central Research Question: How do adults with DD construe their lived experiences with belonging and citizenship?

Subsequent secondary research questions included:

Sub question 1: What key social determinants of belonging and/or citizenship and connections to their communities are discerned by adults with DD when they describe their photographs?

Sub question 2: Are self-identified depictions of belonging better explained through ontological interpretations of their DD rather than as pathologies?

Sub question 3: What does it mean to live as a person with a DD?

## Frameworks

This research was informed by self-determination and disability theory and complemented by their conceptual underpinnings (see Pothier & Devlin, 2006; Ryan, 2016). Qualitative case study research can begin with a question or social problem personally meaningful to the investigator (Creswell, 201)3. Discovering and exploring the relationships between members of a community can be conducted via qualitative research methodologies like case study and photovoice (Creswell, 2013; Hyett et al., 2014; Mitchell, 2011; Rose 2016). Disability theory posits people with cognitive disabilities experience exclusion with few opportunities to enjoy equitable treatment by others or a sense of belonging and citizenship (Lid, 2015). As such, vulnerability and disability should be theorized as related if inclusion and social justice are to be realized and belonging can unfold in the tension and dynamics between the objectives of inclusion and experiences of exclusion (Lid, 2015).

Researchers are required to provide opportunities for people with intellectual disabilities to be included in research that affects their lives (Carey & Griffiths, 2017). In this study, I reported on the inclusion of adults with DD. Moreover, the lived experiences of people with DD as citizens were explored by way of interpreting personal photographs taken by research participants (see Mitchell, 2011; Rose, 2016). Individual circumstances and a lack of socialization outlets, support networks, and public policies defining their care and needs can pose barriers to people with DD belonging and making connections with the community. A person's citizenship in this milieu can be a dynamic process embracing complex interactions between individual and environmental factors that provide opportunities and challenges for people with DD (Carey & Griffiths, 2017; Overmars-Marx et al., 2014).

Lived experiences with disability can be value laden as imposed by others without the disability creating an interrelationship between vulnerability and disability complex (Lid, 2015). When living with disability, the person can be susceptible to the many exclusionary tendencies of society (World Health Organization, 2011). As such, the theoretical and practical experiential aspects of disability provide relevancy for research (Lid, 2015).

With a focus on understanding inclusion, belonging, and citizenship, people with DD are recognized as contributing members of the community in this study. The examination of the lived experiences, non-medical models, and positive expectations of people with DD can mitigate the reduction of disability to "a negative characteristic instead of recognizing this dimension as inherent whereas the case study research supports a transactional method of inquiry, where the researcher has a personal interaction with the case[s]" (Hyett et al., 2014, p. 2). The cases are developed into a relationship between the researcher and informants to engage readers (Hyett et al., 2014).

## Definitions

*Belonging*: A person's perception of *feeling they belong* is a core facet of social inclusion (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012) and a fundamental universal human need and right (United Nations, 2007). Participants in this study used personal photography as visual vehicles to demonstrate their sense of belonging and understanding of inclusivity. The Convention on the Rights of Persons with Disabilities (United Nations, 2007) characterized the development of a sense of belonging as an outcome of disability-related policy as "… the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging" (p. 6).

*Developmental disability (DD)*: In North America, DD has been defined by two different classification systems – the American Association on Intellectual and Developmental Disabilities (AAIDD; 2010) and the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (American Psychiatric Association, 2013). Both of these systems classify DD severity based on intensities of support needed to achieve a person's ideal personal functioning (National Institutes of Health, 2015). The participants in this study are part of social group classified as having mild to moderate DD. People with mild DD take longer in areas of conceptual development, social, and daily living skills (National Institutes of Health, 2015).Significant to this study was determining the level of self-care people with DD require to function semi- or fully independently. Baseline definitions for this include minimal to basic support (AAIDD, 2010; American Psychiatric Association, 2013; Statistics Canada, 2015). According to the AAIDD (2010) and National Institutes of Health (2015), 85% of people with DD are in the mild category of severity with IQs estimated as ranging from 50–69 and can live independently with nominal levels of support. Ten percent are classified as having moderate severity of DD with an approximate IQ range of 36–49 (AAIDD, 2010). For these individuals, independence may be achieved with moderate levels of support such as group living settings (AAIDD, 2010, National Institutes of Health, 2015)

*Stigmatization*: An adjunct to marginalization and can ultimately lead to people with DD feeling like outsiders (Clement et al., 2014). As a construct, stigmatization renders individuals labelled as DD vulnerable to prejudgements and impacts their sense of belonging and self-determination (Corrigan & Bink, 2015). Stigma is recognized as a significant barrier to individuals with DD seeking to belong and fulfill self-actualization (Clement et al., 2014; Corrigan & Bink, 2015). Moreover, stereotypes are harmful and disrespectful beliefs about social groups that they are incompetent to achieve life goals, attain group identity, and connections (Angermeyer, & Corrigan, 2005; Angermeyer & Dietrich, 2006; Corrigan & Bink, 2015; Rusch,).

## Assumptions

I confined this study to engaging participants with a mild to moderate designation of DD as outlined by the AAIDD (2010); the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (American Psychiatric Association, 2013); and Statistics Canada (2015) who may reside independently or in group living settings with marginal supports. Reflective of case study design, I intended this investigation and analysis to capture the complexity of belonging and citizenship. Qualitative case study research "draws together naturalistic, holistic, ethnographic, phenomenological, and biographic research methods … a palette of methods" (Stake, 1995, pp. xi–xii). Case study is defined by focus on individual cases rather than the inquiry methods employed (Stake, 1995). Hyett et al. (2014, p. 2) posited, "The selection of methods is informed by researcher and case intuition and makes use of naturally occurring sources of knowledge." Essentially, I assumed the selected cases would advance insight and understanding of the subject being explored.

Another assumption concerned the functional abilities of someone with DD and the idea that complex medical impairments are primarily static. However, other mental and health issues concurrent with DD may evolve and change over time. The classification of mild to moderate DD determined inclusion at the time of screening sample group members for this study.

I also supposed the participants could differentiate between belonging and experiencing token acceptance because others' world views may dictate that people with DD must be taken care of but not necessarily become part of their community. The level of sophistication in this regard was difficult to determine in a short-term study such as this. Moreover, it was anticipated participants would have readily available and proper means to take photographs.

It was also expected interviews were effective qualitative research methodologies for this study. The use of this practice with people who have DD requires adaptation, careful design, and improvisation when things do not progress as planned. However, it is commonly accepted that such research provides emancipatory, participatory, and empowering contexts for people with DD (Kaehne & O'Connell, 2010). Interviews permit the participants to engage in the debate in a stress-free setting and increases the likelihood of exploring the research from various perspectives (Kaehne & O'Connell, 2010).

As a qualitative research approach, interviews are informed by a constructionist view of reality (Kaehne & O'Connell, 2010). The central units of data were the opinions and interpretations of belonging and citizenship articulated with words and photographs by the research participants themselves. According to Kaehne and O'Connell (2010) the resultant data combine to give a "cumulative view of reality through discussion and debate" (p. 134). Furthermore, studies intending to obtain data on the experiences of people with DD in their social contexts can do so using interviews. In turn, this fulfills an "important objective of research: the inclusion and empowerment of service users … [and that] research should not be conducted on people but with their active participation" (Kaehne & O'Connell, 2010, p. 134).

## Scope and Delimitations

The scope of this study was to examine how individuals with mild to moderate DD consider what it means to them to belong in public spheres. Central to these interpretations was what they felt were agreeable representations of their community engagement with the use and debriefing of personal photography. This study was relevant to individuals receiving some form of support in the community, resulting from a validation of societal attitudes regarding deinstitutionalization and the welcoming of people with DD into community settings.

Due to the variability of various criteria informing profound to borderline DD, it was important to establish the focus of this study as an exploration of perceptions from a sample group of adults with DD who possess cognitive skills, self-awareness, and can make personal decisions. The general DD population has been the subject of research in the past; however, I found little exploration specifically examining how this subgroup of people with DD identify and recognise their place in the community, more so when society expresses a collective predisposition to discriminate without regard for individual capabilities (i.e., Duffy, 2010; Martin et al., 2012; McCauley & Matheson, 2016; McCormack & Farrell, 2009; Ontario Ombudsman, 2016).

The Select Committee on Developmental Disabilities (2014) identified the tendency to discriminate as creating and/or perpetuating a form of marginalized citizenship, advancing the need for further investigation of how people with DD interpret their citizenship. The essence of a person feeling they belong is their quality of life, their relationships, and how these inform the relationships people with DD have with their community social network. Minimal research is available on this subject, and therefore, the effort to add to this knowledge base drove this study.

## Limitations

The limitations of this study included individuals demonstrating maladaptive behaviors as the study wore on or not fully comprehending either the intentions of the study or the demands and expectations placed on them as research participants. In addition, the proper use of photography without infringing on others' privacy could have limited the volume of useable photos for this project. Moreover, insufficient operative photography could have restricted the accurate interpretation of the photos' subject matter and/or participants may not have been able to discern what the picture means to them or how it aligned with the scope of the study.

Other limitations included that purposive sampling may not be representative of those individuals with mild to moderate DD not participating in the research. There was also potential for bias in the composition of the sample group. Moreover, assurance of participants' reliability could be questionable.

## Significance

With this study, I aimed to contribute to an understanding of how people with DD define their sense of belonging and the nature of their connections with the community in which they live, work, and socialize. A study like this, significantly informed by participants' photography and follow-up dialogues, can serve as a template for future research examining how social policy making can be influenced by factoring in the perceptions of people with DD. Their views can provide enlightenment as they negotiate potential stigma and stereotypes while developing relationships between community structures, services supports, and the people who interact with them (see Carey & Griffths, 2017).

The exploration, synthetization, and interpretation of research data regarding participants' lived experiences of belonging may help inform those designing and working with social policies and services for this population group (see McCauley & Matheson, 2016; Ontario Ministry of Community and Social Services, 2012; Select Committee on Developmental Disabilities, 2014). In this study, I aimed to investigate the extent by which the Ontario government's DD social policy and its declarations of equality and social inclusion have been actualized (see McCormack & Farrell, 2009; Ontario Ministry of Community and Social Services, 2012). Furthermore, the findings of this study may redefine community norms and social definitions of DD while rethinking the application of historical medical models of support and replaced with those that promote inclusivity and self-determination.

The connection between stigma and an individual creating relationships with their community can be complex. Individual and societal attitudes and structural policies either encourage or discourage active participation toward fulfillment of a person’s self-determination and sense of belonging (Corrigan & Bink, 2015). Understanding the dynamics of the self-directed decision-making of people with DD is central to this research scenario (see Frawley & Bigby, 2011). My examination of the transition from institutional and medical models of care toward more inclusive community supports in this study provides a backdrop to understanding new thinking about the self-determination, empowerment, choice, and person-directed care of people with DD (see Brown, 2015).

## Summary

The qualitative instrumentation in this study included case study design, photographs taken by research participants that speak to their interpretations of what it means to belong to a community (see Mitchell, 2011; Rose, 2016), follow-up interviews, document content analyses, social policy, and governmental public position on social inclusion. I employed the following research conventions: an interview protocol for consistency in questioning about the photographs taken, a consent form explaining respondents’ rights to privacy and withdrawal at any time during the project, and a description of how respondents’ information and photographs would be used and/or disseminated. Chapter 2 will present a literature review including how my study’s findings relate to previous literature.

# Chapter 2: Literature Review

## Introduction

The Canadian province of Ontario has a long history of custodial care with people with DD. From 1876 until 2009, the provincial government operated institutional-based facilities to provide food, shelter, and medical-model supports in segregated settings (Brown, 2015; Ontario Ministry of Community and Social Services, 2012). Often, these institutions were located some distance from populated areas, allowing for little meaningful interaction with surrounding communities (Cobigo et al., 2012; Ontario Ministry of Community and Social Services, 2012).

Medical models configured in institutional environments informed a reliance on “treating” people with DD, later replaced by a search for community acceptance regardless of the level of DD (Brown, 2015; Verdonschot et al., 2009). The social concern highlighted in this study was the influence of long-established social isolation on community awareness and thinking regarding people with DD. The purpose of this study was to examine enlightenment surrounding the inclusivity and belonging of people with DD.

In Canada, the proclamation of the Ontario Developmental Services Act (Government of the Province of Ontario, 1974) signaled a new direction in the acceptance of people with DD as participatory members of the community (Ontario Ministry of Community and Social Services, 2012). While institutions continued operating, an emergent cultural shift away from segregationally founded and medical model-informed therapies occurred. Social policies evolved to espouse inclusivity and repatriation of long-institutionalized people back to their communities (Brown, 2015).

The literature has suggested quality of life generally improved for adults with DD during and after de-institutionalization (Bock & Joiner, 1982; Doody, 2011; Emerson & Hatton, 1994; Griffiths et al., 2015; Lemay, 2009; Mansell, 2006; Ontario Ministry of Community and Social Services, 2012). More than two-and-a-half decades later, however, definitive acceptance appears lacking. In general, people agree adults with DD are more empowered and supported to be contributors to their communities (Brown, 2015); however, the ongoing strong presence of discriminatory beliefs and actions cast ambivalence about how successful Canadians have been in advancing integration of people with DD (Prince, 2014).

Being active and involved members of a community reflects a level of social inclusion, a necessary component of life, and an improvement in the means through which individuals take part in society (Ontario Ministry of Community and Social Services, 2012; Select Committee on Developmental Disabilities, 2014). The Select Committee (2014) members suggested the degree of social inclusion can be judged by the equality of opportunity to participate and the dignity accorded to marginalized groups who may be judged by others' perceptions of them. In this context of belonging, I found little research in the literature about understanding how people with DD see themselves compared to those without a DD diagnosis insofar as their relationships with the community. I have not found research providing an understanding of how adults with DD perceive their place in society (see Cobigo et al., 2012; McCauley & Matheson, 2016; Thornicroft, 2014) or that adequately answers my research questions.

## Literature Search Strategy

I consulted multiple academic sources for this literature review, including SocINDEX, PsycINFO, ProQuest, and PsycARTICLES databases; North American, European, and Australian developmental service journals; government-sponsored and advocacy websites; white papers; and parliamentary reports. These sources were consulted to help decipher the present public policy on inclusivity and self-determination of people with DD. I used search terms and combined terms containing the following words and phrases: *learning and developmental disabilities, social inclusion, deinstitutionalization, community living, self-determination theory, belonging, citizenship, disability theory,* and *ostracization.*

Central to my qualitative research design incorporating these definitions was an understanding of the theoretical foundation underpinning it and the broad influence on the process of facilitating qualitative research. Anfara and Mertz (2014) purported useful theoretical foundations are those that tell a compelling story about a social curiosity. New insights and a widening of the researcher's–and by default, readers'–comprehension of the natural phenomenon are offered through a study informed by theoretical foundations (Anfara & Mertz, 2014).

## Theoretical Foundation and Propositions

This study was anchored by disability and self-determination theories that highlight self-awareness and freedoms to make individual choices (see Browne & Millar, 2016; Hewitt, 2014; Hughes, 2015; Lid, 2015; Prince, 2012) and helped form the basis of the theoretical framework. There are tensions between various Canadian structural, social, political, and cultural systems that posit various interpretations of the level of success achieved in embracing people with disabilities as part of their communities (Brown, 2015; McCauley & Matheson, 2016). Some have argued that despite their belief that Canada is a country of liberty, equality, and inclusiveness, many people with DD and other disabilities experience social exclusion and marginalization and live their experiences as socially constructed second-class citizens (Devlin & Pothier, 2011).

Imenda (2014) suggested theoretical propositions determine researchers' formulation and exploration of their topics and meaning of accrued data. In this respect, I found self-determination and critical disability theories are what Imenda (2014, p. 186-187) termed *blueprints*, showing how the structure and interrelationships of each element of the theories relate to one another and concepts are depicted. Moreover, the incorporation of self-determination and disability theories in this study exposed a pressure between theory and practice (i.e., praxis), resulting in multilayered and unexpected outcomes. In other words, theory can also be contrasted with the construct of practice, and as an individual exalts theory, detractors may respond by dismissing it as unproven, suggesting actual practice as being more relevant and what really counts (Imenda, 2014). Over time, there has been a narrowing of the conceptual and operational definitions of the two. Some theories relate to ideas rather than direct observable empirical phenomena, while others suggest proposed explanations or empirical phenomena (Imenda, 2014). In this study, I planned to show people with DD self-identifying and attaching individual meanings to their connections with the social world.

I chose self-determination and disability theories because I considered them conducive in helping to shed light on how individuals with DD identify their importance to the community and go about living their lives despite extraordinary challenges not necessarily faced by others with DD. In an interesting meshing of self-determination and disability theories, Brooks (2015) followed the line of thought that when disabilities are categorized, they do not allow individuals to define their disability for themselves and thus limiting their individuality (Brown, 2015; Lid, 2015; Ontario Ministry of Community and Social Services, 2012; Prince, 2012; Select Committee on Developmental Disabilities, 2014).

Researchers have suggested the general population can either directly or indirectly endorse or perpetuate stereotypes and discrimination against people who they identify via labels (Corrigan & Bink, 2015). This can impact and negatively affect others' self-determinant pursuits and can influence the quality of advances people achieve on their own because barriers are erected against them and present inequitable opportunities afforded to unlabeled individuals (Corrigan & Bink, 2015). Moreover, self-stigma can occur when a person internalizes corresponding prejudice, and structural stigma is characterized by social and institutional policies and practices undermining prospects for people with DD to feel as belonging to their community (Corrigan & Bink, 2015). In this study, I investigated some key elements of supporting people with DD to assess their personal sense of belonging to communities. Access to information, knowledge and skill development, engaging in processes, and forming relationships are part of self-determination theory (Frawley & Bigby, 2011). In turn, these interpersonal connections, relationships, and life experiences can be influenced by societal attitudes and the value others place on the participation of persons with DD (Frawley & Bigby, 2011).

I asked individuals with a mild DD to participate in this study. In Canada, mild DD implies a lower IQ level (i.e., an IQ of 70 designates mild DD and includes poor adaptive behavior like social, practical, and conceptual skills; Chartier et al., 2016). These deficits affect people's socialization and continue to a varying degree throughout life (Chartier et al., 2016). A nonprofit with a presence in the DD field, the Canadian Association for Community Living (2017), has noted on its website that stereotypes, negative perceptions, and discrimination result from different ways of learning and communicating. Moreover, according to a governmental system planning branch, Developmental Services Ontario (2016), the need for assistance with daily living routines are often desirable to support independence.

## Disability Theory

Not all Canadians share equally in the good life or feel adequately included in the free, equal, and inclusive societies North Americans take pride in promoting (Devlin & Pothier, 2016). People with DD face "recurring coercion, marginalization, and social exclusion are persons with disabilities" (Devlin & Pothier, 2016, p. 1). Disability theorists have argued that this systemic discrimination has failed to respond to the needs of people with disabilities and may have compounded existing problems experienced by many, resulting in a system rife with "deep structural, economic, social, political, legal, and cultural inequality in which people with disabilities experience unequal citizenship, a regime of dis-citizenship" (Devlin & Pothier, 2016, p. 1).

Assumptions inform conventional understandings of disability that characterize its various iterations as unfortunate twists of fate that privilege the normal over the abnormal (Devlin & Pothier, 2011). Subsequently, these understandings can broaden to include the assumption that societal hierarchy is founded upon the supposition able-bodied and able-minded norms are predictable and the best to be done is for the nondisabled to show empathy or pity (Devlin & Pothier, 2006, 2011, 2016). Others have purported that society needs new ways of thinking about disability and a new understanding of participatory citizenship that comprises people with disabilities as well as new policies to respond to their support requirements and entitlements (Developmental Services Ontario, 2017; Emery et al., 2016; Lid, 2015; McCauley & Matheson, 2016).

Disability theory provides an overarching understanding of citizenship (Devlin & Pothier, 2016; Duffy, 2010; Hewitt, 2014; Hughes, 2015; Kabeer, 2002). For some, citizenship has formal significance, such as the privilege to hold a passport and to vote, while for others the term is denoted more substantively like the capacity to share fully in all societal institutions not just those that fit conventional political definitions (Devlin & Pothier, 2016). Therefore, central to disability theory is the core value emphasizing citizenship as not just an individual status but also as the substantive overtones of citizenship as

> A practice locating the person in the larger community and raises questions of access and participation, exclusion and inclusion, rights and obligations,

> legitimate governance and democracy, liberty and equality, public and private, marginalization and belonging, social recognition and redistribution of resources, structure and agency, identity and personhood, and self and other. (Develin & Porthier, 2016, p. 2)

Disability theory can be further subdivided into prominent models. For instance, Brooks (2015) and Haegele and Hodge (2016) posited depictions of disability fall under one of two prevailing modern-day theories: the social and medical models. These concepts are polar opposites; nevertheless, the way disability is theorized and defined is central to the argument that the way people use language to describe others with disabilities is important because it influences their expectations and interactions with them (Haegele & Hodge, 2016).

The medical and social models of disability warrant investigation to better understand the prevalent perspectives of detractors and proponents of each theoretical framework. First, it is important to note the debate about the prominence of the medical model began when doctors and scientists displaced religious leaders as cognitive authorities (Haegele & Hodge, 2016). The literature suggested the role of cognitive authority was attained by the abilities of the medical profession to define and heal ailments, positioning it to lead the discourse on many aspects of life that dealt with the body and mind, including disabilities (Haegele & Hodge, 2016). Since the medical field operates from a biological perspective, disability is conceptualized as a biological and not an ontological product (Haegele & Hodge, 2016; Overmars-Marx et al., 2014; Parsons, 1951). A closer look at the medical model framework follows.

## Medical Model of Disability Theory

The medical model is typically referred to as the “old paradigm” (Mitra, 2006 as cited in Haegele & Hodge, 2016, p. 196). It views disability as a problem with the person caused by disease, trauma, or other health realities which must be treated with the goal of curing the individual (Brooks, 2015). On the other hand, the social model of disability explains people are disabled by society-created and perpetuated barriers; thus Brooks (2015) and Kabeer (2002) would agree this further reflects the conceptualization of citizenship as an able-bodied privilege, the premise being human beings are conditioned not to acknowledge the ways and means race, gender, or ability have been organized on hierarchical levels (Brooks, 2015). However, advocates of the medical model propose it situates the individual in normalized settings as much as possible (Roush & Sharby, 2011 as cited in Haegele & Hodge, 2016). It is because of normative nature of the medical model, the prime objective is to fix disability and rehabilitate the individuals to the point where they can cope with life with the same level of functioning as nondisabled persons (Mitra, 2006 as cited in Haegele & Hodge, 2016; Palmer & Harley, 2012). In contrast, the social model contests the notion that people with disabilities need to be fixed; instead, the focus is on changing societal attitudes and understanding of disabilities (Haegele & Hodge, 2016).

Disability is understood in the medical model narrative as an individual and/or health phenomenon resulting in limited and deficient functioning (Bingham, Clarke, Michielsens, & Van De Meer, 2013; Palmer & Harley, 2012). In this interpretation, disability is the outcome of an impairment of body functions and structures, including the mind. The causes are rooted in disease, injury, or other health conditions. This view conflates impairment and disability with someone being sick and his/her disability seen as a problem requiring a medical remedy or cure so they can function in society (Haegele & Hodge, 2016).

In contrast to the approach taken in this study is the medical model's explicit core belief that, similar to ill health, disabilities which include cognitive ability challenges like those of DD, are seen as problems in need of medical cures so people can function in society (Brandon & Pritchard, 2011; Haegele & Hodge, 2016). Bluestein (2012) agreed; limitations affiliated with having a disability are observed as a product of the individual's structural or functional deficits caused by physical, sensory, affective, or cognitive issues. Furthermore, Bluestein thought the medical model suggests something inherently and globally disabling exists for a segment of the population with disabilities and that changes to the societal organization could not give them equal opportunities as those who are typically functioning within the socially organized environment. Furthermore, the medical model assumes the issues faced by people with disabilities are independent of wider sociocultural and/or sociopolitical settings with outcomes such as embedded pervasive negative perceptions of disabilities (Brittain, 2004 as cited in Haegele & Hodge, 2016).

Roush and Sharby (2011) acknowledged some disabilities cannot be eliminated or ameliorated using medical science advances. This group of individuals then are considered requiring help leading to the commonly response of disability-related charity and fundraising (Roush & Sharby, 2011). For people with disabilities, the medical model is profoundly reliant on medical professionals acting as significant gatekeepers with access to resources and benefit. In doing so, they use labels and diagnoses to determine individuals' suitability to receive services (Humpage, 2007 as cited in Haegele & Hodge, 2016). At issue with this approach is that little to no consideration is given to what individuals want, need, and value resulting in their feeling they are left with limited options (Haegele & Hodge, 2016).

Brooks (2015) argued no singular model has yet to capture the definitive experience of disability because each model has limited perceptions. The efforts to incorporate most experiences of impairment resulted in Brooks' proposed model instead – "able-bodied acceptance" (Brooks, 2015, p. 4). The model proposed the ways and means societies create worldviews of disabilities are based on acting as acceptance gatekeepers to those who can conform to able-body norms and standards, thus disability becomes a social construction (Brooks, 2015).

As referenced in Chapter 1, the medical model has long been a basis of how Ontarians viewed their fellow citizens with DD often with an outcome of institutionalized care. Brooks (2015) posited such an understanding emanates from the disease model first proposed by Parsons (1951), suggesting when a person has an ailment or becomes disabled, their role transitioned into that of a sick person. Parsons believed medicine's central purpose was to "regulate and control individuals … so physicians can return the individual to normal" (Brooks, 2015, p. 4). As this relates to the underlying medical approach to DD in Ontario, a person's physical and/or psychological limitations determined their level of participation in society. In the institutionalized scenarios, the only solution it seemed, was to find a treatment if not a cure, to make normalize the abnormal (Brooks, 2015).

Pointed out by Brooks and others (Brisenden, 1986; Smart, 2006, 2009; Nagi, 1969 cited in Brooks, 2015), the medical model was seen as deeply and unduly rooted in clinical diagnosis that lent itself to a partial and minimized view of the person with a disability (Brisenden, 1986). Brooks (2015) asserted by ignoring the social dimensions of disability and underscoring standardized treatment plans, the medical model view is one of the individual as a diagnosis instead of a person. It carries the notion disabled people are left in the lurch and by default, need to lead a life constructed for them.

The medical model perceives people with disabilities through the lens of their impairments, creating a dehumanized portrayal (Brooks, 2015). Following this line of thought, DD does not permit people to choose how to define their disability and thereby placing limits on their individuality (Brooks, 2015). However, as this study will show, public outcry and appreciation of disability and self-determination theory have played a role in cultural dialogue about people with DD and their integration in mainstream society (Fyson & Cromby, 2013; Ontario Ministry of Community and Social Services, 2012; Ontario Ombudsman, 2016; Select Committee on DD, 2014). It is worth noting a global picture of DD cannot be as simple as presenting a dichotomy between the medical and social models (Brooks, 2015; Cobigo et al., 2012; Haegele & Hodge, 2016; Owens, 2015).

Although presented as opposing, some scholar-practitioners claim the medical and social model can each contribute important understanding to disability (Bluestein, 2012;

Haegele & Hodge, 2016). What is perhaps more important is for those who interact, advocate for, and support people with DD to think critically about how they define and interpret disabilities. Barton (2009 as cited in Haegele & Hodge, 2016) asserted the language used to define others influences our expectations of them. As we shall see below, this holds equally true with the social model.

## Social Model of Disability Theory: An Effective Modality

The social model of disability is an effective means for individuals with disabilities to link human rights to sociopolitical activism and claim their rightful place in society (Owens, 2015). Activists argue it is a powerful driver by which people with disabilities can challenge lived experiences of oppression and produce social and political change (Anastasiou & Keller, 2011; Owens, 2015). Social barriers to inclusive and participatory citizenship can be removed while simultaneously placing the burden of responsibility for these issues onto society, seen as creating settings whereby people with disabilities become dependent on others for acceptance (Owens, 2015).

Disability is a social construct, with people's differences defined by labels. Individuals are evaluated through a power stratagem serving to separate them from mainstream society and because of deviation from dominant norms, their differences are not valued (Brown, 2015; Ontario Ombudsman, 2016; Owens, 2015). As the disability rights movement gained momentum in the 1990s, it took to communicate that no policy decisions should be made without the full and direct participation of those whom policy decisions affected. In North America, this iteration of social model of disability incorporated a conceptualization of individualization as the basis for its activism objectives (Owens, 2015).

In contrast, the idea of pluralism in the social model of disability is engaged to explain the exercise and distribution of power throughout society. The notion of pluralism is a good fit for my research due the deeply rooted multicultural pursuits of Canada, where this study takes place, and the country's history of power-sharing amongst various segments of society (Hiebert, 2016). There is alignment with pluralists not accepting that members of society share common interests and concerns towards all issues; the recognition of diversity underscores a mediation of power between various groups and the interests of one are not given permanent dominance over other groups of people. Democracy encourages the diversity of socio-political opinions, interests, and actions representing all sections of our population (Owens, 2015).

As some have suggested (Bingham et al., 2012; Brandon & Pritchard, 2011; Haegele & Hodge, 2016; Palmer & Harvey, 2012), society is responsible for imposing disability on people. In this context, references to disability (considered a disadvantage or restriction caused by a social organization which excludes them because of it) and impairment, (perceived as an abnormality or deformity of the body) – an important distinction proposed by Barney (2012; Haegele & Hodge, 2016, Roush & Sharby, 2011) – that the social model suggests it is not one's lack of bodily function that limits his/her abilities, it is society. Bluestein (2012) asserted in this framework there is nothing disabling with having an impairment; rather, disabilities are imposed in addition to impairments by way of isolation and excluded from full participation in their community

(Bingham et al., 2013; Brandon & Pritchard, 2011). As noted by Haegele and Hodge (2016), society's inability or unwillingness to remove environmental barriers faced by people with disabilities play a significant roles in creating and perpetuating their isolation, exclusion, and perceptions of individuals with impairments being less able to participate in their communities (Ontario Ombudsman, 2016; Palmer & Harley, 2012).

Although the social model suggests the construction of solutions should be aimed at society as a whole and not the individual member with disability; this a form of diversity that should be celebrated and embraced (Bingham et al., 2013; Roush & Sharby, 2011). In fact, the social model posits by altering social arrangements, many problems associated with disability might vanish if there is public policy with focus on the removal of environmental barriers (Brittain, 2004 as cited in Haegele & Hodge, 2016). While there can be general agreement this requires social change and a response, societal arrangements such as these could significantly affect the narrative, according to Bluestein (2012). Although this may be a more just and ethically preferable to the current status (Bluestein, 2012; Haegele & Hodge, 2016) and can guide society away from discrimination and toward inclusion, the social model does have detractors (Palmer & Harley, 2012).

## Social Model of Disability: An Imperfect Modality?

In the past 20 years, the social model of disability has influenced public policy on disability matters in the United Kingdom, Europe, and a wider international stage including Canada (Anastasiou & Kauffman, 2013; Kauffman & Bader, forthcoming). The core positions of the social medical model were articulately formulated by in the mid-

1970s by the Union of the Physically Impaired Against Segregation (Anastasiou & Kauffman, 2013). People who are disabled are done so by the society that neglects them; disability is imposed on individuals in addition to the physicality of impairments with unnecessary isolation and exclusion – creating what Anastasiou & Kauffman (2013) called an oppressed group.

The social model of disability can be condensed into 5 interconnected theses (Anastasiou & Kauffman, 2013):

1. Disability is the loss or restriction of opportunities to participate equally in the normal life of a community due to physical and social barriers
2. Disability is the product of social organization
3. Disability is not pathology but symptomatic of particular social and economic pressures responsible for social exclusion, further exacerbated by society's failure to provide services to ensure the needs of people with disabilities are factored into account in its social organization
4. Oppression is the outcome of industrial capitalism's structures and production whereby people with disabilities are marginalized and when the emergence of scientific medicine, medical ideology devalued persons with disability at the same time it naturalized the causes of the devaluation
5. Disability is not a matter of personal tragedy or victimization of circumstance; nothing about a person with disability is wrong and/or needs to be fixed via medical intervention; rather, it is society that needs to change

Social model proponents maintain the biological and cognitive characteristics of disabilities are illusions determined by social context and values (Anastasiou & Kauffman, 2011 as cited in Anastasiou & Kauffman, 2013). Moreover, disabilities in and of themselves, are not necessarily the central problem; instead, they are neutralized when social barriers are eliminated. For many people with disabilities, the discrimination, isolation, ostracism, and hostility are worse than the physical or mental impairment they experience. However, social, political, cultural, and economic marginalization can exist independent of disabilities and do not define disability itself (Anastasiou & Kauffman, 2013).

Anastasiou and Kauffman (2013) proposed this compelling question in their critique of the social model of disability: If we had an ideal predominantly caring and compassionate society, could that mean the disappearance of disabilities? They argued, the eradication of disabilities by altering only the sociopolitical context is not possible thus rendering null the argument that disabilities can be understood within ontological parameters. The labels we ascribe to physical or DD do not create disabilities or turn disabilities into abilities (Kauffman & Lloyd, 2011). Of course, labels have their influence too because they circulate in social contexts and turn back on the people who are labeled and the quality of lives for people with disabilities can be enhanced substantially – not a trivial matter by any means. Yet, whatever labels are deployed in societies, most people with disabilities will be affected in some way (Anastasiou & Kauffman, 2013).

According to Anastasiou and Kauffman (2013) and others (Lid, 20125; McCauley & Matheson, 2016; Overmars-Marx et al., 2014; Prince, 2014), a discussion about social context is an important one to have. Disability can be conceptualized with specific social contexts and defined by discrepancies between an individual's actionable abilities and the social group's demands and values; inevitably conceptualization of disability is inevitably value-laden (Anastasiou & Kauffman, 2013). Moreover, identification of disability relies on judgment which in turn, are linked to judgmental identification of disabilities. However, not making these judgments precludes what is necessary for an evolving social justice (Anastasiou & Kauffman, 2011).

Anastasiou & Kauffman (2013) referred to the social model of disability as an over socialized analysis that casts aside biological analysis breaking the link between biological processes and social experience. Proponents of a social model they argued, claim that disability exists because of labeling or cultural attitudes toward others' differences, not because of difference itself. Their central belief was if individuals with disabilities are disadvantaged and marginalized it has nothing to do with the individual or medical factors, thus denying medical and psychological particularities (Anastasiou & Kauffman, 2013).

Counter social modelists argue the glossing over of the medical specifics concerning cognitive, emotional, and social problems that are the defining traits of DD and other brain malfunctions involving other disabilities. Anastasiou and Kauffman (2013) argue this is the wrong approach because people's disabilities may be due to severe cognitive, language, emotional, and social problems. They claimed comprehending disabilities is too complex to be done through the application of single-dimensional cultural and/or biological explanations. Instead, what is needed instead is a cohesive, multi-dimensional grasp involving clarification of biological, social, behavioral, and psychological factors which influence the lives of people without rejecting these analysis levels (Anastasiou & Kauffman, 2013).

An argument can also be made for the power of politics to transform the world along with some degree of utopian ideals such as what Kauffman and Lloyd (2011) and Anastasiou and Kauffman (2013) referred to as a fictional world that satisfactorily met the needs of everyone with a disability. According to these authors, the existence of the past and today's socio-political systems and today's people who live in a nonimaginary world cannot be discounted; to them, acknowledgement of this reality is critical for the imposition of radical and transformational political strategies (Anastasiou & Kauffman, 2013).

Kauffman and Lloyd (2011, as cited in Anastasiou & Kauffman, 2013) argued defects in the social model are compounded by an over-reliance on false arguments that ignore realities and scientific truths. Such dubious theories about disability, informed by denial of biological conditions, cannot serve in the best interest people with disabilities. Kauffman and Lloyd (2011, as cited in Anastasiou & Kauffman, 2013) suggested deeply flawed concepts of disability make for vulnerability to negative sociopolitical shifts. Furthermore, Meekosha and Soldatic (2011) warned that a concentration on human rights, may mean the further exacerbation rather than the resolution of the problems faced by people with disabilities. Yet, the social model of disability has also demonstrated success for people with disabilities by challenging discrimination and marginalization as explained in the following counterargument for its use.

## Self-Determination Theory

Self-determination cannot be contemplated without reflexing on human rights. The Joint Committee on Human Rights' (2008 as cited in Fyson & Cromby, 2013) emphasis on the human rights of people with DD is frequently invoked as essential to the solution of the multiple disadvantages they face including social exclusion, poverty, and abuse. More often policies and services for people with DD are organized and aligned with ideology emphasizing individual responsibility, personal choice and self-determination (Fyson & Cromby, 2013).

The DD population is heterogeneous in nature and means individual capacities for decision-making and independence varies (Fyson & Cromby, 2013). In order for choice to be meaningful, there must be an understanding of options available, the personal consequences for making a specific choice, and the likelihood a choice can be reversed without permanent harm (Fyson & Cromby, 2013). One of the criticism against casting self-determination in too broad a range has to do with the unreserved acknowledgment that if an individual lacks capacity to make meaningful choices, it is because if people with DD were able to be fully independent and make important life choices without support, then they would not be receiving publicly-funded services in the first place (Fyson & Kitson, 2007 in Fyson & Cromby, 2013).

Notwithstanding individual capacity limitations, there needs to be recognition of the need to facilitate meaningful involvement in decisions influencing their quality of life. Supported decision-making has been touted as one possible solution to people with DD to be in autonomous control of their lives and support. In Ontario, there has been nuanced and helpful ways to think about supported decision-making (Fyson & Cromby, 2013). Bach and Kerzner (2010 as cited in Fyson & Cromby, 2013) posited instead not exercising self-determination as isolated, individual selves but rather interdependently and inter-subjectively with others.

Others have stressed the persistent absence of control, power imbalances, and poverty have limited the potential of people with DD and perpetuate their dependence and vulnerability (Seth et al., 2015). Advocates like Seth and Slark (2015) insisted the issue of lack of control is central to self-determination. They and their supporters argued there are discrepancies in institutional thinking, but its foundation still stands. This continuing legacy of inequality in social conditions make labelled people more vulnerable to isolation, abuse, and hopelessness (Seth et al., 2015). Shared power, community driven support is a way to confront the issue; the process of institutionalization is far from over (Seth et al., 2015). The message for professionals is to employ self-reflection and open collaboration; asking rather than telling and continuous presuming competence and acting from a place of least dangerous assumptions (Seth et al., 2015).

Self-determination can involve a process of individuation – the transition from being largely dependent on others to being mainly dependent on oneself and autonomy (Wehmeyer, 2014). This transition can be especially difficult for people with DD. According to Wehmeyer (2013), numerous studies documented that people with disabilities experience higher rates of social isolation, reduced quality of life, and are more likely to live with family rather than independently unlike their peers without disabilities. Further, Wehmeyer (2014) maintained research is clear adults with DD have fewer opportunities to make choices and exert their self-determination. Examining how to provide necessary protections while permitting choice opportunities is important.

In the self-determination theoretical framework, quality of life is introduced as a complex construct viewed from multiple perspectives and operationalized in various ways. A prominent component of self-determination theory is historically rooted in Wolfensberger's (1972) stance on normalization, independent living, and disability rights movement. The term 'self-determination' first affiliated with the right of nations to self-governance was appropriated by the disability rights movement to refer to the right to control their lives. Schalock (1996) further augmented this by the assertion self-determination is composed of core principles: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights.

The concept of self-determination is a product of Western thought with an individualistic slant as described by Leake (n.d.) stressing individual rights, pursuit of personal interests, setting and achieving personal goals and being true to one's own values and beliefs. However, Leake asserted if Westerners seriously and honestly reflected on their self-determined goals, they would probably conclude other people in their lives have provided essential supports in achieving their goals. Thus, interdependency and reciprocity are important themes to emerge in Leake's research.

These relationships are central to self-determination because of the promotion of psychological health and a secure emotional base from which people can begin developing their intrinsic motivation for wanting to attain particular objectives in their lives (Leake, n.d.). Furthermore, Leake asserted that due to the varying levels of capacity of people with DD, self-determination often requires to be theoretically recast as process whereby individuals with DD take an active role but also rely on the counsel and support of people they trust (an alternative interdependent avenue to self-determination).

Leake (n.d.) maintained social capital is required by all individuals – with and without disabilities – to attain self-determination. Social skills can contribute to self-determination theory by promoting social relationships and greater community-based independence but in contrast, self-determination and the closely related empowerment, are too often perceived as fostered by the personality traits of autonomous individuals rather than as a by-product of interconnected relationships (Sprague & Hayes, 2000 as cited in Leake, n.d.). Leake suggested the self-determination theories he encountered in the disability literature specified sets of traits or capacities targeted for training to underpin self-determination in environments that stressed the importance of social capital.

## Photovoice as a Data Collection Methodology

Research is understood as a cultural practice helping to define social and scientific understandings of disability (Povee, Bishop, & Roberts, 2014). Ideological frameworks can shift over time as these understandings evolve. An important outcome, according to Povee et al. (2014), was for people with disabilities to seek together with academic scholar-practitioners, research methodologies that did not perpetuate oppression. Instead, what was sought were endorsed meaningful social roles, autonomy, and empowerment.

Povee et al. (2014) noted participatory approaches are growing amongst researchers and community members with DD; however, it is not widespread. Povee et al. further asserted the most popular research methodologies with people with DD remain restricted to interviews and focus groups. Likewise, Matthew and Sunderland (2013) argued the preference for the articulated word in disability research continues to be problematic for individuals who could present their narratives using alternate forms of communication.

This study utilizes the photovoice method for its collection of data. As per the photovoice website (Photovoice, 2018), the central purpose of this approach is driven by providing people opportunities to represent themselves and their personal stories with the use of ethical photography to promote social change. Photovoice is an alternative communication medium growing in popularity for facilitating research with people who have disabilities; photovoice is a particularly significant part of the increasing growth of participatory research approaches with people with DD (Povee et al., 2014). Its prerequisite is for the researcher to share power and control throughout the study process and to endure possibilities it will not be seamless or challenging (Matthews & Sunderland, 2013; Mitchell, 2011; Povee et al., 2014; Rose, 2016). Moreover, photovoice's primary objectives, according to Wang and Burris (1994, 1997) who were among the first to introduce the idea of self-advocates using personal photography to tell stories and affect social change, is to empower and engage.

Gubrium and Harper (2013) posited that despite a large body of participatory enquiry over the past 30 years, there has been very little about this type of photovoice study with people who have DD to provide a guide for future research. Photovoice attempts to capture the authenticities of individuals' lives and make these realities accessible to others with the use of photographic images (Povee et al., 2014). Furthermore, photovoice engages research participants in taking photographs to represent the research question(s) through the following six phases of photovoice as outlined by Booth and Booth (2003 as cited in Povee et al., 2014):

1. Compiling a group of interested individuals to participate in the study.
2. Identifying a theme collectively to be investigated using photovoice.
3. Research participants taking multiple photographs to represent the study's purpose.
4. Selecting, contextualizing the photographs best reflecting the project.
5. Codifying collective themes, issues, theories occurring across the individuals' photos.
6. Targeting an audience external to the group, such as policymakers.

Photovoice was developed by Wang and Burris (1994, 1997) and traditionally used in public health research to collect participatory needs assessments, evaluation, and communication to policy-makers. They credited the evolution of photovoice to three main influences: Freire's (1970) seminal work on education for critical consciousness, feminist theory, and documentary photography (Povee et al., 2014). Freire suggested community problem-solving and social action organization could be accomplished through the visual image. Change, participation, personal and social transformation and justice – central to Freire's work, featured heavily in Wang and Burris' (1994) photovoice development. Second, likewise to feminist theory which views women as authorities on their own lived experiences (Povee et al., 2014), photovoice underscores participants' own voices and visions (Wang & Burris, 1994).

Photovoice values grounded experiential knowledge and aims to create forums whereas marginalized groups like people with DD (Overmars-Marx et al., 2014) can be empowered to usher in social change (Povee et al., 2014). Finally, like documentary photography, photovoice uses images to chronicle life stories and events as part of the social conscience (Booth & Booth, 2003 as cited in Povee et al., 2014; Wang & Burris, 1994). However, a major differentiation between the two is that with photovoice, the camera is in the participants' hands of those whose dominant reality is powerlessness and the images are owned by them (Wang & Burris, 1997). Furthermore, Wang and Burris (1994, 1997) contended that through dynamic participation in the visual documentation of their reality, marginalized individuals could be the catalyst for change in their community. The substance of change will be determined by the research participants themselves. The post research mechanism to do this may include a public exhibition of their photographs and the dissemination of this study's outcomes to the community, policymakers, and DD service providers.

## This Study's Relevancy to the Social Work Profession

As referenced earlier, I have found few studies in the literature using photovoice with people with DD to specifically explore their self-awareness of citizenship. However, one significant recent enquiry (Brake, Schleien, Miller, & Walton, 2012) deployed photovoice with a group of self-advocates with DD to examine their lived experiences with access, participation, and social inclusion in the community. Such research can help participants engage community members in dialogue about their worldviews, challenges, and support needs to achieve potential (Gubrium & Harper, 2013). The present dearth of this knowledge can be improved with additional studies as the one proposed.

This study will align with three core values of the current Canadian Association of Social Workers (CASW; 2005) Code of Ethics. First, social work in Canada is founded on a long-established obligation to respect the inherent dignity and individual worth of all people and their human rights; also recognizing and respecting the diversity found in Canadian society. Pertinent to this value is the upholding of individuals' right to self-determination, consistent with that person's capacity and rights of others.

The second value involves the pursuit of social justice and the obligation of society to provide resources and opportunities for the overall benefit of humanity. Social workers act on behalf of others to reduce barriers and expand choice, with special focus on people who are marginalized, disadvantaged, vulnerable, and who may have exceptional support needs. Additionally, social workers oppose prejudice and discrimination against any person or group of persons, on any grounds, and specifically challenge views and actions that stereotype persons or groups (CASW, 2005).

Third, the social work profession must remain consistent with its core professional objective of social justice, balancing individual needs, and rights and freedoms with collective interests in the service of humanity. Central to these values, the social work profession aims to contribute to knowledge and skills that assist in the pursuit of an equal and equitable society for all (CASW, 2005).

Consistent with the professional obligations outlined by the CASW (2005) Code of Ethics, this study seeks to empower the research participants by providing opportunity for people with DD to exert control, make decisions, and share power (Povee et al., 2014). Moreover, empowerment and control also applied to photovoice interviews and selection of photographs. Participants control how their realities and lived experiences are represented by the stories they told of their photographs (Povee et al., 2014; Wang & Burris, 1994, 1997).

Photovoice will capture a unique perspective to assist social work's better facilitation of advocacy and support for people with DD. Using photovoice, social workers can obtain a rounder insight into how the world is perceived and experienced by people with DD. As important, is that data collection does not need to be restricted to only times the researcher is present (Mitchell, 2011; Povee et al., 2014; Rose, 2016; Wang & Burris, 1994, 1997).

Photovoice gives the social work practitioner-researcher a forum in which to be a participant-conceptualizer, as s/he is involved actively in the processes while also attempting conceptualize or understand them (Povee et al., 2014). A study's members are valued co-researchers and experts in their own lived experiences. This study design will challenge the traditional researcher-researched relationship (Povee et al., 2014).

## Summary

*Nihil de nobis sine nobis* – Nothing about us without us (Owens, 2015, p. 389)

The above Latin slogan was adopted by disability rights movement to establish their assertion of gaining control over events influencing their lives. In a poignant way, the slogan drives my research, keeping me mindful of this expectation while exploring a topic previous research has not examined. My review of the literature has shown there has been much more research conducted *about* people with DD than *with* people with DD. Consequently, there is little I have seen in the research literature whereby the voices of the individuals with DD are evident in the study. This is also noted by my more than 30 years of direct experience working with people with DD and chairing various government committees with a focus on this population, thus the motivation to fill this research gap.

A central value held is being rooted and affiliated with our community where our differences and diversities are celebrated and accepted. Pitonyak (2014) strongly felt the most important, yet least recognized need of the human soul, is to be rooted. Significant to this study is an understanding of what it means to belong.

Pitonyak's research (2014) claimed many people who have disabilities live their lives in extreme isolation and others depend almost exclusively on their families for companionship and social contact. Others have lost their connections and rely on people who are paid to support them. For individuals experiencing these uncertainties are fundamentally alone; a sense of belonging appears to be a basic human – as basic as food and shelter (Pitonyak, 2014).

The notion espoused by Pitonyak (2014) that the nature and quality of social interaction may be linked to health, contradicts traditional medical model assumptions that DD are organically based and require pharmacological treatment regimens (Brooks, 2015). Although the reasons why socialization leads to better health are not completely understood – one theory is immune function is improved by belonging – the implications are profound for people with DD. According to Pitonyak it may be that much of what is observed as pathology (such as poor health, mental health issues, problem behaviors), is in fact, a symptom of social isolation and exclusion.

The concept of belonging can be broadened to include citizenship. Marshall's (1950) seminal writing on citizenship referenced non-participants in society as having an excluded but temporary status that could be adjusted so that full citizenship could eventually be attained. Marshall interpreted citizenship as having the potential to mitigate social inequality by extending rights to all; however, this has been criticized as being overly simplistic (MacIntyre, 2014). Citizenship is a complex social construct because of its inherent obligations to societal norms making it problematized, targeted by policies aimed at promoting responsibilities that come with active citizenship (MacIntyre, 2014).

Such traditional conceptualizations of citizenship have potential for exclusionary norms for those who are already marginalized due to disability. The continued focus on traditional contributions to society (financial, for example) further excludes people with disabilities. Moreover, it perpetuates a flawed understanding about disabled persons' potential to contribute in other ways (MacIntyre, 2014). As the next chapter will demonstrate, I explore the notion of belonging and how this relates to participatory community membership.

# Chapter 3: Research Method

## Introduction

The purpose of this qualitative case study was to understand the lived experiences of a group of adults with DD as they explored and shaped their world views of belonging and connections with their community (see Johansson, 2003; Yin, 2014). The study was designed with multisource, in-depth data collection, attained via individual interviews, photo selection dialogues, provincial government DD social policy content analysis, and a focus group. I have not found the literature conversant on the perspectives of people with DD in an examination of this sort whereby the construct of belonging is the focal point of the investigation and where research questions targeted the personal conceptualizations of adults with DD belonging to their community.

In this study, I used a case study approach (see Johansson, 2003; Yin, 2014) together with a photovoice (see Rose, 2016; Mitchell, 2011; Wang & Burris, 1994, 1997) methodology. In the pursuant sections, I demonstrate the appropriateness of this design and core concepts of this study; my role as observer-participant and the power relationship over participants; researcher biases; and finally, ethical challenges in conducting research within my career field. This chapter concludes with a discussion of trustworthiness and a summary.

## Research Design and Rationale

The central question of the study was: What key social determinants of belonging and/or citizenship and connections to their communities are discerned when they describe their photographs? The secondary research questions were:

Sub question 1: What key social determinants of belonging and/or citizenship and connections to their communities are discerned by adults with DD when they describe their photographs?

Sub question 2: Are self-identified depictions of belonging better explained through ontological interpretations of their DD rather than as pathologies?

Sub question 3: What does it mean to live as a person with DD?

I conducted this case study as an inquiry investigating contemporary viewpoints within a social world context (see Hollweck, 2015; Yin, 2014). This case study was driven by the notion that case studies are considered a separate and all-encompassing method with its own research design (see Hollweck, 2015; Yin, 2014). In turn, I linked theory and practice by presenting the breadth of the research and its historical significance at a practical level. The approach and processes of this study were given careful attention in an effort to achieve a high-quality case study as a chief outcome (see Yin, 2014). Moreover, my study was underpinned by the belief that the skills and expertise of me as the researcher played an important part in this endeavor (see Hollweck; 2015; Yin, 2014).

## Rationale for the Case Study Approach

I chose the combination of case study and photovoice design to advance future qualitative investigations with people who have DD (see Hyett et al., 2014). I adapted the interviewing methodology because a study such as this with a DD population needs to accommodate participants' different ways of learning so they can absorb instructions (see Brown, 2015; Denzin & Lincoln, 2011; Yin; 2014). Insofar as keeping with research design, this case study was characterized by my interest in capturing the intricacies of belonging by examining individual and collective cases of people with DD exploring their personal interpretations of belonging. Furthermore, this case study was informed by my experience working at various levels with people with DD and will make use of naturally occurring information in people's natural space (see Hyett et al., 2014).

I used interpretative and social constructionist approaches to garner an understanding of belonging as understood and expressed by people with DD (see Browne & Millar, 2016; Facer & Enright, 2016; Hewitt, 2014; Owens, 2015). The results of this study are intended to help support possible future inquiry into the understanding people with DD have of their belonging. Additionally, the outcomes could inform the development of shared assumptions about this social reality.

The findings of this study were derived from personal interactions with participants in this research; therfore, it will invite readers to immerse themselves as codiscoverers alongside me, which is a chief outcome of successful case study design (see Stake, 1995 as cited in Hyett et al., 2014). Flexibility and a level of artistic license to distinguish practice, reflexivity, and origination were applied in this research (see Denzin & Lincoln, 2011). This artistic license was coupled with prudent accounting of the justification for the research design I have chosen, without which the study could appear inaccurate at best and dishonest at worse (see Hyett et al., 2014).

## Rationale for Data Analysis

I planned to use this coproduced research to help facilitate a deeper immersion into the community of people with DD to help augment inclusiveness, equity, and accessibility (see Brake et al., 2012). Honest accounts of photovoice methods and data collection and analysis can assist future scholar-practitioners in designing and implementing methodologically rigorous and ethically sound studies (Walmsley, 2004 as cited in Povee et al., 2014). Additionally, reflexive descriptions can contribute to a collective knowledge for using visually based participatory research with people with DD (Gubrium & Harper, 2013). These descriptions were driven by careful consideration of the role I played and the power relationship I had with the participants.

## Researcher's Role

### Observer-Participant

The role I had as an observer-participant in this study allowed me to work from a critical paradigm consisting of commonalities like a social justice focus, emancipation, transformation, and empowerment for vulnerable people (see Sitter, 2017). Moreover, engaging in emancipatory-specific research reflected my value position that was central to guiding the purpose and chosen methods of the inquiry. This included the narrowing of the power dichotomy (Ponterotto, 2005 as cited in Sitter, 2017). I needed to be cognizant of unequal power distribution when working with marginalized people (Ponterotto, 2005 as cited in Sitter, 2017).

This study was fortified by an engendering of inclusivity and democratic processes to help people discover and explore their realities to better understand and perhaps change them (see Sitter, 2017). Noted educator and social activist, Freire (1970) posited that people traditionally considered objects of investigations should instead be empowered to act as coinvestigators of their lived experiences. The intention of these coresearched studies is not for the generalizations of their findings to all settings but to enable meaningful change relevant to a community (Freire, 1970).

## Mitigating Researcher's Biases

### Avoiding Data Collection Bias

The central premise of confronting researcher bias was that I had to take all reasonable precautions against doing things that may have threatened data accuracy and reliability. I had to be neutral and objective in every phase of the study (see Regoniel, 2013). In the conduction of research, any hint of partiality can lead to flawed conclusions; the egregious progression is known as researcher bias (Gubrium & Harper, 2013; Hollweck, 2015; McCauley & Matheson, 2016).

In this context, bias can be committed either intentionally or inadvertently by favoring a direction to take the investigation. I have had a career spanning 35 years of involvement with the community of people with DD; this could have inadvertently exposed the study to vulnerability due to my familiarity with the subject matter, obstacles faced by people with DD, and contextual presence in Canadian society. Although the elimination of all bias sources was difficult, caution needed to be observed throughout each phase of the study and straight through to its conclusion.

I intended to address bias by averting what Regoniel (2013) referenced as personal convenience in data collection that results in failed research. For instance, instead of a carefully considered sample composition, there is a scattered approach not conducive to objectivity. Instead, I had to recognize this potential risk. Taking steps to mitigate or eliminate it helped to sustain research neutrality (see Regoniel, 2013).

Favoring a preconceived position because of previous articulations of a long career in the DD sector may have caused bias in the results of the investigation by steering evidence in the direction I would want it to go (see Regoniel, 2013). Presenting the outcomes as they developed and avoiding manipulation of results helped ensure the transparency and authenticity of my study. Committing and adhering to these standards was my responsibility to honor the participants' personal investment in the research.

As with other qualitative research approaches, this study demanded I share control and power in the study process. This included recognizing and tolerating uncertainty (see Bishop, 2007 as cited in Povee et al., 2014). Moreover, I planned to demonstrate flexibility and adapt methods to reflect the context of the study and participants' cognition of what my intentions were in facilitating this study (see Bishop, 2007 as cited in Povee et al., 2014).

## Reflexivity and Awareness During Research

To promote ethical awareness, I engaged in reflexivity practices. I focused attention and mindfulness on the nuances of ethics at each research stage, engaging in active and critical reflection on the type and quality of research knowledge created and bear in mind ethical principles (see Damianakis & Woodford, 2012).

I heeded the advice of Frederick (n.d.) who advised Ph.D. students to pick a subject they were passionate about. I wanted to become an expert on the topic of this study and pursued new knowledge throughout the research process. However, this same passion could have also blinded me to ethical vulnerabilities.

Facer and Enright (2016) held another view. They believed coproduced research can be complex and inherently messy but argued for the systematic inclusion of “mess” in research as a conceptual framework from which I could pronounce areas of complexity and messiness as an integral part of coproduced research. In doing so, I achieved the broader objective of democratizing knowledge (Horner, 2016). Awareness of these risks and cognizance that coresearch may not circumvent all paradoxes of power allowed me to pursue establishing democracy, social justice, and human rights as a value base in knowledge generation and dissemination (see Beebeejaun, 2015; Pain, Kesby, & Askins, 2012). Transparency underpinned this study to identify and negotiate the motivations behind the research, including full disclosure and visibility of objectives, accountabilities, philosophies, and worldviews.

## Ethical Concerns

Walden University’s Institutional Review Board approved my research study (Approval Number 12-18-18-0494761). I was cognizant of the shift in power and control that may occur during the evolution of the study and coped with a redefinition of roles that permitted an empowerment process (see Povee et al., 2014). Although I used analysis and interpretation processes to keep high levels of reliability and inclusive collaboration, credibility could be called into question by participants’ exclusion in the content analysis of interviews and focus groups (see Kramer, Kramer, Garcia-Iriarte, & Hammel, 2012).

To address risks for bias and unintended ethics violations, I drew on a thick description of the processes used to collaborate with participants to help readers understand the nature of data produced and analyzed through concerted procedures (see

Kramer et al., 2012). Furthermore, I took the additional step of filtering my interpretations when writing the research and accurately conveying the perspectives of the participants to reflect their interpretations of the experience (see Kramer et al., 2012). My plan for data collection, group analysis of selected photos and their possible meanings, and familiarity with data collection tools fostered an inclusive analysis and interpretation. This provided for participants' increased empowerment and heightened awareness. Moreover, creating an audit trail and debriefing with a peer helped ensure the mitigation of bias and ethics violations (see Kramer et al., 2012).

## Methodology

A central tenet of quality research is to provide the steps required for other investigators to replicate the study (Creswell, 2013). To meet this criteria, I present the following descriptors. Replicability is like reliability in that both concepts refer to the extent to which a research operation is consistently repeatable so as conviction is placed in the truth of the findings (Creswell, 2013).

### Participant Criteria and Recruitment

This qualitative case study sample comprised 5 individuals who have a mild to moderate level DD (see Developmental Services Ontario, 2016). Mild to moderate DD is determined as needing longer time for conceptual development and social and daily living skills (National Institutes of Health, 2015). I identified the level of self-care participants required to function semi- or fully independently with minimal to basic supports (see AAIDD, 2010; American Psychiatric Association, 2013; Statistics Canada, 2015). According to the AAIDD (2010) and National Institutes of Health (2015), 85% of people with DD are in the mild category of severity with IQs estimated as ranging from 50–69 and who can live independently with nominal levels of support.

The plan for soliciting suitable participants was to deploy purposive sampling. Purposive sampling is frequently used in qualitative case study research for the identification and selection appropriate cases related to the phenomenon of interest (Palinkas et al., 2015). What this signified was that the sampling would be a series of strategic choices regarding whom, where, and how I conducted the research and how it fundamentally tied to my objectives (see Simon Fraser University, 2018).

Another implication: there was no one best sampling strategy because what is considered best is predicated on the context and nature of this study (see Simon Fraser University, 2018). Not all research participants are created equal; the need to have people from the DD community who can understand and articulate the mission of the study will advance the research much more efficiently than a randomly chosen sample from the community (Simon Fraser University, 2018). People with DD who have similar mild to moderate cognitive functioning levels, have experienced some form of institutionalization for them to compare with community living, and were independent enough to travel within their communities to take photographs as assigned by the study were approached through this iteration of purposive or criterion sampling.

The sampling group consisted of 5 persons. It was important to focus on the similarities and contrasts of individual cases to enhance the study by their selection to participate, thus the smaller number. Coding and identification of themes were evident and efficient for this purpose. The participants were selected based on their responding to a study announcement flyer distributed to community centers, libraries, and other similar community resources in the greater metropolitan area.

I arranged via phone call or e-mail to meet research participant candidates personally and ensured they comprehended the study at this first level recruitment. Their names and contact information were retained. Each candidate had to have access to a camera or cell phone with picture-taking capabilities.

## Informed Consent and Participants' Rights

The term *vulnerable population* is used in social services, counseling, and research (Power, 2013; Schippers, Zuna, & Brown, 2015; Select Committee on Developmental Disabilities, 2014). The implication is that this specific group is considered a sub segment of the community requiring utmost care, specific ancillary considerations and augmented protections in research. In Ontario, Canada government programs provide assistance for vulnerable populations (Ontario Ministry of Community and Social Services, 2017). For this study, the vulnerable population is identified as the community of people with DD – in this case, the group of people the study will have as co-researchers – and whereby safeguards will necessitated to protect their well-being when research is designed and conducted (Shivayogi, 2013).

The freedoms and capabilities to protect themselves from intended or inherent risks is variably abbreviated for vulnerable individuals. This can range from decreased freewill to inability to make informed choices (Shivayogi, 2013). To address the need for the protection of participants, I plan to ensure the research design is thoroughly understood by them throughout each phase and by asking them to articulate the study's instructions by repeating them back once given. This too will be done several times as the research progresses. They were asked to sign the consent form once fully explained to them and they indicated their comprehension indicated by repeating back what the form entailed. Frequent repetition and performing tasks by rote techniques are commonly seen as encouraging better comprehension and considered effective for working with people with DD (Martin et al., 2012).

To attain optimum informed consent caliber, I included language on the form that was equivalent to that of local middle school level of education and essentially *nontechnical* to suit the solicited community. The *font* of the informed consent form was easy on the eye, *concise,* and contained a simple *summary of goals* for the study enumerated for empowering comprehension (see Shivayogi, 2013).

During the preannouncement period and before the recruitment phase, I planned to check with colleagues on the study design, recruitment, and informed consent. This was to help ensure overall safety and efficacy strategies in the ensuing research. Moreover, ethical dilemmas not previously considered were be highlighted by these objective observers in regard to communications, data privacy, and right to terminate participation. The well-being of this community was not compromised; research with this sub segment of population was validated by reasonable direct benefits in compliance with local legal regulations (see Shivrayogi, 2013).

I ensured participants were not unjustifiably influenced by the expectations of predicted benefits associated with participation. I did this by clarifying the purpose of the research was for the pursuit of an academic exercise toward a personal education achievement. The added benefit was contributing to the knowledge of this community; thus, there were no linkage between participation or support services. To adhere to the priority of securing vulnerable participant safeguards, I ensured a comprehensive informed consent process, authorized substitute decision-makers where appropriate, addressed privacy and confidentiality concerns one-on-one with participants and then repeated the process, and had participants repeat back instructions to indicate comprehension.

Interviews were conducted with the pool of candidates using an interview protocol, tailored to help ensure comprehension of the study's purposes and individuals' right to participate willingly. It was made clear their support services were unaffected in any way from either participating, refusing to participate, or dropping out of the research. Their right to terminate participation at any time, and to ask questions for clarification at any phase of the study, was explained. Participants owned the photographs they took and had decision-making authority over the photographs analyzed. Participants were entitled to full confidentiality regarding documents, photos, and any other identifying details.

## Data Collection

Themes and emergent data patterns were easier to detect with a sample size ranging between 3 and 5 people with DD. Given the visual nature of the data collection, similarities in content emerged and the contexts in which the photographs were taken showed themes much more readily.

The primary data collection instrument was photovoice, used to help determine perceptions of what social inclusion looked like through the eyes of research participants

(Mitchell, 2011; Rose, 2016; Wang & Burris, 1994, 1997). Previous scholar-practitioners built upon the seminal work of Wang and Burris (1994) who published their work through photo novellas documenting and reflecting the reality of life endured by women in rural China. I employed photovoice as an instrument to foster further exploration through the time I spent with the participants interviewing and analyzing the pictures. In concrete terms, this data collection method enabled participants to record and reflect strengths and barriers regarding belonging in their communities, engage in critical dialogue about feelings of inclusiveness through dialogue of photographs, and play an active role in reaching the public and policymakers with their personal observations.

## Data Analysis

The central data – photographs – were linked to the primary research question of comprehending what it was like to be a person with mild to moderate DD living in the community and how inclusiveness was interpreted by them. The tool of choice to help with the organization and analysis of unstructured datasets was the latest software version of NVivo (2018). It was used to keep track of project data, classify, sort, and arrange information to determine theme and coding. The objective was to find insight into the raw, unstructured data as it was analyzed with the help of photographic analysis software and NVivo.

Each research participant was unique and their personal interpretation of belonging to their community meant the study was a representation of how a group of people with DD saw their inclusion in their social world despite variant views. However, participation was not guaranteed and people were required to meet recruitment requirements. All candidates were informed in advance of the possibility they might not be chosen to take part. Each person was told by me whether they had been selected or not within two weeks of being interviewed for the study.

## Credibility and Trustworthiness

The central principles of this qualitative case study research were credibility and trustworthiness (Cope, 2014; Pedersen, Hack, McClement, & Taylor-Brown, 2013). Qualitative research credibility is considered the truth of the data and/or participants' interpretation and representation of them (Cope, 2014). Credibility was augmented when I described my experiences as a researcher and verifying research findings with the participants. According to Cope (2014), a qualitative study is considered credible if the descriptions of participants' lived experiences are recognized by others who share the same experiences. I supported credibility of this study by demonstrating engagement, methods of observation, and producing an audit trail to ensure research trustworthiness standards at all phases. The data stemmed completely from the participants themselves not from any predispositions as a researcher.

In keeping with rigorous qualitative case study design (Denzin & Lincoln, 2011; Stake 1995 as cited in Hyett et al., 2014; Johansson, 2003; Yin, 2014), the study's frameworks embraced rigour and trustworthiness so readers could make their own judgements of research quality. I turned to components like: adequately defined cases; a sense of story to the presentation; sought to provide a vicarious experience for the reader; paid attention to multiple contexts; fulfilled data sources in a suitable number; triangulated observations and interpretations, transparency, exploration of personal intentions, and empathy shown for all sides (Stake, 1995 as cited in Hyett et al., 2014; Johansson, 2003; Yin, 2014).

### Authenticity

The faithfulness in which I presented the feelings and emotions of the participants' experiences determined this study's authenticity (see Polit & Beck, 2012 as cited in Cope, 2014). As per Cope (2014), the evocative approach will help readers grasp the core of the lived experiences. In the case of my study, the lived experiences were expressed through photovoice and rich text provided by participants during interviews.

### Interviewing

Once the photographs were collected and selected, the interview phase of the data collection process called for vigilant wording of questions (Kramer et al., 2012). To reduce the possibility of bias, I circumvented asking leading questions that could have encouraged participants to provide responses they thought I wanted to hear or that were unreliable. Additionally, people with DD have differing cognitive levels and may take longer to answer so, in this regard, patience was needed to not answer for them or have others who may be present influence their answers. This study built on Regoniel's (2013) recommendations to ensure participants were ready and willing to be interviewed, ensured the questions are clear, conducted interviews for no longer than 30 minutes, informed the respondents their responses would not be used against them and that they could stop or refuse to answer at any time.

### Triangulation

Finally, I used triangulation methods to avoid the pitfalls affiliated with reliance on only one source of information. Janssen (n.d.) warned inaccurate and unreliable data collection can lead to spurious conclusions. Qualitative research, by nature highly subjective, can be verified or validated through triangulation (Janssen, n.d.; Regoniel, 2013; Yin, 2014). Triangulation is comprised of three methods is to verify the accuracy of data collected from the field – the key informant interview, survey, and focus group (Janssen, n.d.). The questions posed in qualitative case study design represent people's viewpoints. Having several information sources helped instil confidence in this study's data supports the truth (see Janssen, n.d.; Yin, 2014).

### Dependability

Dependability (or reliability) refers to the constancy of data during similar settings (Polit & Beck, 2012 as cited in Cope, 2014). In this study, dependability was sought and determined by the consistency of the photographs and explanations attributed to them by the participants. Moreover, dependability can also be achieved when a colleague concurs with the decision trails at each phase of the research process. According to Koch (2006, as cited in Cope, 2014), the processes and descriptions of research of this nature is deemed reliable if findings are replicated with similar participants in comparable conditions.

### Confirmability

To achieve confirmability, I faithfully represented the participants' responses and interpretations through the data and excluded biases and viewpoints (see Polit & Beck, 2012 as cited in Cope, 2014). I showed this by describing how conclusions and interpretations were established. Additionally, I exemplified that the findings were openly consequential from the data. Rich quotes from participants depicting emerging themes were included (see Cope, 2014).

## Transferability

The applicability of this case study's outcomes to other settings or groups, illustrated transferability (Houghton, Casey, Shaw, & Murphy, 2013). My case study achieved this criterion by the research having meaning to others external to the study. Moreover, further transferability is achieved if readers can associate the results with their own experiences (Cope, 2014). The readers should be able to assess the findings if sufficient information has been provided regarding the participants and the context in which the research took place. However, this is dependent on the objectives of a study and may only be relevant if the objective is to generalize about the topic or phenomenon (Sandelkowski, 1986 as cited in Cope, 2014).

## Confidentiality

Damianakis and Woodford (2012) proclaimed that qualitative researchers had a dual mission: to create new knowledge via rigorous research and to espouse high ethical standards. In my study, participants and data collection came from a connected community in which relationships may already have existed amongst the participants. For instance, confidentiality could have been an issue during the research during the pursuit of this dual mandate (see Damianakis & Woodford, 2012). Individuals taking part in the research could also have been tempted to divulge the personal viewpoints of others they may have been acquainted with in the sample group (see Damianakis & Woodford, 2012). It can be a difficult for a researcher to account for all ethical aspects of emergent research. Researchers purposefully foster trust to learn from study participants and to achieve the aims of the project (Damianakis & Woodford, 2012).

As a qualitative researcher, I was aware of the epistemological origins and affiliated ontological positions underpinning the study design. When research is constructed within this relational presence, a genuine and honest representation provides rich, contextualized data (Daminakis & Woodford, 2012). This also increases ethical vulnerability and possibly pose risks of confidentiality breaches. Inclusion of this raw data and participants' own words may unintentionally disclose participants' and others' identities; an option is to give participants the choice of being identified in the study (Damianakis & Woodford, 2012).

## Summary

Chapter 3 provided an explanation of the case study design's distinctive use of photovoice as data collection method (in combination with interviews and focus group work). Research literature on such an approach has been sparse, especially regarding working with a population of people with DD. The research was challenging given the intricacies and nuances of social citizenship as a notion and participants' varying levels of cognitive abilities. However, the aim of this study was not diminished by these complexities. A central objective was to augment and/or produce new knowledge for better understanding and possible future research.

The rationale that drove this study was to bring to others' attention the lived experiences of people with DD as they navigated through their understanding of belonging to a community. Their interpretations, coupled with the current social determinants of belonging, were key to clear comprehension of their personal worldviews. Concurrent with this, I hoped to gain competence as an academic investigator in this research area.

The choice of research design and subject was predicated on my personal and professional interests in the subject matter. Having worked for many years in the DD sector in various capacities, I understood how people with DD saw the world without influence from others or uninhibited by communication limitations. However, this is where personal and professional boundaries were drawn. For this study to be recognized as having research excellence, devoid of preconceived notions and assumptions, a strong adherence to academic standards were top of mind.

Particularly noteworthy was the sharing of power and decision-making required for securing the trustworthiness of this study. In my experience, people with DD viewed those responsible for their care as authority figures (Ontario Ministry of Community and Social Services, 2012; Ontario Ombudsman, 2016). How the participants received coresearcher responsibility and ownership would either appeal to them or require work to get the group to take it on. The reward was in the power of photovoice to bestow benefits upon the individual photographer and others collectively as the self-awareness of the sample group was explored (see Pitonyak, 2007; Power, 2013; Prince, 2014).

Case studies seek to provide a better understanding of phenomena and context-reliant data but as literature shows, there is still confusion about the proper use of case study methodology (Welch at al., 2011 as cited in Ridder, 2017). While case study research design is often constricted to an explorative function, the broad range of possibilities case study provides is often neglected (Ridder, 2017). My study aimed to avoid similar pitfalls of other case studies.

Finally, I wanted less homogeneity, not more. Case study research, in general, share characteristics, but the incorporation of a unique design that included photovoice had heterogeneous goals used several features to attain these goals (see Ridder, 2017). The objectives of this case study were outlined accurately to make the exploration significant and meaningful. This study demonstrated an adaptation of case study designs by introducing photovoice as a combined research scheme. I described the understudied phenomenon of belonging through the eyes and narratives of people with DD to educate others, develop new constructs, and relationships (see Ridder, 2017). Chapter 4 presents the findings of my study.

# Chapter 4: Results

## Introduction

This chapter contains the results of a case study, photovoice research facilitated to explore the central research question: What key social determinants of belonging and/or citizenship and connections to their communities are discerned by adults with DD when they describe their photographs? I also asked the following secondary research questions: Are self-identified depictions of belonging better explained through ontological interpretations of their DD rather than as pathologies, and what does it mean to live with a developmental disability?

In this chapter, I discuss that the analysis conducted was consistent with the case study and photovoice methodologies and how the data analysis circles back to the research questions. The process was used to analyze transcripts from the five participant interviews to determine emergent codes and themes described in this chapter. Coding and theming were done manually, then inputted to the NVivo 12 software to help gauge any significant similarities or differences. There were two levels of data analysis deployed: (a) open coding and (b) selective coding. At each level of data examination, I used a comparison to filter the data further until themes emerged. Also included in the chapter are the graphics used to present data codes to help emphasize the key ideas in the resultant findings of this investigation.

*Figure 1.* Movie theater frequented by MC, usually with neighborhood friend. “I go to movies with a friend who also lives in the community. It’s a good way to escape for a while” (MC, Participant).

## Sample

For this study, I purposely recruited and interviewed five participants. Appendix A indicates the recruitment requirement sought. Each person had a mild DD, as described in Chapter 3, to be considered for participation. All had some form of employment: One with a few hours per day per week, two with part-time hours at 1 to 2 days per week, and 2 with full-time hours 5 days per week. Each participant strongly identified work as being central to their perspective of belonging and citizenship. It is of note that the individuals’ employment represented a diversity of settings: a furniture-making factory, a federal government office, a grocery store, a childcare assistant, and a law firm. The sample group consisted of one female and four males with ages ranging from 30–55 years old. I drew the sample group from other groups the participants had regular contact with, either through a day program (1) or social support group (4).

## Data Collection

I conducted 5 semi structured, contextual research interviews, each approximately 40 minutes long with adults with mild to moderate DD. I manually coded their responses as one batch for emerging themes. Then, I embedded the interview protocol throughout the data collection phase, and the approach allowed for follow-up or clarification questions to be asked, as required, so respondents clearly understood. See Appendix A for the interview protocol.

The photographs taken by the participants and interviews served as the central sources of research data. The photography entailed participants were to be given 1-time use, disposable 27-exposure cameras with preloaded 35mm film. During recruitment/orientation interviews, they were shown how to use the cameras over 2 weeks and returned to me for film processing. I reviewed personal safety while photographing with each participant. Appendix B provides details in the tips sheet distributed to them. Upon getting each participant's processed prints, interviews were arranged and later transcribed.

I manually open coded each interview informed by participants' description of their photographs as the initial stage of qualitative data analysis, building directly from the raw data to ensure the validity of the study. Appendix C shows the common node themes extrapolated from the interviews. Additionally, the transcripts were uploaded to NVivo 12 software to add an extra layer of analysis. This aided in carrying out a consistent comparative analysis to emphasize critical points during coding. The manual open coding resulted in six standard codes (devised from the wording used by participants) for demonstrating their concept of belonging and citizenship in a community.

### Code 1: Belonging as a Right to Be Someplace

When describing why they took particular photographs, the participants placed themselves in the settings, although only 2 of the 5 were in the pictures themselves. They spoke in terms of “I” and “me.” As one person said: “It [community] makes me feel I’m part of something bigger.”

### Code 2: Decision-Making is a Right When Choosing Where to Live

There were no indications from the interviews or photographs that the participants lived in areas where they did not want to be. One person spoke with pride about the community where he lived for more than a dozen years. He photographed and talked about essential buildings, such as a library, theatre, stores, and subway station, which he frequented and found convenient. Others chose to highlight the family home or apartment building as the mainstay of their community life or have had a role in choosing to live there. Responses indicated there were no issues of acceptance from community members.

### Code 3: Meaningful Employment is Crucial to Belonging and Citizenship

Working figured most prominently in all five interviews. Each person either worked full-time (i.e., 1) or part-time (i.e., 2 worked either 1 or 2 days a week for 4 hours or less; the other 2 persons worked full-time hours). Statements like these emphasized employment’s importance to them:

> I wish there were more hours I could work – it's a little bit frustrating. I have a resume, but it's just hard to find a job. People don't want to hire someone with a disability, or they don't want to train them.

When I asked a participant if she could change one thing about her lived experiences so far in the community, the response was, "I don't know … I guess working more, being out more. I guess better living with no poverty. Yeah. It would get me out, meet more people in different surroundings."

Another person was not happy with the current employment status and wanted, "… a real job that pays me a good wage instead of one day here, one day there." An interviewee who worked more steadily said, "I've been doing that [working in a federal government office] 1.5 years … holy shit, almost 2 years in July. I like them [employer] too, and that's another community."

Those working full-time perceived having a job as also belonging to a different community: a community of coworkers: "It's a community based on serving people. People come in, and you provide service to them; they make me feel active; like I'm doing something." Another said, "I always like going to work. I go to work, and I go home."

*Figure 2.* Subway stop used by MM to get around town – especially work. “I learned how to take the subway when I was about 12, so it prepared me to travel around the city.” (MM, Participant)

**Code 4: Independence to Move About and Engage with Others**

Each interviewee either had access to limited use of independent transit or unrestricted use of public transit to travel within or at some distance from their immediate neighborhood. Four of the 5 participants discussed the freedom to go whenever and wherever they wished. The one person who was not able to have such freedom of movement spoke of discontentment with the circumstances, preferring to be able to make decisions about how they spent the day. He expressed displeasure at how he felt others treated him in the day program environment but spoke highly of community members, such as coworkers at his job and his dentist where he visits frequently. At the day program he attends, he chooses activities of interest, but he did not see this as having control even though there were compromises. He only attends 2 days a week with the rest of the time divided between job sites and volunteering at another organization. The others expressed liking to meet others, being with people, and looking for more opportunities to do so. The convenience and knowledge of public transit was the leading factor in their mobility to explore beyond their immediate neighborhood.

### Code 5: The Importance of Friendships

Four of the 5 interviewees identified their sense of belonging as being informed by nonemployment-related friendships they had in and external to their immediate neighborhoods. One individual perceived connection to others to be through working with them or someone they had a long-time relationship. He had no interest in socialization activities with others preferring instead to engage with his dentist, whom he frequently visited socially. The other four interviewees expressed having close friends with whom they met and socialized frequently.

*Figure 3.* Community dental office preferred by CP over a clinical setting "I like to visit my dentist because he's a family guy. I've known him since I was little. His office is in a house; I don't like clinics because they make me nervous." (CP, Participant)

### Code 6: Personhood and Self-Advocacy

All but 1 participant referenced being accountable to themselves and standing up for themselves (or others as two people indicated). It is of note that this self-confidence was expressed by those who had more freedom, choice, and more employment than the individual who had restricted decision-making, knowledge of public transit, and preferred socializing with a small group of coworkers. This person's work routine was limited to just a few hours per week.

The 4 interviewees made sure they were understood. For example, one person said this about demanding a say in where she lived:

> I had to pick where I wanted to live and what floor I felt comfortable on because you know, you have a say and a choice. People can't just label you and then decide for you. People can't make choices for you, and that's the problem today – people make choices for you. You don't have your say and stuff, so it's hard.

*Figure 4.* Apartment complex and home to LW for more than 15 years. "I had a choice of where I wanted to live; anything five floors and lower." (LW, Participant)

Another interviewee was recently elected vice president of the Ontario chapter of an established self-advocacy group for people with special needs, and he saw this as another form of belonging and community. To him, it was an obligation to stand up to discrimination, “I can advocate for myself, but I want to advocate for others. I already know to do things for myself, but I want to be able to do it for others.”

In the next analysis phase, selective coding, I looked to find new categories from similarities in the open codes. After manual open coding was complete, the transcripts were uploaded to NVivo 12 software to help determine the classes through the software’s word counts of transcribed interviews for a second check for any additional codes or themes. Appendix D helps visualize the mutual language participants used to articulate community belonging.

## Self-Worth-Centric Themes

**Wanting to make a difference**. As part of participants’ depiction of what they felt belonging and citizenship means to them, 4 of the 5 participants aspired to make a difference, primarily by standing up to discriminatory behavior in the workplace. The participants shared whether they felt respected and had control of decision-making as well as whether it made any difference. The following comment described what it meant to have choices: “You guys [support services] have to smarten up. When people say what they want, you gotta go with what they want.”

Each of the participants thought of themselves not in pathological terms as in having an illness or something was wrong with them (i.e., they did not use the words “developmental disabilities” or “disabilities”). They expressed their personhood as being as much value as anyone else’s. These statements underscored the ontological concept from which their nature of being was framed, showing the relationship between the notion and category of being a person in their families and the wider community. It is important to note that none of the participants used the term DD during the interviews to self-identify:

- "Well, I'm an uncle, a godfather, and I confirmed my niece a couple of years ago. I'm a person just like everyone else." (CP, Participant)
- "Well, this is my parents' house. So, I guess yes, I do have housemates … my parents." (MC, Participant)
- "Well, yeah, it's just nice. Sometimes we get together for dinners, and we always have a Canada Day barbecue in the backyard. There aren't a whole lot of people my age on my street, they're closer to my parents' age, but we're all family, of course." (MC, Participant)

It was crucial to participants to be role models for others so they could be inspired to also lead good lives as integral members of the community. This statement sums up that feeling:

> That they pass it on to other people that are struggling like me and finding it hard to get around and find resources or trying to find a job. Or, they could find a good community [where] they can meet people. So, this could help them. It would be great for people to take on my experience and inspire other people to get motivated and headed in the right direction (LW, Participant).

**Discrimination.** The word *discrimination* was referenced 12 times by three of the interviewees. Interestingly, each reference occurred only in a work setting. Some notable comments are below, showing how they were affected when they encountered bias:

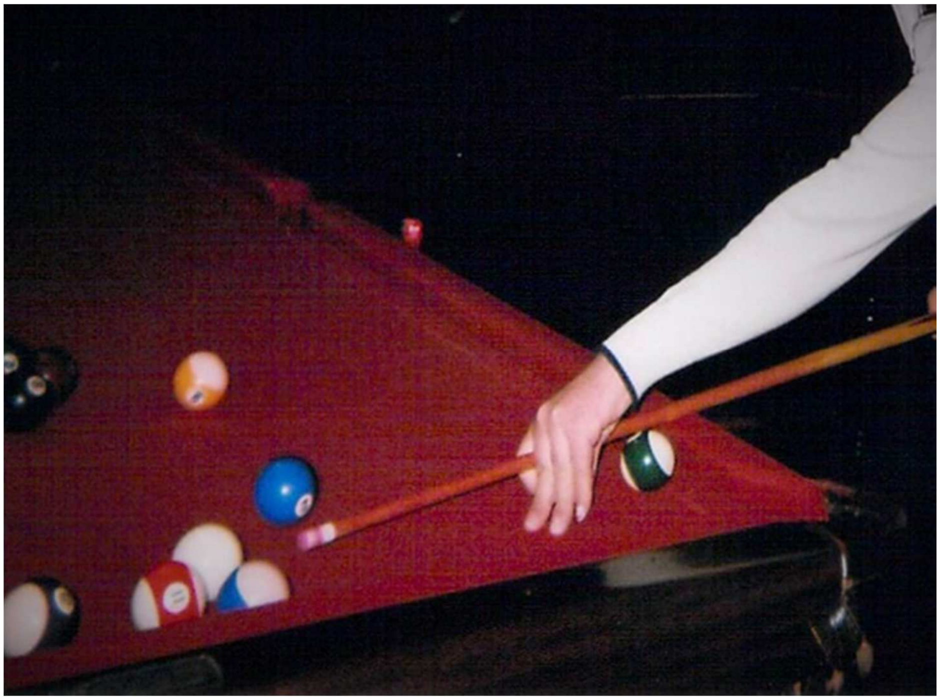
- "Some people are nice to me at work, but there's a coworker at work that calls me 'stupid' and calls me names … I get mad." (SC, Participant)
- "If my boss sends me to help you, you shouldn't say I'm 'too stupid or too slow.' That other guy always wants me to go faster, faster, faster!" (SC, Participant)
- "My parents taught me to be responsible and be independent and think for myself and speak for myself – not have someone else speak for me." (LW, Participant)

**Taking risks to establish belonging**. Most of the participants (4 out of 5) felt they needed to put themselves out there and experience life to feel like a member of the community. For them, this seemed not only a rite of passage but an adventure too. For example:

> I'd like to say to really be accepted in life and feel satisfied you must go out and explore, don't be timid, be bold, be adventurous … That bad experience is not representative of the community as a whole. I'm sure Bloor West Village has someone who's not super nice, but that's just one person. Bloor West Village has thousands of people, and they can't all be assholes.
>
> There's always going to be rotten people in any community. That's just part of life. But don't focus on that. Focus on the good. Also, always look for the best in something. Don't seek out the wrong. Seek out the good, and you will find it. (MC, Participant)

> … I'm very outgoing, and I find a community that's not always in the area. There're other forms of communities. That sometimes, a community can mean you're with other people. Being part of an advocacy group is also community because you're with people who support you. (MM, Participant)

*Figure 5.* SC's favorite pastime after a week of work. "I like going to the pub on Friday nights and play pool with a friend." (SC, Participant)



**Hope for the future.** Despite the challenges they faced with discrimination and lack of sustainable employment, all interviewees expressed a hopeful outlook for the future. There were 24 references to the word *hope* indicated by NVivo 12. The participant responses were mainly about how much they loved the environs of their communities and endorsed living there. Others were inclined to comment about their hopes for permanent employment in a job they liked and earned a living wage. This statement mostly captured these sentiments: “I try to put my foot forward and see what happens.” (LW, Participant) and “[I need] a resume. My niece is helping me with it.” (CP, Participant)

The sample group recognized themselves as regular persons doing regular and routine things like living independently, working, and enjoying social-recreational activities either within their neighborhoods or elsewhere in the metropolitan area with traveling via public transit required, as other people might do. One participant emphasized the importance of giving others support when feeling down about themselves:

> … my friend was feeling down and insecure about herself. I reassured her that she was beautiful in every way. So, I got her out of her feeling like she wasn’t herself and she started feeling more [sic] peppy and a little livelier, and that was great, you know? I don’t like to see anyone feeling sad because that makes me feel sad. You know, people like to judge people because they don’t know the situation. It’s just good to give a bit of a hand, too, to give them the support that they need. (LW, Participant)

Asked what the participants wished for in their lives, the following statements stressed the importance and dignity of employment:

> [Long pause]. I don’t know. I guess better living with no poverty. I guess working more like where I am, not just one day, like three days a week. If you want something, you have to make it happen. You can’t just stay at home and wait for it to happen. It doesn’t work that way (LW, Participant).

**Security of family home.** Each participant referenced their home as either being central to their feeling of safety or comfort. There were 37 references to home safety/security when describing their neighborhood. For one person, 22.94 % of the interview contained remarks identifying their home as a place of refuge and protection, which defined their belonging in the community. For another, it was clear the family home was the most important building in the city: “Well, that’s my house; this is where I live; this is the most important part of the community.” (MC, Participant)

*Figure 6.* MC’s most important place in the community – the family home. “My house is the most important part of my community.” (MC, Participant)

## Work-Centric Themes

**Employment.** Working at a job the participants liked and getting paid for their performance at work presented in the five interviews, 41 references were made to either current jobs or desires for more work in the future. Some interviewees spoke about their capabilities and job longevity as accomplishments, and even though something was not known or clear to them, they were confident they could figure it out. One participant spoke about his job at a federal government office where he was uncertain about being able to do the work, but with time, perseverance, and support from the employer, he was able to master critical tasks of the job.

> I work twice a week. My place of employment is not in [my community]. I'm at [a major office building corridor in the city]. I work for the federal government. I do administrative stuff – input data and filing – stuff like that … almost two years this July. (MC, Participant)

**Wish for a job or more work hours.** Having employment loomed large in the interviews. From an early age, one participant saw work as crucial to his identity and self-worth. He commented on why he did not pursue moving on to higher education upon finishing high school:

> I would have, but my teacher picked one person to learn to read and write. And then the teacher said: '_____, I'm sorry; with your abilities, you're better for work.' I didn't learn anything at school. At work, I learned maintenance, how to interact, to experience other people, to have lunch. I went to the SkyDome [a professional sports stadium in the city]. (SC, Participant)

Others want more work to enhance their self-worth and happiness:

> It's only part-time, so it's not the same as some of the other people … I wish there were more hours I could work – it's a little bit frustrating. (LW, Participant)
>
> Well, if I wasn't here, at home on the computer … [I want] a real job that pays me a good wage instead of one day here, one day there. (CP, Participant)

**Support in finding employment.** Participants discussed the importance of having specialized support in finding opportunities for employment. They said, “I got it through an agency called Corbrook [a multi-developmental services agency in the city].” (MC, Participant). “[I got the job through help from] … the Career Foundation.” (MM, Participant)

**Performance-based culture.** Three of the 5 interviewees felt their work culture was based more on getting the work done accurately, efficiently, and to a defined quality standard than being at work a set period. One role presented as being quite flexible with the person traveling outside the office each day delivering documents and representing the law firm for which he worked. He said this sort of flexibility was a good fit for him because it allowed him the freedom to set his schedule if by the end of the workday, he completed his assigned tasks. Another preferred having a set routine and structure within the grocery store where he worked. Both settings provided satisfaction to be able to do their jobs well and as expected from long-time employers.

## Identification of Community Themes

**Community defined by physical boundaries.** When asked to describe their idea of ‘community’ all interviewees identified it in terms of physical locations on a macro level within the city and on a micro level with their neighborhoods as being the center of that community. For the participants, landmarks such as buildings were central to their identification with the environment in which they lived. These boundaries were defined by name or built around familiar sites such as malls, plazas, office, and apartment buildings. The surroundings were well-known to the participants and described their photographs as being within these boundaries.

- That's the pharmacy. Sometimes, I pick up my mother's prescriptions there. (CP, Participant)
- Now, this is St. John's West Anglican Church. It's a 10-minute walk, a two-minute drive from my home. It's where I was baptized and confirmed. (MM, Participant)
- Oh! That's the Runnymede Public Library. Now, I can't say it's my favorite library because it's quite small, but it is the only library that I volunteer at. (MM, Participant)

*Figure 7.* A nearby plaza in CP's neighborhood. "Sometimes I pick up my mother's prescriptions at the pharmacy in my neighborhood." (CP, Participant)

- I picked this picture because although Bloor West Village is a wonderful community, I must not forget that my community isn't in a vacuum and for me, not having a car and particularly, not wanting a car and me not having a [driver] license, I take the subway. (MM, Participant)

*Figure 8.* The local library where MC volunteered. "Here's the library in my community. It's important to me because that's where I had my first volunteer job."

- I would change a lot of things. I would like to see redevelopment. It would mean a new mixture and layout similar to what you see in Regent Park [a recently gentrified area of the city]. (MM, Participant)
- Well, this is a picture of Runnymede Subway Station [a stop on the metropolitan subway system].

*Figure 9.* The local church, an important feature for MC's community life. "This is the church I was baptized and confirmed at; I know the parish priest and a lot of the parishioners." (MC, Participant)

Notable too, was the idea that travel outside of one's physical setting helped with discovering new communities and people.

> I learned when I was about 12 years old to use transit on my own. I learned on my own how to get around. I figured out I was well-equipped to deal with whatever came. I took a train to Carlton Place, near Ottawa [Canada's capital] and we drove down [to Peterborough, a small eastern Ontario city]. In this picture, I had just finished preparing my presentation [for the advocacy group People First], and I was looking out the window because of this how I see myself … as if looking out and saying 'I'm ready to go out there.' I'm a very outgoing person so I feel the need to connect with someone is important and you never know who you're going to meet … I'm usually out a lot with friends. So, one of the things I did take a

> picture of that didn’t turn out, was me and my friends were in Chinatown [a cultural section of the city’s downtown] getting some food. (MM, Participant)

### Community Defined in Abstract

The data suggested interviewees also thought of communities being without boundaries; people were the defining factors in making up a community regardless of a physical presence or place. One participant thought of the World Wide Web as a community defined by people logging on to their devices:

> I’m very outgoing, and I find a community that’s not always in the area. There’re other forms of communities. That sometimes, the community can mean you’re with other people. Being part of an advocacy group is also community because you’re with people who support you. A community can mean a lot of things. [A] community is being with people and your friends. Computers and technology are [also] like a community. You can actually use online to reach out to others across the globe. So, online is almost like a community. It’s all about the perspective of the person. (MM, Participant)

*Figure 10:* The busiest intersection in LW's neighborhood. "This is a busy intersection in my neighborhood." (LW, Participant)

*Figure 11.* The coffee shop frequented by MM, usually on way home from work. "This is where I grab a coffee on my way home from work." (MM, Participant)

*Figure 12.* For LW, a grocery store is a necessity in any community. “People need to shop; it’s important to have a grocery store.” (LW, Participant)

- [My employer treats me] very well, and I like them too, and that’s another community.
- This this is another community [St. John’s West Anglican Church].
- Well, it’s a public telephone because some people don’t have a cell phone and you might need to call someone in an emergency; this was taken at Eglinton West [subway station] on my way to see you. I don’t use a pay phone. I have a cell phone, but for someone who doesn’t have a cell phone or if the battery isn’t charged, they can make a phone call in an emergency.

## Conclusions

This chapter contained the results of the analysis, connected it back to the research questions, and demonstrated an approach consistent with case study and photovoice research. Interview questions were semi structured, and when required, clarification and follow up questions were used to help the person understand. The research was predicated on a purposefully selected group of citizens with DD – one female, 4 males. The primary requirements for participation were that the sample group be aged between 30 and 55 and not exceeding 65 years. I drew on participants from the metropolitan area, representing communities in the north, south, west, and east areas of the city. A mild to moderate level of developmental disability as defined by Developmental Services Ontario (2016) was also an essential requirement.

The central focus of the study was to elicit in their own words and photographs, what the group's lived experiences have been as a person living with a developmental disability and what the construct of belonging/citizenship meant to them. The data indicated several similarities and differences in the sample group's perceptions. For instance, buildings such as office complexes, libraries, churches, malls, and plazas defined their notions of what consisted a community. Each interviewee perceived access to and ability to travel independently within and external to their communities supported their concepts of community membership. Some held more conjectural notions of society as not being restricted by physical boundaries such as roads or geographical designations but rather, defined by engagement with others either in-person or via alternative communication means such as the internet or cell phone.

What stood out to me was the prominence of employment in these individuals' lives. Familiar to 2 participants was the impact of not having enough work opportunities had on their happiness. While the other three participants expressed higher positivity, cheerfulness, and satisfaction with life as a whole, they had stable and consistent connections to long-time jobs ranging from 2 to 10 years. The underemployed participants, on the other hand, experienced more isolation and self-imposed restrictions to traveling only within their immediate neighborhoods, rarely venturing further than a bus ride away from home.

The loneliness conveyed that despite the social advances made by and with this population of citizens, many continue to experience marginalization in Western society (Overmars-Marx et al., 2014). The data also supported prior research (Griffths et al., 2015; Seth et al., 2015), that despite strong community repatriation efforts in Ontario during the past 30 years and a generally progressive community supports infrastructure, the degree, and frequency of total participatory citizenship have achieved mixed results and qualified success. Chapter 5 includes the summary for the critical analysis and discussion; it should be noted that for the protection of their privacy, I did not include a participant demographics chart due to the small sample size from the same community.

# Chapter 5: Discussion, Conclusions, and Recommendations

## Introduction

The purpose of this qualitative case study, photovoice research was to explore the lived community experiences of adults with DD. This chapter includes a discussion of the significant findings of the study as related to understanding the perceptions people with DD hold about community belonging and citizenship. The chapter concludes with an analysis of the limitations of the study, areas for future research, and a summary.

In this chapter, I present discussion and possibilities for future research to potentially help answer the following research questions:

> Central Research Question: How do adults with DD construe their lived experiences with belonging and citizenship?

Subsequent secondary research questions included:

> Sub question 1: What key social determinants of belonging and/or citizenship and connections to their communities are discerned by adults with DD when they describe their photographs?
>
> Sub question 2: Are self-identified depictions of belonging better explained through ontological interpretations of their DD rather than as pathologies?
>
> Sub question 3: What does it mean to live as a person with a DD?

### Study Findings and the Literature

While individual circumstances and lived experiences varied between the five participants, I interpreted their employment and the respect they want from others as fundamental to their ideals of citizenship; both were prominent factors in the understanding of belonging for each person. Moreover, there are dynamic dimensions to these findings because the participants articulated a desire for future supplementary, consistent, meaningful employment and respect by others. I provide my interpretations of these factors in the following subsections.

### Desire for Employment

The results of this study led me to conclude that employment is a prime objective of individuals with DD and those who are underemployed, and this is consistent with the findings of existing literature that indicated systemic and societal barriers continue to exist, preventing full community integration. The statements made by the participants coincided with the current realities of the challenges they face in overcoming these obstacles (see Morris, Fawcett, Brisebois, & Hughes, 2018; Neilssen, Hulsheger, van Ruitenbeek, & Zijlstra, 2016; Select Committee on Developmental Disabilities, 2014). As a demographic group, people with DD in Ontario have an employment rate below 25% and average income below the poverty line (Spurgaitis, 2019). For the participants in this study, this participation as citizens in the economic health of their community meant more than earning money: It helps define them as contributing members to their community.

Currently, there are more than 500,000 Canadians with DD, and while they have far better prospects than at any other point in history and are not living in government-operated institutions, significant barriers to living-wage employment exist according to the literature (Spurgaitis, 2019). It is valuable to briefly review the progress of people with DD in Ontario attaining the same status as other Canadians. The Charter of Rights and Freedoms (Government of Canada, 1982) provided people with DD with equal standing to other Ontarians, followed by a provincial human rights code (Spurgaitis, 2019). Changing societal attitudes and cost concerns led to the winding down of provincially funded institutions, and by the late 2000s, just a handful of remained operative across the province of Ontario (2012). After the facilities closed, Canada ratified the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006).

While Ontario has made progress in creating opportunities for employment, people with DD are still at less than a third of the overall employment rate of nondisabled Canadians and remain far from full economic citizenship (Neilssen et al., 2016). According to a 2017 Statistics Canada survey (Morris et al., 2018), people with DD who have jobs in Ontario often work part-time or less – as some of the study participants do – and make less money. Ontarians with disabilities can earn nearly 45% less than those without disabilities (Spurgaitis, 2019). Today, the average earnings of people with DD are $18,000 per year, according to Statistics Canada (2017), and nearly 50% receive social assistance from the province. In comparison, the average annual earnings of people without disabilities are approximately $30,000 (Morris et al., 2018).

The Ontario Disability Support Program (ODSP) and Disability Savings Plan and Disability Tax Credit (Ministry of Community and Social Services, 2016) created some incentives and aid, about $15,000 per year for single people, but the ODSP system infrastructure can be challenging to steer through and extremely difficult for adults with any disability to find an employer willing to hire him/her. As essential to note is that if their earnings, regardless of how modest, are high enough, they no longer qualify for ODSP assistance (Spurgaitis, 2019), which was also a finding in the current study through background discussion with the participants.

Two participants articulated they wanted steadier employment when asked what the one thing would be if they could change anything about their community experiences:

- I don’t know … I guess working more, being out more. I guess better living with no poverty … I have a resume, but it’s just hard to find a job. People don’t want to hire someone with a disability, or they don’t want to train them.
- “… a real job that pays me a good wage instead of one day here, one day there.”

There are several reasons people with DD encounter employment barriers. Provincial income support programs penalize people for earning more than the capped limits; employment services that keep people underpaid and segregated from the regular workforce, and as stated by the participants, the negative community and employer mindsets about people with DD (see Spurgaitis, 2019). As my study also found, this segment of the population wants and able to work.

Moreover, employers are missing opportunities to advance business cases for more employment accessibility in the future. According to the Conference Board of Canada (2018), the half-million working-age adults with DD could augment the competitive labor force of Ontario during the next 10 years if employment opportunities are made available. That could raise Canada’s gross domestic product by nearly $17 billion by 2030 when anticipated skill shortages and labor-market supply challenges in Ontario will be severe (Spurgaitis, 2019).

Historically, workshops and day programs in sheltered settings provided some vocational and employment readiness training (Neilssen et al., 2016; Ontario Ministry of Community and Social Services, 2014; Ontario Ombudsman, 2016). Although these were the most common employment support approaches the participants experienced, the settings were exclusive and segregated yet filled a gap in the absence of viable employment options. The more significant problem, however, is that such enclave-based employment reinforced the marginalization the participants were caught in when completing contracts for agencies without being paid a minimum wage. Instead, they received a "training" stipend for activities the literature classified as a combination of employment readiness, day program, and training (see Select Committee on Developmental Disabilities, 2014; Spurgaitis, 2019).

The importance of consequential employment in the "real world" away from day programs, for instance, featured prominently as a common denominator in the five interviews conducted for this study. Participants made 41 references to employment throughout the interviews, and one participant made it clear how he felt about being in a day program twice per week:

> Question: "If you weren't here [day program], where would you be if you had your choice?"
>
> Answer: "Having a real job that pays me a good wage instead of one day here, one day there."

Question: “So, that’s your dream? To have a full-time job and not come to [the day program]?”

Answer: “Mm-hmm.”

According to advocates, there is some good news on the employment front. The demand for the sort of subwage employment in vogue until recently has fallen across the country and is much less customary in Ontario (Spurgaitis, 2019). In mid-2018, the former party in power introduced the Fair Workplaces, Better Jobs Act (Bill 148, Legislative Assembly of Ontario, 2017), which eliminated an exemption in provincial labor legislation that allowed for people with DD to work for less than minimum wage. In this study, I found this legislative development helped move 4 out of the 5 participants from low-paying, unfulfilling jobs to work that paid at least minimum wage and resulted in greater satisfaction. This is how one participant responded to a question from me regarding his job:

Question: “How did you find the job?”

Answer: “I got it through an agency called Corbrook [a multi-developmental services agency in the city].”

Question: “Your employer treats you well?”

Answer: “Very well and I like them too, and that’s another community … and as important as this community is to me [pointing to his picture of his home in his immediate community].”

However, a newly elected provincial regime in 2018 proclaimed the Making Ontario Open for Business Act, Bill 47, which delayed the exemption's repeal indefinitely (Matthews-Dinsdale, 2018).

## Employment-Centric Prejudice

Extant research indicated meaningful employment of people with disabilities can be facilitated to reach higher levels of acceptance, integration, and social inclusion (Neilssen et al., 2016; Spurgaitis, 2019). Work has a central place in people's lives, and jobs help facilitate integration in society. Within this setting, there is an urgent need for additional corporate responsibility to form a new consciousness on employment issues (Neilssen et al., 2016). However, as the study participants articulated, barriers faced by people with DD included the stereotypes and prejudices of employers and employees. When asked what equal treatment at work meant to the participants, they replied:

- "… people treating you the way you want to be treated."
- "He [employer] tried to help. He told the guy: "These guys are here to help. If you call him 'stupid' and 'slow,' that's not right."

Negative perception is one of the reasons why people with disabilities experience bias in the way they are treated at work (Neilssen et al., 2016). The findings of this study align with those of Filia, Jackson, Cotton, Gardner, and Killackey (2018) who found improvements in areas of social inclusion with a focus on employment and social supports could result in a significant reduction in insolation, greater satisfaction with life in general, and better emotional health.

The outcomes of this study also aligned with the implication that integration and achieving a workplace of respect and equality has a broader significance. Inclusion is possible when "people with disabilities are accepted, helped and treated as others by their coworkers" (Colella & Bruyere, 2011 as cited in Neilssen et al., 2016, p. 1611). The findings of this study were consistent with the notion of inclusion, demonstrated by how highly one participant thought of his employer and coworkers because he felt accepted:

Question: "Your employer treats you well?"

Answer: "Very well, and I like them too …"

Supporting people with disabilities in the workforce anchors an elevated level of inclusion for a population group often stereotyped as incompetent – a paternalistic stereotyping characterized by disrespect and pity toward them (CITE). Employers and employees use stereotypes to evaluate others and consequently make assumptions on how they will perform at the workplace; this performance expectation will affect the treatment of people with disabilities (Neilssen et al., 2019), as evidenced by one study participant's negative encounter with a coworker, "If my boss sends me to help you, you shouldn't say I'm 'too stupid or too slow.' That other guy always wants me to go faster, faster, faster!"

Inclusive organizations who employ people with disabilities may bring out prejudices held by their staff that impact on how others treat people with disabilities at work. Personal beliefs and work pressure play roles in determining the character of this relationship (Neilssen et al., 2016). It appears, however, that the generally positive workplace statements made by the study participants corroborated the premise of Neilssen's et al. (2016) research that if there is a demonstration of inclusive behavior, people with disabilities should become better integrated and included into their workplace. Employers and their employees who have positive attitudes of people with disabilities are more likely to display inclusive behavior and actions, allowing people with disabilities to perform better – a prerequisite toward inclusion and potentially sustainable and long-term employment (Neilssen et al., 2016).

## Social Policy Implications

### Community-Centric Prejudice

Countering prejudice and discriminatory practices have been critical strands of social policy, better known as social inclusion, since the 1980s (Bigby & Wiesel, 2015). Internationally, the central objective in addressing prejudice has been the dynamic involvement and social inclusion of people with disabilities (United Nations, 2006). Signatory countries like Canada committed to the United National Convention on the Rights of Persons with Disabilities and in turn, bound Ontario to the proclamation. The success of this obligation remains debatable. Prior studies posited mixed results and people with DD continue to look in from the periphery of society (Bigby & Wiesel, 2015; Gray et al., 2014).

Employment and neighborhood domains identified by Filia, Jackson, Cotton, Gardner and Killackey (2018) ranked consistently high on a list of social determinants affecting inclusion. However, exclusion through employment and other subjective experiences varied; prejudices can cross between work and social domains and present fluctuating levels of inclusion/exclusion in both (Filia et al., 2018). Although social inclusion and belonging can be contested constructs based on personal perception and circumstance, I interpreted each of my participants' shared insights of employment and respect from others as prized objectives that concretely informed their feelings of belonging and citizenship.

The journey for community citizenship will continue for people with DD. Although discriminatory and prejudicial practices may not be as overt as they once were, they still linger. People need to own proving themselves and make their way in life, not necessarily a bad thing, but the rules of success must be equitable for everyone (Neilssen et al., 2016; Nelson, 2019; Spurgaitis, 2019). Advancing the continued engagement of people with DD and ensuring they are the caretakers of their destiny can go far toward abating biases cultivated by ignorance. The results of my study suggest people with DD want to be heard and included. Hopefully, the rest of us will understand and act sooner than later through non-judgemental lens.

It was interesting to find that not one of the five participants considered themselves as *sick* or *disabled*; nor did they once use the words *developmental disabilities*. They self-identified (Nelson, 2019) as people who learned differently. It was obvious to me they had not accepted nor really cared for others' classification of DD having pathological origins. During their dialogues with me, they indicated frustration as to why they were not simply seen as people first with unique abilities and character traits. Filia et al. (2018) underscored the lack of research that embraced the need for robust input from the people most affected by social inclusion/exclusion – a gap my study strived to fill and upon which my social work policy and practice specialization will help address in the future.

Disturbing trends of ostracization and injustice have historically dominated people with DD. These recurring themes were documented as far back as 400 B.C. and continue to impact their lives today (Nelson, 2019). People with DD are regularly dehumanized and devalued; when a group of people deemed as less important or deserving of less respect than others, they become vulnerable to abuse, neglect, discrimination, and exploitation in virtually every aspect of life. Discriminatory practices in Ontario nurture stereotypes and misunderstanding and contribute to a culture of ignorance. People with DD are misperceived as a homogeneous group rather than people with unique skills, needs, and personalities – traits by which nondisabled individuals are defined (Nelson, 2019).

In Ontario, a lack of access to supports perpetuated the exclusion of people with DD. As the statements of my study's participants demonstrated, the result is isolation and limited opportunities to participate and contribute as full citizens, diminishing their potential to play a role in Ontario's future (Canadian Council on Disabilities, 2018). It is necessary social policymakers are aware their fellow citizens with disabilities are twice as likely to live in poverty as nondisabled persons and excluded from quality education, employment, and participation from their communities – social requirements from which Ontarians are not immune. Moreover, rates of violence and abuse against people with disabilities are among the highest for any segment of society (Canadian Council on Disabilities, 2018).

Consequential of political and legislative impediments to the economic citizenship of people with DD are employers' attitudes and reluctance to hire them

(Neilssen, et al., 2016). A report from the Institute for Research and Development and York University (2014), both situated in Toronto, employers overwhelmingly worried about associated costs for the additional training, supervision, work accommodations, and potential legal liabilities of hiring people with DD. However, implemented legislative action has fallen short of the desired outcomes, according to advocacy groups.

The Accessibility for Ontarians with Disabilities Act (2005) mandated the province develop and implement accessibility standards for hiring and employment practices. An objective was to ensure public and private sectors meet them. The ultimate objective of the legislation, however, was to make Ontario fully accessible to more than 1.8 million people with disabilities by 2025 (Government of the Province of Ontario, 2005) but advocates point out plans to roll out implementation to meet that deadline have fallen behind in recent years (Spurgaitis, 2019).

In contrast to provincial initiatives, the Accessible Canada Act (Bill C-81, Government of Canada, 2019) is navigating its way through the Senate, aimed at highlighting, extracting, and preventing barriers for the estimated 1.8 million Canadians with physical, sensory, mental, intellectual, learning, communication, and other disabilities. Its scope though, is restricted to government agencies, programs, and sectors in Ontario and other jurisdictions that fall under federal authority (Government of Canada, 2019; Spurgaitis, 2019).

The participants of my study saw a connection between gainful employment and independence, and as they and their families grow older, they feel the urgency of being able to support themselves as nondisabled employed persons often do. For them, there is not a lot of estate planning so that people can manage their own life once their parents are gone. What is needed, according to Wiltshire (2019), are the opportunities that will allow them to become fully contributing members of society. Thus, this aligned with my study's 4 of the 5 interviewees getting assistance from community agencies and service providers in helping them find and keep sustainable, good paying employment that placed them in retail, maintenance, and office positions (Spurgaitis, 2019).

The 3 participants who had more independence and overall life satisfaction stressed it was because having higher hours of work afforded them more opportunities to explore and engage with others within and external to their immediate communities. They also indicated their sense of adventure and independence were derived from their upbringing and agreed with the notion that higher expectations from family lead to better employment outcomes:

- If I needed someone to help me, then yeah, but otherwise I've always been the type of person to fend for myself … my parents taught me to be responsible and be independent and think for myself and speak for myself – not have someone else speak for me. (LW, Participant)
- I go to work on my own. I always like going to work. I go to work; I go home. (SC, Participant)
- My parents taught me at 12 years old to be independent and be prepared for anything [work]. (MM, Participant)

Employment advocates in Ontario encourage parents of children with DD to, "… dream bigger and ask more of [your children]," (Muschta, 2019, p. 5). For the three of five participants in this study, this appeared to have served them well and while two of the five voiced wishes for enhanced employment opportunities, those whose unique circumstances were a good fit (access to travel and support), the prospects were brighter. The person whose job in a federal government office entailed administrative and computer work, was primarily on a right path because, "Mailing, faxing, retrieving documents, setting up meetings, and greeting customers and clients – these are all soft skills that will be increasingly important for people with DD in the workplace, especially with digitization and automation," (Muschta, 2019, p. 5 ).

## What an Inclusive City Could Be

If the people want to achieve an inclusive and non-discriminatory society, we need to pay more attention to the voices and narratives of people with DD. We have been slow to create environments that embrace people of all abilities, and social policies have not adequately equipped vulnerable populations to engage and participate as they should (Select Committee on Developmental Disabilities, 2014; Spurgaitis, 2019). In making this right, meaningful social change can be pursued at the micro, mezzo, and macro levels.

On a micro level and grassroots levels, any social policy developments initiated and designed to provide and nurture equity for vulnerable populations should specifically highlight the needs of people with DD through consultation and engagement. This would replace the current paternalistic approach of service providers knowing what is best to provide. At a mezzo level, people with DD must be encouraged and assisted to in self-advocacy, representing themselves when government policy makers announce new consultative processes to either bring in new or change present social policies. Those most impacted by these initiatives should have their voices heard. The ideas and thoughts of people with DD cannot be excluded when service providers and social policy makers move to either alter, restrict, or enhance access to services.

When broad and national change is considered at the macro level, people with DD should be invited to the discussion tables. Instead, the prevalent practice is to mix their needs within general and broader classifications of groups. For instance, provincial housing policies to address homelessness does not specifically name or include the special needs and protections people with DD require to access affordable housing. This segment of the population tends not to be mentioned at all while named disabilities or disenfranchised groups are emphasised. Thus, needs are mistakenly elevated to an urgent status while the needs of unnamed groups are relegated to a lower priority. In fact, the support and equity requirements of people with DD are just as, if not more, severe because of their most marginalized status (Select Committee on Developmental Disabilities; Ontario Human Rights Commission, 2016).

To accomplish inclusion, the citizenry must embrace understanding and acceptance to reflect its absolute values. An inclusive and accessible city is one where needed disability-related supports are available and reachable to people with DD to benefit from all that being community citizens has to offer. It is a city where people with disabilities have the means and opportunities that make social, economic, cultural, and political citizenship equitable to all. The outcome is that people with disabilities benefit from society in ways universal to others (Canadian Council on Disabilities, 2018).

Moreover, we need to acknowledge and create consensus on the following realities in the larger context of a national consensus that merges with a provincial priority, and address them through public education, the involvement of legislators, policymakers, and people with disabilities working together (Canadian Council on Disabilities, 2018). The issues extend beyond provincial reach:

- Two thirds of Canadian adults with disabilities lack one or more of the educational, workplace, aids, home modification or other supports they need
- Slightly more than half of the Canadian children with disabilities do not have access to needed aids and devices
- Almost 60% of working-age adults with disabilities are currently unemployed or out of the labor market
- For women with disabilities, nearly 75% are unemployed/out of the labor market
- According to the International Labour Organization, the annual loss of global gross domestic product due to the exclusion of persons with disabilities from the labor market is between $1.37 trillion and $1.94 trillion (US)
- More than 10,000 persons with intellectual disabilities remain warehoused in institutions across Canada

## Social Inclusion Policy Implications

My findings were consistent with the literature as related to the importance of feeling connected to a broader community beyond immediate circles of family and close acquaintances. My participants referenced this need and expectation throughout their experiential narratives and led me to interpret the two domains affecting community citizenship and belonging: (a) employment, (b) having the respect of others. The sentiments of the participants inferred that these objectives held the key to their independence, happiness, and life enjoyment.

Understanding belonging as a basic human need much like what Maslow (1964) envisioned could be beneficial. His theory of a hierarchy of needs which reflected the universal needs of society as its base and then proceeding to more acquired emotions (Maslow, 1964). It included the suggestion that only upon fulfilling the lower requirements for security, safety, and belonging, can a person truly realize self-actualization and growth. In my study, a good job and supportive community most closely linked to the security and safety layers of Maslow's hierarchy. The results of my research aligned with Maslow's position that basic needs are essential and confirmed that receiving a good salary, enjoyment of work, and ability to connect within their community were priorities for the study's participants.

Moreover, the participants can provide input to social policy design. Their acute awareness of where inequities and lack of decision-making lay make them well-positioned to identify social policy weaknesses and need for presence. Although disappointed with some of their specific circumstances, they articulated strong motivation to confront and eliminate inequities when compared to peers.

Ongoing biases undermine the prospects for people with DD to attain equality. Social policy can influence legislation for a more balanced approach to development and growth opportunities. The lack of substantive change in these areas has created little movement in moving the dial in driving the equity people with DD are voicing and seeking. My study highlighted parity with what others have found that people with DD have been denied the chances others have and are relegated to the outer margins of society. Whether it is called stigma or discrimination or exclusion, it still harms. Social inclusion is the formal label given to relatively new sets of government policies focused at including marginalized people more meaningfully in society with a high priority placed on protecting social cohesion and lessening threats to progress (Select Committee on Developmental Disabilities, 2014).

Social policies are not without critics, however, who collectively fear that they fall short of clearly and forcefully stating how much they value diversity "or at worst, that they are simply assimilation or colonization dressed up in a new language" (Everett, n.d., p. 3). The OHRC (2016) has taken a firm stand on defeating discrimination and inequities. It acknowledged that in Ontario and across the world, people with disabilities have long experienced abuse, neglect, exclusion, marginalization, and discrimination and listed this adverse treatment as: restrictive immigration policies preventing people with disabilities from entering the country; involuntary sterilization to stop people with disabilities from having children; inappropriate and harmful institutionalization, seclusion and restraint; and significant barriers to accessing educational opportunities, employment opportunities and fairly paid work (OHRC, 2016).

The dark side of our provincial history of its treatment of people with DD has continuing effects today. The ongoing negative experiences resulted in societal structures and negative attitudes premised upon *ableism*; ableism refers to attitudes in society that devalue and limit the potential of persons with disabilities and (OHRC, 2016). Ableism is a belief that sees persons with disabilities as less worthy of respect and consideration, less able to contribute and participate, or of less inherent value than others; it can limit the opportunities of persons with disabilities and reduce their inclusion in the life of their communities. Such attitudes inform view that disability is an anomaly to normalcy, rather than an inherent and expected variation in the human condition (OHRC, 2016).

My study agreed with the OHRC's assessment that while there have been some significant gains in recent years, tremendous impediments to equality remain. Statistics Canada (2015) reported that Ontarians with disabilities continue to have lower educational achievement levels, a higher unemployment rate, are more likely to have low-income status, and are less likely to live in adequate, affordable housing than people without disabilities. Clearly, people with disabilities continue to experience difficulties accessing employment, housing, and various services throughout Ontario (OHRC, 2016).

The path to belonging is rooted in the establishment of supports that help establish (or for many, re-establish) unique social roles. Social policies are criticized for being in silos and "cut off from their communities and thus, failing to promote independence and integration. Policies of social inclusion, if carefully thought through, may provide openings for full participation and a chance to belong" (Everett, n.d., p. 3). Developing a long-term disability strategy requires a comprehensive, coordinated, inter sectoral, multi-jurisdictional collaborative approach. A progressive, long-term solution to the exclusion and persistent marginalization of people with DD is achievable. Committing to a long-term disability strategy is a commitment to building a better Canada for all (Canadian Council on Disabilities, 2018).

## Limitations and Recommendations for Future Research

While I still agree qualitative research was the correct approach for this study, qualitative tools like 35mm photography made it difficult for the participants to capture quality, high definition photos. The old technology of print processing was challenging and delayed the start of the study once the ethics review process was cleared. Inexpensive but capable one-time-use cameras were difficult to find and once found, their delivery further delayed the research process.

The cameras were designed for outdoor use; regrettably, the participants were not able to take clear photos indoors; thus, they discarded parts of their narrative because of poor picture quality. Consequently, once the pictures were snapped, there was further delay due to having to schedule the return of the cameras to me for the processing, which took additional time for out-of-city processing and delivery. The ubiquity of digital photography and the ability to send photos electronically has progressed rapidly in recent years. This quick form of receiving quality data would advance future research in both time efficacy and material. Another limitation was the overrepresentation of males to females (4:1) in the sample size, restricting the more robust exploration of the female perspective.

A dimension that could add to future research is an examination through a longitudinal study format. The intent would be to track shifts over time in the progress of a person with a developmental disability from the end of high school to late adulthood in the areas of employment and societal inclusivity. Another demographic to further explore will be to study if females with DD experience employment and societal discrimination more than their male peers.

## Conclusion

A genuinely inclusive, non discriminating Ontario society remains elusive for people with DD. Although some of the participants were optimistic about their future outlooks, the underlying premise was that individual strengths, motivation to succeed, supports, and opportunities predicate the overcoming of bias. People with DD want to mirror what any other citizen intends to achieve. One exception is that often, the inconsistency of support access and lack of public awareness of the voices and narratives of people with DD suggest opportunities are still a barrier today.

The pictures and narratives that drove my study suggested the success people with DD described embraced two dominant themes: (a) accessibility to employment opportunities, (b) the right to self-determination which will afford them better prospects of living their lives on terms acceptable to them. Employment is central to individuals' self-interest. Employment unlocks many doors of possibilities for them and their feeling productive and contributing to society by earning their pay and paying taxes as we all do. The participants implied that achieving sameness meant having a job and that it was critical to emotional well-being.

While the participants expressed positive attitudes as they shared their experiences, it was somewhat disturbing to hear the pervasiveness of prejudice and other belittling attitudes and commentaries. The participants in this study presented themselves with competence, dignity, and a willingness to make themselves and others better. They spoke of their belonging to their communities in high regard. Each articulated or implied their need to be valued and what this meant to them. Learning to new skills and earning the trust of others to perform them underscored their sense of value and respect.

I hope my study honored participants who represented a small segment of a population that has overcome so much but with still a considerable distance to go. However, with challenges come opportunities to transform society so no mention of marginalization and inequities are referenced by people with DD in their worldviews and future research. As they progress through their lives, people with DD want to tell their stories and they ought to be heard.

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# Appendix A: Interview Protocol

**Institution**: Walden University

**Interviewee ID Number:**

**Interviewer:** Tullio Orlando, Student (Ph.D. Social Work Policy & Practice)

**Introductory Protocol:**

*Thank you for agreeing to participate in this study data collection project.*

*Please note the following three important declarations and commitment to you as a participant in this data collection exercise and to meet ethical standards for human subject research: (1) all information will be held confidential, (2) your participation is voluntary and you may stop at any time if you feel uncomfortable, and (3) to harm in any way is intended.*

*For your information, as lead investigator, I will be the only person to know the details you provide in your answers. After the research has completed, the data analyzed and interpreted, a final report will be written. You and the other participants will get to see the report to make sure it represents what you have said about the pictures you took and other information you provided. After this, these interview sheets will be destroyed.*

**Introduction:**

You have been asked to participate in this qualitative research study to get your insights into how you experience self-determination and the community in which you live, work, and socialize. Your responses, in addition to photographs you will take in the community, will help others understand your views of being part of the community.

**A. Interviewee Background:**

Please describe an experience(s) that stands out in your mind that made you feel like you belonged in the community.

What has been your involvement in and with the community?

1. Briefly describe how you interacted with the community (for example, various resources like community centers, libraries, people, and friends).

Probe: How did you get involved?

2. How important is it to you to feel like you belong to your community? Why?

3. How would you describe your community? Is it safe, welcoming, fun to be in, a place in which you want to continue to be involved?

**B. Perspective:**

4. How did you decide to be part of your community?

5. Describe how your decision was made to live, work, and/or socialize in the community?

Probe: What would you change about your experience(s) living, working, and socializing in your community? Why?

**Purpose, Development, Recent Initiatives:**

6. Would you encourage others to live, work, socialize in your community? Why or why not?

7. Do you feel welcome in your community or do you think you are treated differently? Why? How?

8. Describe how you understand (or what you don’t understand) about being a member of the community? What would you change? Why?

9. What do you feel is the most difficult part of making deciding for yourself where you want to live, work, or socialize? Why?

Probe: What do you think can be done for people to feel like they are an important part of a community? Why?

# Appendix B: Photography Instruction Sheet

## **Photography Instructions Sheet**

It is important to follow these instructions as discussed. You will need to have a personal digital camera or cell phone capable of taking quality photographs.

It is suggested you take a few 'test' photographs first to ensure the camera is working properly and the photographs are saved.

I want you to take pictures of 'a day in the life of your community'; what is most important for you and that you want others to see about your community. To do this, I need you to follow these instructions very carefully:

1. Photograph scenes in your community from a safe spot – SAFETY FIRST ALWAYS! This means not standing on the road or any high traffic areas to snap your photographs.

2. Take photographs from the ground only and only in your community that you are most familiar with. In other words, no other parts of the city.

3. Ask permission if you want to photograph someone you know. Please bring the information or consent form containing my name and contact information with you each time you go photographing if anyone has questions.

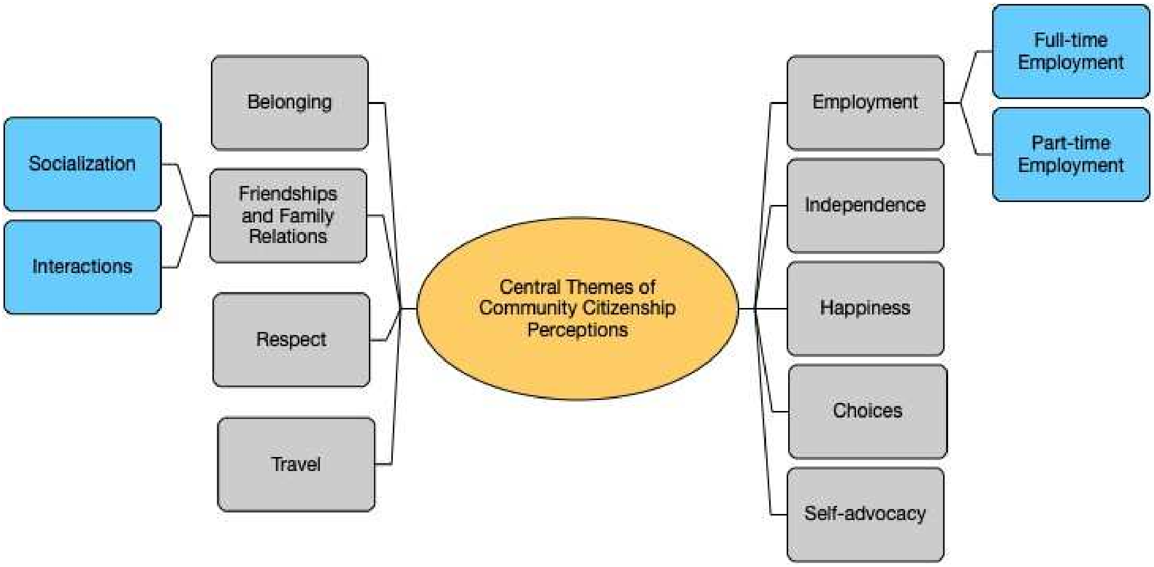
4. Respect others' privacy – only photograph public spaces and/or the outside of public buildings

5. Take no more than 20 pictures. You will choose the top 5 to talk about with me and the focus group when we meet after everyone has completed their photographs.

6. I will help you download copies of your photos to the hard drive I will use to safely and securely store your photos until the end of the study. Once the study is done, I will destroy the copies or give them back to you. These are your photos.

7. We will review these instructions together. I will ask you to repeat back each step to indicate you understand what you are being asked to do.

# Appendix C: Theme Nodes Graphic



# Appendix D: Word Cloud Graphic