

BEYOND SPATIAL SEGREGATION DEBATES: DEFINING ‘SOCIAL INCLUSION’
FOR PEOPLE WITH INTELLECTUAL DISABILITIES IN NOVA SCOTIA
THROUGH GROUNDED ACTION METHODOLOGY

by

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This thesis is dedicated to the memory of my father,
Ian Dempsey (1953-2015).

My father's journey came to an end at the time
I began to write the concluding chapter to this thesis.
He could not be with me in person for those final weeks,
and neither will he be here for my convocation.
Yet I know he has been, and will be, with me in spirit;
cheering me onward:

“To infinity, and beyond!”

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ABSTRACT

Through the application of grounded action methodology, the following research issue emerged from interviews with the study's participants in Nova Scotia: even though all participants believed in social inclusion for people with intellectual disabilities, they expressed conflicting opinions about spatially segregated environments and activities (i.e. segregated education, special care homes, Adult Service Centres, and Special Olympics). This reflects a lack of clarity and consensus around the definition of social inclusion, and how it should be facilitated.

Grounded in an analysis of the interview data, this study's explanatory theory indicates that participants were able to justify various opinions by focusing on one or more of the following three pairs of concepts: respect and equality, opportunities and self-determination, or friendship and belonging. Building upon the explanatory theory, this study presents a holistic definition of social inclusion for people with intellectual disabilities in Nova Scotia that can bypass gridlocked debates about spatial segregation.

LIST OF ABBREVIATIONS USED

| | |
|-----------------------|--|
| ARCs | Adult Residential Centres |
| ASC | Adult Service Centre |
| CACL | Canadian Association for Community Living |
| EPA | Education Program Assistant |
| IPP | Individualized Program Plan |
| MAPS | Multidimensional Assessment of Providers and Systems (Ontario research program) |
| NSACL | Nova Scotia Association of Community Living |
| NS Advisory Committee | Nova Scotia Joint Community-Government Advisory Committee |
| NSDCS | Nova Scotia Department of Community Services |
| NSDCSSPD | Nova Scotia Department of Community Services: Services for Persons with Disabilities |
| RCFs | Residential Care Facilities |
| 'Roadmap' report | <i>Choice, equality and good lives in inclusive communities: A roadmap for transforming the Nova Scotia Services to Persons with Disabilities Program</i> (NS Advisory Committee, 2013) |
| RRCs | Regional Rehabilitation Centres |
| SPD program | Services for Persons with Disabilities Program |
| SOHs | Small Option Homes |

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*[Utopia] is on the horizon... I go two steps closer, she moves two steps away.
I walk ten steps and the horizon runs ten steps ahead.
No matter how much I walk, I'll never reach her.
What good is utopia? That's what: it's good for walking.*

-Eduardo Galeano (1997, p. 326)

CHAPTER 1: INTRODUCTION

1.1 LACK OF CONCEPTUAL CLARITY PREVENTS INCLUSION

Social exclusion continues to be a pervasive reality for many Canadians (Banting & Myles, 2014; Hyman, Mercado, Galabuzi, & Patychuk, 2014; Raphael, 2012; Standing Senate Committee on Social Affairs, Science and Technology, 2013; Walks, 2013). Determinants such as disability, age, class, ethnicity, gender, race, and sexual orientation, interact with political and social discrimination to produce barriers; preventing many Canadians from fully participating in society and accessing the opportunities necessary to reach their life goals (Cushing, 2003; Mikkonen & Raphael, 2010; Richmond & Saloojee, 2005; Taket et al., 2009). Disability-related determinants of exclusion are often overlooked by development experts and social researchers (Fremstad, 2009; Khan, 2012; Prince, 2009; United Nations New York, 2011; Yeo & Moore, 2003), and yet these determinants are “considerable social forces that deserve a more critical and empirical analysis” (Prince, 2009, pg. 86). Exclusion and discrimination on the basis of disability is a form of *ableism*; an ideology that privileges ‘normative’ forms of bodily appearance, behavior, or expression (Ashby, 2010). Non-normative ways of being are those which deviate from the dominant projection of what constitutes a ‘typical’ and fully capable human being (Harpur, 2012; Wolbring, 2008). Ableism is supported by the medical model, which frames people with disabilities as faulty, defective humans with biomedical disadvantages who need to be ‘treated’, rather than accepted and included (Brisenden, 1986; Wolbring, 2008). When compared with other people who have disabilities, such as physical and sensory disabilities, people with intellectual disabilities (particularly *profound and multiple* intellectual disabilities) face the greatest barriers to inclusion (Klotz, 2004; Lacey & Ouvry, 1998; Lippold & Burns, 2009; Reinders, 2008). Independence and rational thinking are two human capabilities that are highly valued in an ableist society (Kittay, 2002). Since these traits are difficult for many people with intellectual disabilities to manifest in their lives, a discriminatory, ableist perspective justifies their exclusion. Furthermore, people with intellectual disabilities do not always benefit from, nor have access to, the political and theoretical gains achieved by the mainstream disability movement and the academic field of disability studies (Race, Boxall, & Carson, 2005; Goodley, 2001). Numerous disability researchers point out that

people with intellectual disabilities have often been excluded from the disability movement, and marginalized in its scholarly productions (Chappell, Goodley, & Lawthom, 2001; Chappell, 1998; Goodley, 2011).

Social exclusion, as both an outcome and a process, can be prevented by enacting its opposite counterpart; social inclusion, which can be defined generally as the opportunity for full participation in all key aspects of society (Cushing, 2003; Guildford, 2000; Toye & Infanti, 2004)¹. Social inclusion has been identified as a social determinant of health at both a national and international level, and as a factor that contributes to quality of life (Mikkonen & Raphael, 2010; World Health Organization, n.d.; Expertise Center, 2011; Schalock, 1997). It is a concept that has gained significant popularity in recent years and maintains a ubiquitous presence in organization mandates, government policies, and academic literature (Cushing, 2003; Kendrick & Sullivan, 2009; Siemiatycki, 2006; Standing Senate Committee on Social Affairs, Science and Technology, 2013). Motivated by the importance of preventing the detrimental impacts of exclusion for those who face the greatest barriers to inclusion, my research investigates how social inclusion is conceptualized and enacted for people with intellectual disabilities in Nova Scotia.

Nova Scotia has the highest reported rates of disability in Canada (Statistics Canada, 2012) and according to researchers and advocates, social inclusion for people with intellectual disabilities has not progressed as quickly as hoped for and has even regressed in recent years (Barken 2013; Devet, 2014; Encol & Orrell, 2013; Wicks 2010). This lack of progress has occurred despite the fact that the concept is embedded in policy documents and there have been public calls to action to implement and facilitate social inclusion (Dechman, 2003; Nova Scotia Joint Community-Government Advisory Committee, 2013; Nova Scotia Department of Health and Wellness, n.d.; Nova Scotia Government, 2014). For example, Nova Scotia's social prosperity framework, developed in 2007 by the provincial government, outlines five goals that will help us create a vision of social prosperity by year 2020. One of these five goals is '*access and inclusion*'. The framework states that this goal will have been achieved when "the talents and

¹ The various meanings of social exclusion and social inclusion will be explored more thoroughly in Chapter Three.

contributions of all Nova Scotians are recognized, valued, and celebrated—and all Nova Scotians have equitable access to opportunities to meet their full potential and contribute to our social prosperity” (Nova Scotia Department of Community Services, 2007, p. 33). Nova Scotia’s Services for Persons with Disabilities (SPD) program aligns itself with this vision. The program’s policy explicitly states that its goal is to promote “independence, self-reliance, security, [and] social inclusion” for persons with disabilities (Nova Scotia Department of Community Services, 2012, p. 4). These examples highlight the province’s commitment to social inclusion at a policy level, but it is not always clear how these policies translate into action.

This lack of significant progress with achieving social inclusion, despite a clear policy directive and the high level of need and demand for it, indicates a pressing social issue. I decided to focus my research on Nova Scotia with the aim of contributing to the resolution of this social issue through my research. After trialing several approaches, I eventually selected grounded action methodology (Simmons, 2006), which is a recent extension of the grounded theory approach (an established research method that involves the careful development of an explanatory theory through data analysis) (Glaser & Strauss, 1967; Charmaz, 2014). I selected grounded action as the most appropriate methodology for my study because it was “designed specifically for the purposes of investigating and addressing the complexity of organizational and social problems and issues” (Simmons & Gregory, 2003, p. 3)². Simmons and Gregory (2003) acknowledge that many researchers are motivated to initiate a study after identifying an unresolved issue or problem in society. However, once the research project commences, Simmons and Gregory recommend that the grounded action researcher suspend the original societal issue that first catalyzed their research (i.e. the *action* problem) and all of the preconceived explanations and solutions they may have associated with it. This is to prevent the researchers from leaping to preliminary conclusions and to prevent the knowledge and/or experience of the social issue from asserting significant influence on the research process. Simmons and Gregory write that “the key to designing effective actions is that they must be grounded in what is really going on, not what you think, hope, or wish is going on” (p. 14). They make a careful distinction between the original

² See Chapter Two for further explanation of my research design evolution.

social issue, which they refer to as the ‘action problem’, and the central, underlying concern that the researcher discovers through investigating the original social issue, which they refer to as the ‘research problem’. The researcher may discover that the research problem is in fact, the same as the action problem, but they do not necessarily equate. Certain societal issues can obscure deeper underlying root causes and problems. Grounded action allows me to effectively address the original social issue through the use of a rigorous and inductive approach that seeks to discover the core variable; *the research problem* that is perpetuating the original social issue, or ‘action problem’. One of the key differences between grounded action and other research methods is that research questions are not formulated in advance of collecting data. The inductive, iterative research process of grounded action involves discovering relevant questions in tandem with the development of a theory that can explain the research problem.

Once I identified the action problem (i.e. the lack of significant progress with achieving social inclusion for people with intellectual disabilities in Nova Scotia), I put it aside and moved forward *without* carefully formulated research questions and associated preconceptions. I embarked on my research journey with an interest in the topic of social inclusion and intrigued by the general, open-ended question of what social inclusion really meant for someone with an intellectual disability. In other words, if social inclusion were achieved, what might it look like in its most authentic form for one of Nova Scotia’s most marginalized populations (Barken, 2013; Crawford, 2011; Prince 2007; Statistics Canada, 2006)? My data collection method involved the use of open-ended qualitative interviewing with people with intellectual disabilities, family members and caregivers, as well as staff members and volunteers belonging to disability-related organizations or departments. Although all the research participants I interviewed expressed the belief that social inclusion for people with intellectual disabilities was a goal that we should aim for, they held varying opinions about what it should look like and how it should be brought about – *this was the research problem I identified*. There was indication that this lack of consensus could potentially impede social inclusion efforts.

The different perspectives held by the participants were most acutely apparent when four examples of segregated environments and activities (and their alternatives)

were discussed during my interviews. These four examples are as follows: special care homes, segregated education, Adult Service Centres, and Special Olympics. Although there is other literature that highlights some of the debates concerning various spatially segregated environments and activities for people with intellectual disabilities (e.g. Migliore, Grossi, Mank, & Rogan, 2008), I did not find any literature that simultaneously assessed and compared perspectives related to *multiple*, spatially segregated environments or activities, such as the four aforementioned examples. This thesis is a contribution to the literature on inclusion and disability in the way that it identifies common themes which intersect with all four types of spatial segregation. Comparing opinions regarding four types of segregated environments/activities provides me with a broader and more holistic perspective. It also enables me to more effectively theorize as to how these gridlocked debates could be resolved in order to facilitate inclusion. The explanatory theory I developed during the analysis of the data indicates that my participants justified their various opinions by *prioritizing one or more of the following three desired outcomes of social inclusion*: Respect and equality; opportunities and self-determination; and friendship and belonging. When one of these concepts appeared in the interview data, it was always mentioned in relation with its pair. I have grouped the desired outcomes as pairs in this way because, according to my participants, treating people with respect produces equality, opportunities are necessary to exercise self-determination, and a sense of belonging results from the cultivation of genuine friendships. As prescribed by grounded action methodology, I extended my explanatory theory to develop my *operational theory*, which asserts that by holistically enacting *all* three of these paired concepts of social inclusion, and by developing a consensus around these three outcomes, we can develop greater conceptual clarity and chart a more confident path to social inclusion. In other words, once we know *where* we are going and what social inclusion should look like, we will be able to more successfully figure out *how* to get there.

1.2 CASE IN POINT: INCLUSIVE EDUCATION RECOMMENDATIONS

To illustrate why it is important to gain a consensus on what social inclusion outcomes should be, I will provide a recent case example which confirms the research problem I discovered regarding the lack of conceptual clarity and consensus. A lack of

clarity and consensus around the meaning and purpose of ‘social inclusion’ at a conceptual and theoretical level, has the potential to impede even the best intentioned efforts to bring about social inclusion for vulnerable members of society (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012; Kendrick & Sullivan, 2009; Martin & Cobigo, 2011; Sherwin, 2010).

On October 30th, 2014, the Minister’s Panel on Education released their report, *Disrupting the Status Quo: Nova Scotians Demand a Better Future for Every Student*, following a thorough review of Nova Scotia’s education system. Based on their research, the panel outlined seven areas that needed improvement – including inclusive education. Nova Scotia’s *Special Education Policy* (2008) guides the delivery of education to students with special needs and disabilities. One of the policy’s key principles is the “Right to Inclusive Education”, defined as that which “embodies the beliefs, attitudes, and values that promote ‘the basic right of all students to receive appropriate and quality educational programming and services in the company of their peers’” (Nova Scotia Department of Education, 2008, p. 5). Many of the respondents who were consulted during the Minister’s Panel’s education review agreed with the right to inclusive education; they believed that inclusion was “great in theory” and approved of its underlying “philosophy”. However, they expressed concerns that the current model of inclusive education was not providing the necessary supports that many children with special needs and disabilities require in the classroom (Minister’s Panel on Education, 2014b, p. 214, 328). The review respondents expressed concern that the “‘one shoe fits all’ approach is not effective”; that inclusion “can be a good thing, but not 100% of the time”; and that more resources and personnel were necessary to ensure that special needs children were supported in their classrooms (Minister’s Panel on Education, 2014b, p. 214).

The Minister’s Panel on Education report (2014a) summarized the findings by stating:

It may be helpful to note that inclusion does not necessarily mean all students are integrated into regular classrooms all of the time. While many agree that the principle of inclusion is sound, few agree that its implementation has been successful since the current model was first introduced in the 1990s. (p. 42)

In light of the data collected during the review, they delivered the following recommendation to the Minister of Education and Early Childhood Development: “Assist schools and school boards to create a range of learning environments for students with special needs, *including congregated classes* taught by highly qualified specialist teachers, where appropriate” (2014a, p. 42, emphasis added). This recommendation provoked a strong response from inclusion advocates. For example, following the publication of the review report, Cynthia Bruce, a blind activist and Ph.D. candidate and part-time faculty member with Acadia University’s School of Education, wrote an opinion piece in the Chronicle Herald that was titled: “Don’t re-segregate special-needs kids” (2014, November 12). She believed the report’s recommendations regarding inclusive education “risks setting the inclusion of disabled people in this province back 20 to 30 years” (para. 1). Bruce was concerned that implementing a recommendation for the use of congregated classes when appropriate, promotes segregation and “will serve to reinforce that a disabled life is one we should fear and that disabled people are better off congregated with others who are like them” (para. 15).

Bruce’s concern was echoed in a CBC News article by Tracey Williams, the CEO of the Nova Scotia Human Rights Commission who equated ‘congregated classes’ with segregation. Williams pointed out that congregated classrooms were not going to help anyone in the education system “envision and create what we would consider an inclusive and welcoming and caring school community” (as cited by MacIvor, 2014, November 19, para. 7). However, a contrasting response to the report’s recommendations was expressed by a mother of someone with a disability, in an online forum (November 18, 2014):

Inclusion and disability have many layers. I would love to see more thought go into this process. *What is the purpose of inclusion and is this method achieving that purpose?* ... In my opinion *true inclusion* – every child having meaningful interactions which result in personal and communal growth – requires a radical change in curriculum, class structure and supporting staff. Real inclusion is expensive. In our personal experience our child begged to be placed somewhere where he could learn with children who were 'like him' – his words. We moved here because N.S. offers the Tuition Support Program, which funds specialist

schools – which on the outside seems like segregation but which has given him the tools to become a contributing member of our community – inclusion.

(Anonymous, personal communication, emphasis added)

Furthermore, the executive director of Autism Nova Scotia, Cynthia Carroll (2015, February 3), pointed out in *The Chronicle Herald* that unfortunately the discussions and debates in response to the education review report “resulted in a heated and misguided dialogue of inclusion vs. segregation, which is not only an inaccurate portrayal of the recommendations... but a disservice to those children who are struggling under the current inclusion model” (para. 2). These varied perspectives confirm the research problem I discovered among my research participants – that there are multiple and often conflicting opinions as to what social inclusion should look like and how it should be facilitated and implemented. The unfortunate consequence of these varying perspectives is that a lack of conceptual clarity and consensus can potentially prevent inclusive progress.

The mother in the online forum called for a more thoughtful articulation of the purpose of social inclusion efforts and referenced her understanding of “true inclusion”. Similarly, a parent respondent during the education review process noted that simply having all students (regardless of ability or disability) sitting in the same classroom together “does not equal inclusion *in the real sense of the word*” (Minister’s Panel on Education, 2014b, p. 214, emphasis added). Their statements caution that if a model of social inclusion is implemented without being directed by an authentic and holistic inclusive vision of the desired outcome, the efforts could be misguided. Kendrick and Sullivan (2009) remind us that not every version of social inclusion is beneficial, even if its adherents and implementers have the best of intentions. They accuse governments and organizations of using the concept carelessly as a “‘catch all’ phrase” or reducing it to “a convenient and fuzzy political slogan” that has no substantial meaning or beneficial impact on society (Kendrick & Sullivan, 2009, p.72, 67, 70). With the broader aim to prevent such misguided efforts, my research investigates the various ways that people understand ‘true inclusion’ – “in the real sense of the word” – for people with intellectual disabilities in Nova Scotia (Minister’s Panel on Education, 2014b, p. 214). Although my research does not focus entirely on inclusive education (it is only one of four contentious

areas I focus on), I anticipate my research results will be a useful guide for anyone interested in furthering the social inclusion of people with intellectual disabilities (including those who are interested in self-advocacy).

On January 29th, 2015, Minister Casey released her action plan report, which is based on the recommendations she received from the Minister's Panel on Education three months earlier. In response to the recommendation regarding the use of congregated classrooms, the action plan document states that "while most students' learning needs can be met through large group instructions within the classroom, some students may periodically require small group instruction and/or intensive individualized programming outside the classroom" (Casey, 2015, p. 27). The implementation of the action plan will occur between 2015 and 2019 and involves "[developing] a new needs-based model of service delivery for inclusive education... [and creating] a continuum of support to provide a broad range of programming options for students with special needs" (Casey, 2015, p. 44). Following through on these actions will require a more holistic understanding of social inclusion and a clearer vision of what social inclusion should look like, in order to be in accordance with Nova Scotia's Special Education Policy's Right to Inclusion principle (2008). My hope is that my research can contribute to creating this clear vision of inclusion and inform relevant policy and program developments, such as the new service delivery model for inclusive education and the creation of an array of options for students with special needs. My recommendations can be found in Chapter Eight.

1.3 SIGNIFICANCE, LIMITATIONS, AND SCOPE OF THIS RESEARCH

My research has the potential to address current social issues and concerns in Nova Scotia through informing policy and programming developments, but it also will contribute to a larger body of literature related to the social inclusion of people with intellectual disabilities. The deinstitutionalization movement that began in the 1980s and brought people with intellectual disabilities out of institutions and into communities was a significant step toward social inclusion (Neufeldt, 2003; Rioux & Valentine, 2006). However, in the past decade researchers have noted that just because someone is *in* the community and has 'community presence', it does not necessarily follow that they will experience community integration or authentic social inclusion (Bigby & Fyffe, 2009;

Bigby & Wiesel, 2011; Milner & Kelly, 2009). Although researchers have attempted to provide insight on how the gap between mere presence and actual inclusion can be bridged (Bigby & Fyffe, 2009), the issue remains unresolved and inconclusive (Amado, Stancliffe, McCarron, & McCallion, 2013; Cobigo et al., 2012). In Ontario, a research program was launched to inform and guide the enactment of *Ontario's Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* (MAPS, n.d.a., para. 1). One of the central aims of the research program, titled 'Multidimensional Assessment of Providers and Systems' (MAPS), is to reach "a consensus on the definition of social inclusion" in order to support the new 'Social Inclusion Act' (MAPS, n.d.b., para. 1). The research team commenced this multi-phase project because they recognized that the "evidence outlining the dimensions of social inclusion is still limited" (MAPS, n.d.b., para. 2), and that this lack of conceptual clarity is a hindrance to achieving social inclusion (Martin & Cobigo, 2011). The MAPS research team have made progress toward addressing this lack of conceptual clarity and consensus, and yet they emphasize that "further work is required to develop a consensus on the meaning of social inclusion and its measurement" (Cobigo et al., 2012, p. 82). Researchers (e.g. Bigby & Clement, 2009; Cummins & Lau, 2003) have criticized the over-reliance on the use of quantitative methodologies to measure social inclusion for people with intellectual disabilities, because they produce outcomes that ignore the subjective components of being excluded or included. My research responds to the call to develop a consensus on the meaning of social inclusion, and through the use of qualitative methodology, it lays the foundation for the development of measures that will probe social inclusion's more subjective components.

In Nova Scotia, the disability community has worked hard to propel forward more inclusive policy developments. For example, in June 2013, following substantial research and consultations, the Nova Scotia Joint Community-Government Advisory Committee (NS Advisory Committee) submitted a landmark document with recommendations to the Minister of Community Services who oversees the province's Services for Persons with Disabilities (SPD) program. The report, which is often referred to as the 'roadmap' report outlines a clear five year plan for the transformation of disability services, which would contribute to greater social inclusion for people with intellectual disabilities. The

potential impact of this document is promising, and yet due to its focus on concrete policy recommendations it did not appear to have the capacity to explore the underlying debates and conflicting opinions about what authentic and genuine social inclusion really looks like, specifically for people with intellectual disabilities. My research responds to these gaps and limitations in the existing literature and policy documents.

At an even broader level, my research will contribute to the global discourse on the concept of social inclusion. Social inclusion has been described by theorists as “a contested concept with multiple meanings” (Taket, et al., 2009, p. 5). To define social inclusion, researchers have attempted to develop lists of associated dimensions, categories, attributes, and indicators (e.g. Cushing, 2003; Hall, 2009; Martin & Cobigo, 2011; Peace, 2001; Shookner, 2002; Simplican, Leader, Kosciulek, & Leahy, 2015). These lists represent a variety of perspectives and they are all valuable contributions to the social exclusion / inclusion discourse. However, Cushing (2003) insightfully points out that “the problem is that [social inclusion] is such a broad concept, and people have such diverse notions about what they ought to be included in, the lists tend to be so extensive as to make it difficult to have a sense of what *priority* each issue holds” (p. 16, emphasis added). In contrast, the explanatory theory produced by my research highlights only three (paired) priority outcomes of social inclusion in more abstract, yet applicable terms; thereby avoiding the inflexible limitations of having many concrete, specific indicators. My explanatory theory indicates that my participants justified their varied opinions (when discussing four contentious topics – special care homes, segregated education, Adult Service Centres, and Special Olympics) by prioritizing one or more of the following three desired outcomes of social inclusion: respect and equality; opportunities and self-determination; and friendship and belonging. Building on my explanatory theory, my operational theory presents a holistic definition of social inclusion and predicts that by facilitating a consensus around these three priority outcomes, greater conceptual clarity will be achieved and a more socially inclusive province will be possible.

Although my investigations into the meaning of social inclusion are situated and grounded in the province of Nova Scotia among a specific population (people with intellectual disabilities), my research has the potential to contribute to the international

body of literature that continues to grapple with the definition and implementation of policies and programs that support social inclusion (e.g. Bigby & Fyffe, 2009; Cobigo et al., 2012; MAPS, n.d.b.; Amado et al., 2013). Future research will be able to test and verify my explanatory and operational theory of social inclusion by applying these grounded action theories beyond the province of Nova Scotia, and among other populations, in order to determine their potential generalizability. However, before the extension of the theories is attempted beyond the context they are situated in, the operational theory and action plan should be verified in Nova Scotia. The explanatory theory developed through my research has been tested through the use of theoretical sampling (see Chapter Two), but given the limited scope of my master's research project and my position as a student, I have not yet been able to empirically test the operational theory and action plan. Consequently I have not yet been able to fulfill the fourth and fifth stages of grounded action method – “the action stage”, which is the realization of the action plan, and the “transformative learning stage”, which occurs through reflection on the efficacy of the empirical test of the explanatory and operation theories (Simmons, 2006, p. 288).

Simmons (2006) emphasizes that the transformative learning process is a necessary fifth, and ongoing stage, “because actions produce changes in systems that, in turn, produce new and/or unexpected outcomes” (p. 288). Simmons and Gregory (2003) stress that “grounded action IS transformative [because] it involves a process of continually discovering, learning, rediscovering, and relearning” (p. 10). Once this study's limitation is addressed through the completion of stages four and five, the theories will be ready to be tested in other contexts and can be used to guide effective interventions (Olson, 2008). Simmons and Gregory (2006) believe that “although grounded action is generated in a particular context for use in that context, because it is about understanding and discovering generic variables, it remains open to modification, application, and transformation in new settings” (p. 11). I am keenly aware of the complexity of social inclusion and even with a well-developed explanatory and operational theory, facilitating social inclusion may not be straight forward or easy. Making social inclusion a reality for people with intellectual disabilities will involve countless people working at multiple different levels of society, as well as numerous

“small instances of social pioneering and experimentation” (Kendrick & Sullivan, 2009, p. 69, 71). Kendrick and Sullivan (2009) recognize that social inclusion is multi-dimensional and they espouse collaboration and alliances as being vital and necessary to this undertaking.

1.4 RATIONALE FOR CHOICE OF TERMINOLOGY

Throughout this thesis I have chosen to use the term ‘people with intellectual disabilities’. Among the wide variety of terms used in the literature this indicates a preference for people-first language and for the use of the intellectual disability construct rather than related constructs such as: cognitive disability, developmental disability, learning disability, learning difficulty, or simply ‘disability’ without specification. Since the use of labels and language is a highly contentious topic in this field, I will explain my rationale for using certain terminology. As a *nondisabled* researcher studying an issue that pertains to people with disabilities, and as someone who is deeply aware of the potential power imbalances between myself as the researcher, and my research participants, I am committed to undertaking this research endeavor with great care and commitment to reflexivity. Therefore, it is of critical importance for me to be fully transparent in explicating my reasons for using certain, contestable terminology, and also to demonstrate my careful consideration of the debates that surround the usage of certain terminology.

1.4.1 RATIONALE FOR USING PEOPLE-FIRST LANGUAGE

The phrase ‘person with a disability’ is an example of people-first language where a postmodified noun is used. In people-first language the ‘person’ is emphasized, while the ‘disability’ is presented as a secondary characteristic. This approach is in contrast to the use of the premodified noun; i.e. ‘disabled person’. People-first disability language has been in circulation since the 1970s, but it was in the 1990s that many governments and organizations officially incorporated people-first language into their policy documents and discourse; prescribing the postmodified noun and people-first language as the most appropriate and respectful way to refer to people living with disabilities (Muredda, 2012; Peers, Spencer-Cavaliere, & Eales, 2014). However, it was around the time that governments first began utilizing people-first language that self-advocates began indicating their preference for the premodified noun and denouncing people-first

language as depoliticized (Muredda, 2012; Titchkosky, 2001). Disability activist and scholar, Titchkosky (2001), acknowledges that efforts to promote people-first language stemmed from a desire to reject the practice of applying demeaning labels to people with disabilities – stigmatizing definitions which left no room for people to create their own self-identities beyond their limitations. However, rather than perceiving people-first language as a progressive response, Titchkosky argues that the consequences of using individual-focused, people-first language have been to undermine a collective disability consciousness and movement, to strip disability of its politics, and to prevent a social understanding of disability.

Whereas *person with a disability* describes disability as a secondary characteristic of an individual's body, *disabled person* is used by self-advocates to highlight 'disability' as an integral component of identity while simultaneously locating the limitation and the problem – in society. Self-advocates who adhere to this social model of disability, differentiate between impairment and disability (Oliver, 1996). While they may live with certain impairments, they claim that it is not their bodies and minds that disable them, but it is society who *disables* and oppresses them by not providing appropriate services and accommodating their needs (Oliver, 1996). However, in light of these arguments, Muredda (2012) does not believe that people-first language is necessarily irrelevant or offensive. Rather, Muredda believes that people-first language, as well as the premodified noun of its counterpart, can represent many different conceptual understandings when harnessed for a variety of different uses. People-first language, which conceptualizes disability “as a secondary rather than definitive trait” (Muredda, 2012, p. 8), can be beneficial and retain its utility in certain contexts.

In contrast to many people with physical and sensory disabilities, people with intellectual disabilities typically prefer people-first language. For example, People First, a world-wide self-advocacy movement that represents people with intellectual disabilities through local chapters, states an explicit preference for people-first language, which is obvious even in the title of the organization (peoplefirst.org, n.d.). As previously mentioned, people with intellectual disabilities often face the greatest barriers to inclusion and are perceived differently by society in contrast to those with physical and sensory disabilities. Gillman, Swain, & Heyman (1997) suggest that it is *because* people with

intellectual disabilities are perceived differently by society that they have chosen to maintain people-first terminology, while those with physical and sensory disabilities enjoy the greater luxury of being able to discard it in favour of the more politicized premodified noun. They write:

It could be argued that whilst the Disability Movement has fought the colonisers of disability (e.g. medical and allied professions) for the right to define disability on their terms, the fight against the colonisers of learning difficulty [i.e. intellectual disability] is of a different order; it is a fight against the denial of humanity itself; hence, this group's insistence on being perceived as *people* first. (Gillman, Swain, & Heyman, 1997, p. 690)

Unfortunately people with intellectual disabilities do not frequently have the opportunity to access the theoretical and academic arena in order to engage with, and debate, the meaning of disability in the same way that people with physical and sensory disabilities do (Gillman, Swain, & Heyman, 1997). Consequently, exclusion from this platform has disadvantaged them in their efforts to define disability on their own terms.

For people with intellectual disabilities (Reinders, 2008; Kittay, 2002), whose personhood status is often precarious and questioned, the use of people-first language, which situates disability as a *secondary* individual characteristic, provides some protection in a society that is reticent to offer them full inclusion. For these reasons, and in alignment with the preferences of the People-First self-advocacy group, I have chosen to use people-first language even though the premodified noun of *disabled person* is currently the preferred choice in the disability studies field, which grounds itself on the social model of disability (Peers, Spencer-Cavaliere, & Eales, 2014; Shakespeare, 2014; Titchkosky, 2001).

1.4.2 RATIONALE FOR USING THE TERM 'INTELLECTUAL DISABILITY'

'Intellectual disability' is the latest reincarnation of a moral, social, and diagnostic category that replaces a long succession of various terminologies used throughout history (Ford, Acosta, & Sutcliffe, 2013). For example, Britain's Mental Deficiency Act of 1913 referenced four categories of classification with titles that are now considered highly pejorative – idiots, imbeciles, feeble-minded persons, and moral imbeciles (Mental Deficiency Act, 1913). These category titles were discarded with the publication of the

first modern classification manual in North America (Heber, 1961), which promoted the adoption of the more general term of ‘mental retardation’. At the time, this term was considered to be ‘more scientific and less pejorative’, even though it has since become a stigmatizing and derogatory label (Greenspan, 2010). Gradually, ‘intellectual disability’ has replaced ‘mental retardation’ in organizations, journal titles, and published research (Schalock et al., 2007). In October 2010, in response to significant advocacy efforts, the United States Congress passed *Rosa’s Law*, which amended the language in all federal health, education and labor laws, by replacing the phrase ‘mental retardation’ with the phrase ‘intellectual disability’ (Obama, 2010). This change was made because mental retardation has acquired “negative connotations, and has become offensive to many people” (Social Security Administration, 2013, para. 6). The recent official status of intellectual disability has set a terminology standard for North America.

The American Association on Intellectual and Developmental Disabilities [AAIDD] (n.d.a) is the “world’s largest and oldest organization of intellectual disability professionals” (para. 13) and their definition of intellectual disability has three components:

1. significant limitations in intellectual capacity (often assessed with an IQ of 75 or less);
2. significant limitations in adaptive behavior which includes social and practical skills;
3. the disability originated before the age of eighteen (AAIDD, n.d.b).

The term ‘intellectual disability’ is often used interchangeably with ‘developmental disability’ even though developmental disability is the larger umbrella term that encompasses most intellectual disabilities. Developmental disabilities include severe, lifelong, chronic disabilities that appear before age twenty-two and are either *cognitive or physical, or both* (AAIDD, n.d.a; U.S. Department of Health and Human Services, 2010). ‘Cognitive disability’ is another term that is frequently conflated with intellectual disability, but again cognitive disability is a larger umbrella term that encompasses intellectual disability. In addition to intellectual disabilities, cognitive disabilities also include learning disabilities such as dyslexia (which have more to do with a different way of processing information, rather than low IQ), and acquired brain injuries or conditions

such as dementia that occur later in life (Saskatchewan Ministry of Health, n.d.; Industry Canada, 2008). In this thesis I am focusing on people who have been labelled with an intellectual disability, although I recognize the overlap with other classifications of disability.

Despite its broad acceptance, the term *intellectual disability* has its critics. Rapley, Kiernan, and Antaki (1998) write that “there seems to be a professional (and perhaps societal) consensus that the identity label of ‘intellectual disabled’ is an aversive, even ‘toxic’ one” (p. 807). It at first appears as an inescapable reality that intellectual disability and the labels that preceded it must describe “limitations in individual functioning within a social context and represents a substantial disadvantage to the individual” (Schalock et al., 2007, p. 117), which is hardly a positive, uplifting identity definition to be bound to. Schalock et al. (2007) remind us that there are significant consequences (both positive and negative) that are determined on the basis of whether or not a person meets the criteria for what Rapley, Kiernan, and Antaki (2008) refer to as a *socially toxic identity*. For example, receiving the label of intellectual disability can make someone eligible or ineligible for services, entitled or not entitled (e.g. for Social Security benefits) (Schalock et al., 2007, p. 118). Therefore, it can be argued that the need for a disability label with definitive diagnostic criteria cannot be dismissed entirely. Schalock et al. (2007) highlight the fact that the diagnostic definition of intellectual disability has improved upon the definitions of its antecedents by taking into account the individual’s interaction with, and adaption to, their environment. However, Rapley (2004) argues strongly that despite this change to the definition, “in practice the hypothetical construct ‘intellectual disability’ continues to be reified as a core, or essential, aspect of personhood” (Rapley, 2004, p. 196). This reification of intellectual disability is problematic.

Rapley (2004) argues that regardless of what labels are deemed appropriate throughout history, any variant label of ‘intellectual disability’ as produced by the professional and medical community, are equivalent on many levels. They are all socially constructed, moral, social and diagnostic categories that can cause harm by conflating personhood with cognitive limitations. Rapley (2004) points out that there is nothing absolute about any of these labels. They are terms that are constructed within certain contexts, influenced by the value systems of society at the time. Therefore, being

assigned the label of intellectual disability will always be a *contestable status*. Labeling a perceived ‘condition’ with a new name does not address the more problematic concerns with creating categories in the first place. Creating an identity category, such as intellectual disability, is problematic for four reasons. First, the category attempts to homogenize diversity. Smith (2002) critiques the category for assuming a shared essence among a group of people when in actuality, intellectual disability describes “an aggregation of diverse human circumstances” (p. 63). Second, categories are defined only in relation to other categories. In this case, the category of intellectual disability is defined in relation to the ableist category of ‘normal’. What is normal competence? Rapley (2004) reminds us that normality “is a notion that is *itself* the product of the psychological imagination” (p. 198). If ‘normal’ is yet another relative, socially constructed category, then there is no external truth that provides the basis for the category of intellectual disability through comparison. Swain and French (2000) also point out that there is “an assumption that disabled people want to be ‘normal’” (p. 573), whatever normal is to be perceived to be by society. This assumption then logically leads to another assumption – that being disabled and defined as ‘not normal’ is undesirable and a hardship. Through the Disability Arts Movement and through the utilization of the affirmation model of disability, people are promoting a positive identity of impairment and “actively repudiating the dominant value of normality”; the very category that enables a category of limitation and difference to even exist in the first place (Swain & French, 2000, p. 578).

Third, the assessments that test intelligence and competence to determine if someone meets the criteria for an intellectual disability diagnosis cannot be wholly objective and are ultimately reflections of the society we live in (Rapley, 2004). For example, the Intelligence Quotient, or IQ test, that is commonly used to measure intelligence and determine a person’s degree of disability, is “based on notions of relative intelligence” (Hall & Kearns, 2001, p. 241). Rapley (2004) criticizes disability studies theorists for “a failure of imagination” for not being able to perceive competence as a relative concept (p. 202). Rapley (2004) insists that competence is “more subtle a social accomplishment than can be captured by standardized testing or the ticking of boxes on adaptive behavior checklists” (p. 77). Instead of perceiving cognitive capabilities as

“fixed, internal, mental attributes” (p. 202), Rapley (2004) believes that competence is context-dependent; it is both actively negotiated and constructed in specific situations and environments. When professionals and academics assign the label of intellectual disability to someone, they are engaging in “the (contestable) construction of a version of ‘identity’ (as an enduring, dispositional, characteristic of persons)” (Rapley, Kiernan, & Antaki, 1998, p. 825). They also risk over-simplifying the complexity and diversity of strategies that are used by those who are labeled, to contest and negotiate their identity through interaction in their varied contexts. As both an academic and professional, I must proceed with caution and reflexivity to ensure that I do not make these errors in judgment.

Finally, creating the identity category of ‘intellectual disability’ is problematic because it can undermine the efforts of people to object to their objectification and create their preferred self-identity. An insidious consequence of this particular identity category is that, due to the perceived nature of the ‘condition’, if someone labelled with an intellectual disability denies this label in an effort to create a different self-identity, their ‘intellectual disability’ label and *assumed* lack of competence discredits their attempt to reject their objectification (Rapley, Kiernan, & Antaki, 1998). In light of the many detrimental impacts of using the intellectual disability label, Rapley (2004) would prefer that the category itself be abandoned. However, if the construct of intellectual disability must be retained, he believes it is essential that there is an explicit recognition that the label is not reified, biological truth, but a socially constructed concept with an “inescapably moral nature” (Rapley, 2004, p. 209). We must deny the label its current hegemonic and homogenizing power in both the social sciences and the medical professions. Being labeled as a person with an intellectual disability must always be ‘contestable’.

In an effort to avoid the implications of the deceptively static and reified identity label of ‘intellectual disability’, self-advocates in the United Kingdom have expressed a preference for the term ‘person with learning *difficulties*’, because it communicates greater fluidity and indicates a capacity to learn (Hall & Kearns, 2001). However, ‘intellectual disability’ continues to be the most widely understood, accepted and utilized term in North America. Therefore, for these reasons, since my research is based in

Canada, I have chosen to use the term ‘intellectual disability’ throughout my thesis. The self-advocacy organization, People First of Canada (n.d.a.), indicate on their website that they are “the national voice for people *who have been labeled with an intellectual disability*” (para. 2, emphasis added). I adopt a similar stance in my research. When I refer to ‘people with an intellectual disability’, I intend for this phrase to refer to people who may have been assigned this diagnostic label by someone else, *not* as a reference to people who are defined by their limitations. It is important for me to specify intellectual disability in my research, rather than to simply refer to ‘people with disabilities’, because those labeled with intellectual disabilities often face different barriers in society in contrast to those with physical and sensory disabilities (Klotz, 2004; Lippold & Burns, 2009; Reinders, 2008). Furthermore, the disability movement (based on the social model of disability) and the disability studies field, have been criticized for being dominated by those with physical and sensory impairments while marginalizing people with intellectual disabilities (Chappell, Goodley, & Lawthom, 2001; Goodley, 2011; Hall & Kearns, 2001). It is assumed that their inclusion is implicit in any writing about disability, when in fact many of the arguments or experiences that are described in the disability literature do not apply to, or represent people with intellectual disabilities (Chappell, 1998). Consequently, I believe it is important that I am explicit about my focus on people with intellectual disabilities.

In summary, although the use of people-first language continues to be contentious (Peers, Spencer-Cavaliere, & Eales, 2014), it is often the preferred choice among people with intellectual disabilities (peoplefirst.org, n.d.). Recently, despite those who disagree with any form of labelling (Rapley, 2004), due to a powerful grassroots movement led by advocates, the term ‘intellectual disability’ has officially replaced the term ‘mental retardation’ and has been widely accepted worldwide as the most appropriate terminology to use (Ford, Acosta, & Sutcliffe, 2013; Tassé, 2013). I hope I have demonstrated a careful consideration of the debates around disability terminology and have clearly conveyed to my reader my rationale for using controversial people-first language and the ‘intellectual disability’ terminology throughout my thesis. For those unfamiliar with the disabilities studies field, this lengthy explanation may seem excessive, but as a nondisabled researcher who is acutely aware of these important

debates and the unequal power distribution between myself (as the researcher) and my participants, it was important for me to reflect deeply on my choice of terminology. I do not want to contribute to the continued discrimination of people with intellectual disabilities and the conflation of their personhood and identity with a diagnostic label. Although I use the phrase ‘people with intellectual disabilities’ throughout my writing, I simultaneously affirm the right of all people to negotiate, redefine, and contest the labels that are assigned to them, and to create positive self-identities that are not centered on limitations.

1.5 SITUATING THE RESEARCHER IN THE RESEARCH

I am a constructivist grounded theorist and as such, I am dedicated to researcher reflexivity and to being transparent about the potential influence of any preconceptions, personal predilections and experiences, theoretical paradigms and disciplinary perspectives I adhere to. Charmaz (2014), also a constructivist grounded theorist, argues that if “we start with the assumption that social reality is multiple, processual, and constructed, then we must take the researcher’s position, privileges, perspective, and interactions into account as an inherent part of the research reality. It, too, is a construction” (p. 13). Similarly, I believe that “the notion of entering inquiry with no preconceptions is itself a preconception” (Charmaz, 2014, p.160). Furthermore, the realizations that result from the practice of reflexivity should be made explicit and openly acknowledged as part of the “research record” (Neil, 2006, p. 259; McGhee, Marland & Atkinson, 2007). To conclude this chapter and situate myself in the research reality, I will acknowledge and describe some of the relevant aspects of my life that have likely influenced who I am as a researcher. There are five aspects that I believe are relevant to this study.

First, there is the transformative experience I had when volunteered and lived in a L’Arche community for several weeks in the summer of 2009 before commencing my master’s program in social anthropology. From the outside, L’Arche presents as a type of group home living environment for people with intellectual disabilities, where they are provided with supports and services offered by people *without* disabilities. However, from within a L’Arche community, it is evident that L’Arche offers a unique community-based model of living that cultivates a deep sense of belonging and acceptance, which

crosscuts differing abilities and blurs the typical divide between the ‘care-giver’ and ‘client’. As will be discussed in Chapter Two, although my research journey eventually *shifted away* from a focus on the L’Arche model, my experience living in a L’Arche community was one of the key catalysts for undertaking this research project. The second relevant aspect of my life, which has influenced who I am as a researcher in this study, was my father’s disability. In 2011, my father acquired a profound disability due to a brain injury, which rendered him unable to communicate, unable to eat, and unable to intentionally use his limbs. As a result of this personal experience, I am aware that I am particularly concerned as to how my theory of social inclusion might apply to people with *profound* intellectual disabilities in addition to those who live with mild intellectual disabilities.

The third relevant aspect that likely influenced the research process is my academic background in social anthropology, which encourages a thorough and in-depth, open-minded approach to researching culture, society, and human behavior. Kasnitz and Shuttleworth (2001) make a strong case for the contribution of anthropology to a disability studies perspective “that includes social and public policy change as major goals” (p. 27). The fourth relevant aspect is my academic and professional background in occupational therapy. Occupational therapy is known for adopting a rehabilitation approach to disability (based on the medical model) that is frequently at odds with a disability rights approach that rejects the idea that disability is a deficit that needs to be ‘fixed’ or ‘rehabilitated’ (Charmaz, 1990; Kielhofner, 2005). In order to address the possibility that a predisposition toward a rehabilitative approach, based on my occupational therapy background, might influence my research process, I immersed myself in disability studies literature that explicitly promotes a disability rights approach (Charlton, 1998; Goodley, 2011; Shakespeare, 1998). This provided me with a more holistic and balanced perspective on disability and its related concepts.

The final aspect worth mentioning is that I consider myself to be a nondisabled researcher and disability ally. As an ‘outsider’ to disability, I am aware that I am limited in my capacity to understand what it would be like to experience social inclusion or exclusion when living with a disability. On the other hand, being a disability ally has influenced me in that it has made me passionate about creating the necessary change that

would enable people with intellectual disabilities (and any disability) to enjoy social inclusion and a higher quality of life. While my position as an ally could also be of concern in the way that it may bias me toward certain outcomes, Charmaz (2014) argues that passion has a place in grounded theory research. She writes:

Topics that ignite your passions lead you to do research that can go beyond fulfilling academic requirements and accruing professional credits. Enter the studied phenomenon with enthusiasm and open yourself to the research experience and follow where it takes you. The path may present inevitable ambiguities that hurl you into the existential dislocation of bewilderment. Still, when you bring passion, curiosity, openness, and care to your work, novel experiences will ensue and your ideas will emerge. As you move from data through analysis to writing the research report, your journey through grounded theory may transform you. (Charmaz, 2014, p. 340)

I can attest to the truth of this quote. My research journey on this topic has been anything but straightforward. Yet by approaching the research process with openness, passion, and enthusiasm, the journey has been personally transformative and has arguably made me a better ally.

1.6 CHAPTER SUMMARIES

In Chapter Two, I describe the evolution of my research design to my eventual decision to use grounded action methodology (Simmons and Gregory, 2003). Grounded action is a relatively new methodology and the methodology it builds on, grounded theory (Charmaz, 2014; Glaser & Strauss, 1967), has developed many variations over time. Thus I will take the necessary space to explain why I chose the approach that I have and how I utilized the methodology in this study. In Chapter Three, I explain the historical context of the social issue (i.e. the action problem) that I aim to address. Chapter four outlines the key research problem I discovered that is perpetuating the action problem, and the four contentious topic areas that emerged in my interviews (i.e. special care homes, segregated education, Adult Service Centres, and Special Olympics). Chapter Five, Six, and Seven, expound the explanatory theory I developed (following my analysis of the emergent research problem) by describing the three priority outcomes of social inclusion that were referenced or utilized by my research participants. Chapter

Eight is where I draw from my explanatory theory to develop an operational theory that is ready for implementation. In Chapter Eight, I also outline my action plan and recommendations for building a more socially inclusive province for people with intellectual disabilities. I conclude the thesis in Chapter Nine by summarizing my research findings, highlighting my contribution to the literature, and outlining recommendations for future research.

CHAPTER 2: RESEARCH DESIGN AND METHODOLOGY

2.1 EVOLUTION OF THE RESEARCH DESIGN

When I began my master's program in Social Anthropology in September 2009, I had a distinctly different focus and research design than I do now. In agreement with Charmaz (2014), I believe it is important to be transparent about the evolution of my research approach and to reflect on how this evolution may have shaped the current study. As I mentioned in my introductory chapter, the catalyst for this thesis was my experience living and volunteering in a L'Arche community during summer of 2009, before commencing my master's program in social anthropology. The L'Arche model, guided by the philosophy of its founder, Jean Vanier, espouses a community model of living, instead of a medical or social service model of care, where "the expected distinction between caretakers and patients is erased" (Angrosino, 2003, p. 944). Angrosino (2003) observes that at face value, "L'Arche may seem like just another group home where people with serious disabilities are cared for. But the agenda of L'Arche, encoded in its countercultural self-understanding, is a more radical one than a superficial view might suggest" (p. 944). He argues that L'Arche aims to demonstrate "the possibility of living in ways that radically upend the values, assumptions and life ways of the mainstream" (Angrosino, 2003, p. 944). Inspired by my experience at L'Arche, I decided to research both the practical and political implications of Vanier's philosophy as it is embodied in the L'Arche model, by examining how L'Arche was *situated* within Nova Scotia's current political context in relation to government policy, other models of long-term facility based care, and disability rights organizations. My initial research design adopted a generic qualitative approach (Kahlke, 2014) and aimed to assess both the capacity and the potential of L'Arche communities in Nova Scotia to contribute to the development of a deeply inclusive province where people with intellectual disabilities are not segregated and excluded, but experience social inclusion.

My original research design was primarily *deductive*. One of my hypotheses was that there would be a measure of resistance toward L'Arche philosophy among other service providers and members of society, due to L'Arche's rejection of independence as the *ultimate goal* of people with intellectual disabilities – a goal typically upheld by liberal societies with their focus on autonomous individualism (Held, 2006; Kelly, 2007).

In L'Arche philosophy, *interdependence* is explicitly valued over *independence* (Angrosino, 2003; Kelly, 2007; Pottie & Sumarah, 2004). By validating this hypothesis, I believed I would be able to assess the potential for L'Arche to influence other agencies. However, immediately after launching into the interview phase of my research project it became apparent that my research questions would not yield the rich, relevant data I was hoping to collect. I quickly discovered that the L'Arche approach was no longer as unique as I had first believed. During my interview with staff members of another long-term care service provider for people with disabilities, they admitted that in the early days of disability services, L'Arche with its 'relationship-based philosophy' was quite distinct from service-providers who were primarily influenced by the 'behavior management field'. However, they explained that over time L'Arche philosophy had influenced other service-providers and they had influenced L'Arche in return. Although L'Arche is still unique in many ways, I found that there was no longer a stark contrast between the L'Arche approach and the approach of many other mainstream organizations and agencies (such as those I contacted for this study). Many of today's service-providers and organizations operate with values and objectives similar to those of L'Arche. A representative of one of the L'Arche communities recognized this. She told me:

Certainly in the early days of L'Arche, we were a little bit standoffish and there was a bit of a sense that L'Arche did things better than everyone else. I think certainly that's how other agencies saw us... I hope it's changing. I know that I've relied a lot on other agencies for support and advice and I'd be more likely in fact to contact some of the other agencies maybe about some things than about I'd contact L'Arche. And really, a lot of the agencies in Nova Scotia are so committed to the exact same kind of life for people with disabilities that we're committed to.

Following my initial forays with data collection, I realized that my initial research design was based on *personal assumptions and hypotheses that were not wholly accurate or relevant*. I was aware that individuals, service-providers and organizations all have different strengths. As Kendrick and Sullivan (2009) point out, if we are to build an inclusive society, many different approaches and expertise are needed. After recognizing my misguided bias in favour of L'Arche, I decided my study would be more relevant and

useful if I broadened the scope of my research.

At the time that I was exploring my original research questions, I was also becoming increasingly intrigued by the conflicting and divergent opinions that were emerging in my interviews (with both those associated and unassociated with L'Arche) when four topics were discussed: special care homes, segregated education, Adult Service Centres and Special Olympics. I decided that I wanted to explore the tensions I was encountering to find out why the divergent opinions were able to exist and *how* people were coming to different conclusions regarding these four spatially segregated environments and activities (and their alternatives) when all participants professed to supporting social inclusion for people with intellectual disabilities. I observed that this lack of consensus had the potential to derail and impede efforts to facilitate social inclusion in the province at a time when, according to researchers and advocates, social inclusion for people with intellectual disabilities was not progressing as quickly as hoped for (Barken 2013; Devet, 2014; Encol & Orrell, 2013; Wicks 2010). I anticipated that my exploration of this lack of consensus regarding segregated environments and activities (and their alternatives) could potentially contribute to the creation of a more socially inclusive province.

Charmaz (2014), a proponent of grounded theory, points out that it is natural for both the research project and the researcher's perspectives to change and evolve throughout the process as they interact with participants and the data. When the research data did not align with my expectations and I realized that my research questions were irrelevant, I revised them in order to investigate what was presenting as most pertinent in my interviews. This is consistent with Charmaz's (1990) directive that "grounded theorists follow interests, leads, and hunches that they find in the data" (p. 1162). Not only did I change my research questions, but I also changed my methodology. When I released my original hypotheses and assumptions, I also had to let go of my deductive approach. I was no longer trying to confirm or validate anything. Instead of using a deductive, 'generic qualitative approach' (Kahlke, 2014), I sought to utilize a more inductive method that would allow me to explore the tensions I was encountering, without a preconceived theoretical framework or set of specific questions and hypotheses to guide me. I required an inductive research methodology that would support me in

developing an explanation (as opposed to a description) for why people were arriving at different conclusions regarding the four contentious topics. Furthermore, I wanted to be able to apply my research discoveries to current social and political dilemmas related to social inclusion for people with intellectual disabilities. For these reasons, I selected the research methodology of grounded action (Simmons, 2006), as developed from grounded theory (Charmaz, 2014). I was initially dismayed at my circuitous journey before adopting grounded action, and I was concerned that by not selecting this methodology at the outset of my project I might have jeopardized the legitimacy of my methodological undertaking. However, I was reassured by the words of other grounded theory researchers who acknowledged that learning how to apply grounded theory (and by extension, grounded action) is an experiential process, rather than a necessary linear progression (Teik-Cheok Low, 2011).

2.2 RATIONALE FOR GROUNDED ACTION AND CONSTRUCTIVIST GROUNDED THEORY

2.2.1 WHAT IS GROUNDED ACTION?

Although Simmons introduced grounded action with Gregory (2003), Simmons (2006) appears to be the key pioneer with this methodology. Grounded action developed from both his solid education in grounded theory methodology, as well as his 14 years working as a therapist with a not-for profit social agency (Simmons, 1994). In his work as a therapist it became blatantly apparent to Simmons (2006) that his clients' various issues were in part, a result of their position within a larger social 'system'. He sought to address the issues he was encountering with an approach he titled 'grounded therapy' (1994); a 'practical application' of grounded theory (Glaser & Strauss, 1967), which would eventually lead to the development of grounded action methodology. Through his dynamic application of grounded theory research methods during therapeutic encounters, Simmons (n.d.b.) was able to address some of the *root* causes of his clients' issues. On the basis of Simmons' success in facilitating change using grounded therapy, Simmons and Gregory (2003) created grounded action research methods. There are some practical differences between grounded therapy and grounded action. For example, the 'coding' phase in grounded therapy must be done in the midst of the therapeutic encounter through dialoguing with the client or "solely in the therapist's mind" (Simmons, 1994, p. 18).

Furthermore, the point of analysis in grounded therapy is “not to arrive at a generalizable theory, but to arrive at solutions to the identified issues or problems, in the particular case” (Simmons, 1994, p. 19). In contrast, grounded action, as developed from grounded therapy and grounded theory, has the potential for broader use and to be applied across many substantive areas beyond therapeutic encounters.

My choice of grounded action and grounded theory did not make for a straightforward methodological journey, but the combination of these methods holds great potential for creating creative and innovative solutions that may not be possible with other approaches (Gregory, 2006). Other research or practice-based efforts to solve organizational and social problems, such as action research, “fall short because they are not systematically derived from data nor theoretically sophisticated enough to address the multidimensional complexities inherent in the problems” (Simmons & Gregory, 2003, p. 3). Simmons and Gregory (2003) write that “grounded action was designed specifically for the purposes of investigating and addressing the complexity of organizational and social problems and issues” (p. 3). Grounded action and grounded theory both adopt a systems perspective and a holistic, open-minded framework that identifies and assesses the various and multiple dimensions of social problems in order to identify latent and underlying social processes (Stillman, 2006). Therefore, these methods are better equipped to effectively investigate and address the ‘root causes’ of social problems, in contrast to approaches that only address the more obvious, surface-level *symptoms* of the root causes and social processes.

Grounded action begins with grounded theory, which creates the ‘explanatory theory’ that explicates the key underlying processes. Once the grounded explanatory theory is established, grounded action extends grounded theory to utilize this new understanding “to generate workable and sustainable solutions to complex social problems” (Gregory, 2006, p. 544). In order to generate a solution to a social problem, grounded action research involves the development of an operational theory that is derived from the explanatory theory after “revisiting the action problem in light of what has been discovered while generating the explanatory theory” (Simmons & Gregory, 2003, p. 9). The ‘action problem’ is a term used by Simmons and Gregory (2003) to reference the original *social problem* or issue that initiated the research project in the first

place. Through comparing the action problem with the explanatory theory, the researcher is well positioned and informed to make a “theoretical prediction about outcomes – what will happen if you take certain actions” (Simmons & Gregory, 2003, p. 9). This theoretical prediction, or the operational theory, must incorporate all aspects of the explanatory theory in order to be effective, and may “take the form of program designs, policies, calculated procedures”, or whatever the explanatory theory indicates is necessary for the situation (Simmons & Gregory, 2003, p. 9). The next step in grounded action methodology is to develop the action plan, which is essentially “the roadmap for measuring and putting the operational theory into motion” (Olson, 2008, p. 4). The action plan addresses the important components of the operational theory, while still taking into consideration practical limitations and available resources to “ensure that the plan is doable” (Simmons, n.d.b., p. 14).

Beyond the realm of academic research in the practitioner/action world of policymakers, change agents and professional human services, the predominant approaches to understanding systems and solving problems can be inadequate because they tend to be reductionist and lack a strong theoretical grounding (Simmons, 2006). Practitioner-based efforts for change that lack an academic, theoretical grounding make the mistake of “focusing more on what they think ‘ought to be’ than discovering and explaining ‘what is’” (Simmons & Gregory, 2003, p. 4). Simmons and Gregory (2003) assert that this “derails the discovery process right from the beginning and leads to a disconnect between actions and what is really going on” (p. 3). Grounded action avoids this pitfall by differentiating between the social problem (i.e. the ‘action problem’) and the ‘research problem’. Grounded action researchers accomplish this by suspending the action problem temporarily, as I did, and letting the research problem emerge from the data – returning to the action problem only when the explanatory theory is developed and the researcher is ready to develop the operational theory (Simmons & Gregory, 2003). By conducting research according to this sequence, grounded action is able to “get at the real problem, not a preconceived problem” (Simmons, 2006, p. 489).

In contrast, while practitioner-based efforts for change tend to be derailed by their focus on achieving a particular ideal outcome, many types of *academic research* that aim to resolve organizational or social problems can be derailed when the researcher

commences their investigation with a set of premises, preconceptions and theories that they apply automatically to the data. Simmons (2006) points out that if all social science research began with the data as grounded theory does, rather than a preconceived theory, the social sciences could be of greater pragmatic use for action. For Simmons, grounded action, as an extension of grounded theory, is unique in that it finds a middle ground and establishes a bridge between the two worlds of the practitioner and the academic. The frequent disconnect between theory and practice is something that I, like Simmons (2006), find distressing and unproductive. Creating bridges between the academic world of theory and research, and the practitioner-based world of relevant and effective social change, is something I strive to do with my professional and academic career. Consequently, grounded action methodology and the strong rationale that supports it, appeals to me immensely.

Since grounded action is a relatively new research methodology and one that has been utilized infrequently to date, it is worthwhile to distinguish it from several other similar methodologies, which it risks being confused with. Similar in name to grounded action research, is the methodology of ‘action research’. Action research utilizes strategies for catalyzing change through an intervention to solve an immediate practical problem identified by a group of people, and then analyzing the change that occurs (Baskerville & Pries-Heje, 1999). Although both grounded action research and action research aim to create practical change and both include a process for direct intervention implementation and then for analyzing the effectiveness of the applied change strategy, the two research methodologies are distinctly different (Baskerville & Pries-Heje, 1999; Simmons & Gregory, 2003). In 1999, Baskerville and Pries-Heje identified a deficit of action research – it frequently fails to support strong theoretical formulation and development. They believe this deficit has not previously been addressed since most action research literature “seems to assume that plain deductive logic will operate satisfactorily during the theory-evolution activities of the action researcher” (Baskerville and Pries-Heje, 1999, p. 4). Baskerville and Pries-Heje illustrate how this deficit of action research can be addressed by merging and embedding action research with grounded theory techniques to make it more theoretically rigorous and produce a “theory-grounded” action research study (p. 5). The key difference between Baskerville and

Pries-Heje's (1999) theory-grounded action research and Simmons and Gregory's (2003) grounded action research, is that Baskerville and Pries-Heje modify action research by extending it to incorporate grounded theory techniques whereas Simmons and Gregory modify grounded theory by extending it to incorporate action research techniques.

Consequently, Baskerville and Pries-Heje (1999) admit that unlike grounded action, their resulting methodological hybrid does not constitute true grounded theory because it violates one of the core principles of grounded theory – action research commences with a goal-directed approach that is limited in scope and often begins with predefined categories and concepts. According to Baskerville and Pries-Heje this “contradicts a grounded theory tenet that a theory must be allowed to wholly emerge from the open coding” (p. 18). Therefore, Baskerville and Pries-Heje's methodological product is essentially action research with select grounded theory principles incorporated to aid theoretical development. I chose to utilize grounded action rather than action research or Baskerville and Pries-Heje's hybrid, because as previously stated, I was seeking an inductive approach that would facilitate the emergence of categories and concepts without relying on pre-existing preconceptions that would limit the development of theory construction.

2.2.2 WHAT IS GROUNDED THEORY?

Grounded action is “the application and extension of *grounded theory* for the purpose of designing and implementing practical actions”, and therefore I believe it will be beneficial for the reader if I provide an overview of the grounded theory method (Simmons & Gregory, 2003, p. 1, emphasis added). Since grounded action involves first completing a grounded ‘explanatory’ theory before designing and implementing practical actions, it can be argued that this study is both a grounded action *and* grounded theory study. Grounded theory was first introduced to the research world in 1967 with Glaser and Strauss's book, *The Discovery of Grounded Theory*. The development of grounded theory method sought to address criticisms about qualitative research being an unsystematic approach and inferior to quantitative research (Charmaz, 2014). Whereas quantitative research was being used primarily for examining variables or *verifying pre-existing* theories and hypotheses, Glaser and Strauss (1967) wanted to demonstrate that actual *theory construction* was not confined to the work of elite academics; conducted in

lofty spheres far removed from the world of social processes and interactions (Charmaz, 2014). With the creation of grounded theory methodology, Glaser and Strauss (1967) aimed to provide “practical guidelines that would enable rigorous construction of theories relating to social processes from raw data” (Dunne, 2010, p. 112). Furthermore, as Charmaz (2014) explains, “*The Discovery of Grounded Theory* provided a powerful argument that legitimized qualitative research as a credible – and rigorous – methodological approach in its own right rather than simply a precursor for developing quantitative instruments” (p. 8). When it was first introduced, grounded theory addressed the perceived limitations of both quantitative and qualitative research.

In order to construct theory from the bottom up, Glaser and Strauss (1967) knew their methodology would need to be *inductive*, in contrast to the more traditional logical-*deductive* approach utilized primarily by quantitative research to “explicitly derive hypotheses from pre-existing theories, which fundamentally structure both the data collection and analysis toward verification or refutation of these hypotheses (and therefore, the theories from which they were derived)” (Charmaz, 1990, p. 1162). In grounded theory, rather than beginning with a preconceived problem or a hypothesis, research begins with ‘a topic’ (Brown, 2012). Through an iterative process of data collection and analysis, the researcher identifies the ‘research problem’; the issue that the participants are consistently discussing and defining. The researcher then develops a theory to explain the research problem and the patterns of behavior or social processes they are encountering in the interviews. Only at this stage is the researcher allowed to begin using a *deductive* approach to verify their evolving new theory with participants through ‘theoretical sampling’ techniques. However, until the researcher is ready to engage in theoretical sampling and test their developing theory, they must rely on induction; defined by Charmaz (2014) as “a type of reasoning that begins with [the] study of a range of individual cases and extrapolates patterns from them to form a conceptual category” (p. 343). Through application of an inductive approach, grounded theory circumvents the limitations of deductive research that is subordinate to pre-existing theories. As previously mentioned, the inductive approach of grounded theory is one of the components that attracted me to the methodology.

I needed a research methodology that would allow me to go beyond qualitative description, which is the aim of other methodologies such as phenomenology for example (Finlay, 2009; Hopkins, 1991; Manen, 1984). I wanted to be able to develop a theory to *explain* why my participants held varied and conflicting opinions about four particular types of spatially segregated environments and activities (i.e. special care homes, segregated education, Adult Service Centres and Special Olympics) Furthermore, how were they able to justify their opinions against and in favour of segregated environments and activities while still upholding social inclusion as the goal for people with intellectual disabilities? The combination of both the rigor *and* flexibility of grounded theory also drew me to the methodology. Grounded theory offers an array of systematic tools and guidelines that are designed to: support the researcher in analyzing *processes* that are occurring in a social reality and creating the ‘research problem’; explain the process(es) in original theoretical terms; and explicate the properties of the resulting theoretical categories (Charmaz, 2014). It is this explication of the properties of theoretical categories that constitutes theory construction. The explanatory theory presented in this thesis is not a concrete set of universally applicable statements that explain an objective external reality, but rather as a constructivist grounded theorist, I agree with Alasuutari (1996) and Charmaz (2014) that theories offer interpretive *frames* through which we can view multiple different social realities. Charmaz (2014) speaks to the power of engaging in theory construction:

A theory can alter your viewpoint and change your consciousness. Through it, you can see the world from a different vantage point and create new meanings of it... My preference for theorizing – and it is for theorizing, not theory – is unabashedly interpretive. Theorizing is a *practice*. It entails practical activities of engaging the world and of constructing abstract understandings about and within it. (p. 233)

Despite the systematic research process that a true grounded theory study entails, Charmaz (1990) notes that one of the major strengths of grounded theory is “its open-endedness and its flexibility” (p. 1168). Constructing theory does not need to be a “mechanical process” (Charmaz, 2014, p. 245). Charmaz (2014) invites researchers to step into the theoretical openings that grounded theory methods create and engage in

“theoretical playfulness” (p. 245). Researchers have the freedom to explore unexpected themes and issues that reoccur in the data, which can “lead grounded theorists in unanticipated directions” (Charmaz, 1990, p. 1162). My theorizing throughout this research process has indeed led me in unanticipated directions, and has altered my viewpoint and my understanding of social inclusion.

2.2.3 CONSTRUCTIVIST VERSUS OBJECTIVIST GROUNDED THEORY

When I first approached grounded theory literature to assess the appropriateness of the methodology for my study, I was confronted with a confusing array of literature. When Teik-Chow Loy (2011) decided to use grounded theory methods for his doctoral research, he admits that “sorting through the various versions of grounded theory was a challenging feat” (p. 49). Crossman, as cited by Charmaz (2014), believes that new grounded theory researchers should read widely on the topic of grounded theory application to understand the various perspectives, but she advises researchers to ensure that the various labels and versions do not hinder their progress just because they may be afraid of straying from an idealized version of grounded theory. The developers of the various versions of grounded theory may present their guidelines as rigid and inflexible; resistant to adaptation. However, Morse (2006) points out that once a research methodology enters the public domain it is rarely replicated with precise replication; rather it is “consciously or unconsciously tweaked, altered, adjusted, and improved” (p. 3). Grounded theory continues to be “an evolving methodology” (Dunne, 2010). This flexible and evolving status can be an advantage of the methodology and even lead to enhanced rigor, but Dunne (2010) emphasizes that grounded theory researchers still need to be “well-versed on the topic in order to take their own informed and defensible position on how to apply it” (p. 113). My aim in this chapter is to respond to Dunne’s (2010) admonishment by carefully outlining my reasons for choosing the methodological approach that I have.

My approach combines a *constructivist* grounded theory methodology, as outlined by Charmaz (2014), with the extension of grounded action, as developed by Simmons and Gregory (2003). The grounded action extension is not based on constructivist grounded theory, but is based on what Simmons (n.d.a.) refers to as ‘classical’ grounded theory; the original version that was created and is maintained by Glaser (1967; 2015).

However, after researching the literature thoroughly, I do not perceive this combination of Charmaz's constructivist grounded theory (2014) with Simmons and Gregory's grounded action (2003), as being problematic. Although Simmons (n.d.a.) has clearly stated in writing that he does not agree with Charmaz's (2014) constructivist version of grounded theory, in my assessment, the extension of grounded action can be appropriately combined with any version of grounded theory. Simmons (n.d.a.) himself admits:

If one's primary interest is in using sociological theory as a basis for practical action, at some point the rhetorical wrestle between objectivists and constructivists and who is which and to what extent becomes largely immaterial and even a waste of time... From a practical perspective, the objectivist / constructivist debate is an age old esoteric argument that will never be settled. (p. 8)

As suggested by Simmons (n.d.a.), my primary interest is to use the grounded explanatory theory I have developed as a basis for practical action.

Despite the perceived futility of endless theoretical and methodological debates, Charmaz (1990) recommends that grounded theorists still examine and explain their epistemological premise to their readers in order to "sharpen the research process and delineate the theory of reality to which the researcher subscribes" (p. 1171). Charmaz (2014) is one of the most well-known advocates for constructivist grounded theory; an approach that "views data as co-constructed with participants" (p. 235). According to Charmaz, it is an illusion to believe that the researcher can stand outside of the research process as a detached observer. She writes:

Rather, we are part of the world we study, the data we collect, and the analyses we produce. We construct our grounded theories through our past and present involvements and interactions with people, perspectives, and research practices. My approach explicitly assumes that any theoretical rendering offers an interpretative portrayal of the studied world, not an exact picture of it. (Charmaz, 2014, p. 17)

Charmaz (2014) rejects positivism; the idea of an objective external reality and the concept of an unbiased researcher as a passive and neutral observer who is able to

‘discover’ the a priori objective truth about an external reality. By adopting Charmaz’s approach I have by implication aligned myself with her ontological and epistemological position. Charmaz (2014) uses the term ‘constructivist’ to distinguish her approach from the ‘social constructionism’ approach used by sociologists in the 1980s and early 1990s; researchers whom she criticizes for not thoroughly acknowledging their subjectivity and for not engaging in reflexivity to discern their role in co-constructing the data.

In contrast to her constructivist approach, Charmaz (2014) perceives the original, or classical, version of grounded theory as being rooted in a positivist worldview that is most commonly found in quantitative research. According to Charmaz, objectivist grounded theory is consistent with a positivist paradigm in that it “attends to data as real in and of themselves and does not attend to the historical, social, and situated processes of their production” (p. 237). Simmons (n.d.a.), a proponent of the original version of grounded theory, rejects this classification of ‘objectivist grounded theory’. Simmons points out that just because classic grounded theory seeks to build and explicate theories from processes and patterns of human behavior, does not mean it assumes an “obdurate, objective reality independent of subjective realities” (p. 7). Although Simmons (n.d.a.) may protest the claim that classic, original grounded theory assumes an objective reality, Charmaz (2014) is at least more explicit and deliberate than classic grounded theorists with emphasizing the constructed nature of social reality. It is apparent that both authors have slightly misunderstood each other’s position. Simmons (n.d.a.) does not hold to an idea of an objective external reality as Charmaz (2014) seems to believe a classic grounded theorist would. Yet he still maintains that researchers should aim for the ideal of objectivity and that it is possible to minimize the interference of a researcher’s preconceptions without overemphasizing their role. Although Simmons (n.d.a.) criticized constructivist grounded theory for asserting otherwise, Charmaz does *not* believe a researcher should *purposefully* incorporate their own perspectives and knowledge; nor does she believe they should automatically apply preconceived concepts and categories to their data. However, she does insist that researchers are unavoidably “part of what they study, not separate from it” (Charmaz, 2014, p. 320). In the midst of these misunderstandings and legitimate differences, both Charmaz and Simmons believe that classifying grounded theory approaches according to concrete binary categories can be

confusing and likely inaccurate. Charmaz (2014) recommends that researchers view positivist and interpretivist approaches to theory as “located on a continuum”, rather than as “separate either/or definitions” (p. 228). While it may be possible to separate different approaches to grounded theory at an abstract level, in research practice, the boundaries between the different approaches are not as obvious. Charmaz believes that the process of *theorizing* “means being eclectic” (p. 259). She encourages researchers to utilize the flexibility of grounded theory by drawing on approaches and guidelines that work for their particular study and determining what fits best.

I have primarily aligned myself with Charmaz’s (2014) constructivist approach to grounded theory because I am highly cognizant of how my own perspectives, previous knowledge, and even my way of interacting with participants, inevitably shape the research process to some degree. Furthermore, the constructivist approach corresponds with my personal epistemological orientation. I also appreciate the flexible and open-minded approach to research that Charmaz describes. Despite this primary identification with constructivist theory, I have responded to Charmaz’s encouragement to use eclectic theorizing and have thus taken the liberty of extending my constructivist grounded theory using grounded action methodology as articulated by Simmons and Gregory (2003) who adhere to a classic / original grounded theory approach. I do not believe Simmons (n.d.a.) would strongly object to this eclectic combination because of his following statement:

In an action scenario, the real test of a theory is the extent to which it works for action. Actors in the social world who want to bring about constructive change have no investment in and usually no awareness of whether or not theories were developed with an underpinning of constructivist or objectivist ontological / epistemological assumptions. They only care if the theory is relevant to and will be useful in their efforts... adopting either a staunch constructivist or objectivist posture may make for an interesting philosophical debate, but in the end it has little impact on the real world... (p. 8)

I have combined constructivist grounded theory and grounded action methodology, because I believe the combination of these methodological approaches in my research process are capable of facilitating action in the social world while acknowledging the

inevitability of co-construction and encouraging continuous and transparent researcher reflexivity.

2.2.4 APPLYING GROUNDED ACTION METHODS

After developing my grounded ‘explanatory’ theory, I returned to the action problem (i.e. the lack of significant progress with achieving social inclusion for people with intellectual disabilities in Nova Scotia) duly prepared and ready to make a theoretical prediction and create the operational theory. My operational theory predicts that if all three of the paired concepts of social inclusion outlined by the explanatory theory (i.e. respect and equality; opportunities and self-determination; friendship and belonging) are simultaneously prioritized and addressed together when making policy and programming decisions, it is more probable that a consensus around the definition of social inclusion can be achieved, which in turn, will support progress toward facilitating social inclusion for people with intellectual disabilities in Nova Scotia. The action plan in Chapter Eight is the roadmap for applying this operational theory. I chose to utilize grounded action methodology, as an extension of grounded theory, because I wanted to apply my research results and theory to current social and political dilemmas related to social inclusion for people with intellectual disabilities in order to create change.

Unfortunately grounded action methodology has not been utilized frequently by researchers since its inception in 2003. In 2006, Stillman wrote that the methodology is still emergent and “its practitioners have only begun to explore its infinite potential” (p. 503). In my recent assessment of grounded action literature, I found limited evidence of its application, which at first made me hesitant to adopt the method. One of the few thorough uses of grounded action I discovered was described in Olson’s (2008) grounded action study that explored how adults achieved literacy in the adult learning education program where Olson taught. As a teacher in the program that he was also researching, Olson was capable of applying *all* of the grounded action steps described by Simmons and Gregory (2003). Olson (2008) attests that by using grounded action methodology to increase his capacity to support his students effectively, he “underwent a paradigm shift” and his “teaching methodology and pedagogy underwent profound transformation” (p. 5). He claims that participants and other educators were also deeply impacted by his grounded action study and interventions. The theory that Olson (2008) developed and

implemented using grounded action “yielded reliable, predictable, and satisfying results where despair and frustration formerly reigned” (p. 5). This powerful example with significant outcomes bolstered my courage to apply a methodology that has been utilized so infrequently in the literature.

I believe the key reason why grounded action methods have not been utilized more often by researchers is that in order to fulfill all the steps of a grounded action study, it is necessary that the researchers are positioned in a way that they can implement and evaluate their action plan. For example, Simmons (n.d.b.) was able to apply grounded action in his role as a therapist and Olson (2008) applied grounded action in his role as a teacher. In another grounded action study, Vinke, Orhei and Bibu (2012) applied grounded action methods to improve the effectiveness of a management program at a business school in the Netherlands. They describe themselves as not only researchers, but also as “trainers and lecturers” in the program (Vinke, Orhei, & Bibu, 2012, p. 199). Therefore, they too were well positioned to implement their action plan. Unfortunately I am not positioned to implement the action plan myself, and therefore this grounded action study is incomplete. This study still remains, however, a completed *grounded theory* study. I have chosen to refer to it as a grounded action study because I have partially completed the steps required for grounded action – to the extent that I am capable of in my role as a student. I have not completed the fourth and fifth step of grounded action – ‘implementing the action plan’ and ‘transformative learning’ (Simmons, 2006). Yet I wanted to extend my explanatory grounded theory in order to at least develop an operational theory and action plan (grounded action steps two and three) with the hope that the action plan could be implemented, and the operational theory empirically tested, in the future.

2.3 POPULATION AND SAMPLE

I have chosen to focus my study on Nova Scotia because of the relevance of my topic for this province. As stated previously, Nova Scotia has the highest reported rates of disability in Canada (Statistics Canada, 2012). It is reported that almost one out of every five Nova Scotians, or 18.8% of the population aged 15 and over has a disability (Disabled Persons Commission, n.d.; Statistics Canada, 2012). This is significantly higher than the national average of 13.7 % (Statistics Canada, 2012). According to

researchers and advocates, social inclusion for people with intellectual disabilities has not progressed as quickly as hoped for in the province (Barken 2013; Devet, 2014; Encol & Orrell, 2013; Wicks 2010). Therefore, there is an evident need in Nova Scotia for research and action in the area of social inclusion for people with intellectual disabilities. Within this population I selected my participants using purposive sampling to ensure I was collecting data from a variety of participants in order to facilitate the emergence of a well-grounded and relevant theory. Purposive sampling is a type of *non-probability* sampling technique that involves strategically recruiting specific participants (see below), in contrast to ‘probability sampling’ where participants are random selected in a way that gives everyone an equal chance of being chosen for the study (Portney & Watkins, 2009). I began by planning to interview 15 participants, but in total I interviewed 19 individuals. As my theory began to emerge I started to utilize the grounded theory tool of *theoretical sampling*. Brown (2012) writes that “when using theoretical sampling, the researcher simultaneously collects, codes, and analyzes data and uses this ongoing process to determine what data to collect next and where to find them” (p. 255). As Brown did, I verified the theory I was developing through theoretical sampling and I used purposive sampling to identify participants whose experiences and perspectives would be most relevant to the evolving concepts and categories that were surfacing in my ongoing analysis. Consequently I interviewed four more individuals for a total of 19 interviews.

I did not apply a strict inclusion or exclusion criteria in this study, I wanted to interview people who had direct exposure to intellectual disability in some way – either because they lived with an intellectual disability, they were family or friend to someone with an intellectual disability, or their employment or volunteer work brought them in direct contact with someone living with an intellectual disability. This preference was based on the likelihood that these individuals would be better equipped to offer a perspective on the concepts and topics discussed in the interviews. However, if I had had the resources and the time to interview more participants, I would have been open to interviewing community members who were not in direct contact with someone with an intellectual disability. There is no consensus on how many interviews are necessary (i.e. how big the sample size should be) for grounded theory construction. Whereas other forms of qualitative research continue to collect data until saturation is reached and no

new information in the data is being discovered, grounded theory aims to saturate the researcher's "emergent categories and concepts" in order to make them robust enough for theory construction (Charmaz, 2014, p. 106). Theoretical saturation, as opposed to data saturation, is "the point at which no new conceptual insights are generated and the researcher has provided repeated evidence for his or her conceptual categories" (Brown, 2012, p. 256).

Reaching theoretical saturation is not, as Charmaz (2014) points out, "the same as witnessing repetition of the same events or stories" although it is often confused as such (p. 213). Because of the confusion around the term 'theoretical saturation' in grounded theory, Dey (1999) has suggested that 'theoretical sufficiency' is a more accurate term to describe the point where researchers have solidified their conceptual categories through theoretical sampling, and are ready to move on to the next step in theory construction. Because grounded theory does not aim to achieve detailed and rich 'description', nor the identification of empirical 'themes', it can establish a grounded theory with a relatively small sample size, provided the theory is not particularly complex and the findings are straight forward (Charmaz, 2014). If I had more time and resources for this study it would have been strengthened by continued theoretical sampling to verify and refine the theory's conceptual categories. However, with data collected from 19 participants I was able to establish a fully formed grounded theory and I witnessed strong indication that I was reaching theoretical sufficiency (or saturation).

Admittedly, due to the shifts in my research design that I discussed previously, a large number of my interviews were conducted with people connected to L'Arche communities. Eight of my 19 participants were connected to either L'Arche Halifax or L'Arche Homefires in Wolfville. From each of the two L'Arche communities I interviewed a core member with an intellectual disability, a L'Arche assistant, a L'Arche staff member in a leadership role, and a parent of a core member living at L'Arche. The two communities operate on the same model, but they have a few differences based on their unique histories. L'Arche Homefires was founded in 1981 and now owns five group homes in Wolfville, along with a store it operates and other workshops and facilitates. In contrast, L'Arche Halifax opened more recently in January 2010 and has only one group home. I initially chose these two communities as case examples for my original research

questions because due to their differences in both age and size, they would provide me with an opportunity to analyze the L'Arche model at different levels of development.

All of my interviewees contributed a unique perspective to my research. I interviewed a government employee from the Nova Scotia Department of Community Services' SPD Program. This program is responsible for overseeing the majority of activities and policies of special care home agencies for people with intellectual disabilities. My interviews with representatives of People First Nova Scotia and the Nova Scotia Association for Community Living (NSACL) were selected because both of these organizations have been vocal in advocating for people with intellectual disabilities in Nova Scotia. In addition to my interviews with L'Arche assistants and staff members, I sought interviews with employees of special care home agencies in Nova Scotia that offer different types of continuing care services for people with intellectual disabilities. I interviewed two staff members from Regional Residential Services Society (RRSS) and two staff members from another agency that chose to remain anonymous (referred to in this thesis as 'a special care home agency'). I secured interviews with a staff representative from Best Buddies Canada, a program that facilitates friendships through the school and university system, between people with and without intellectual disabilities. I also interviewed a volunteer representative from Special Olympics, an employee of the Prescott Group, an Adult Service Centre for people with intellectual disabilities, as well as the manager of an employee with an intellectual disability at Stantec (a community-based employment setting). Although I did not interview anyone who was currently involved with inclusive or segregated education (one of the contentious categories that emerged), several participants had additional previous experience working in the school system and were able to speak to the debate around inclusive versus segregated education.

2.4 DATA COLLECTION

2.4.1 RECRUITMENT

I secured my eight interviews with individuals associated with two L'Arche communities by first contacting the directors of the two communities through email and phone. I explained my study and provided them with a letter of intent and a copy of the consent form. I also expressed my desire to interview someone in a leadership role, a

L'Arche assistant, as well as a core member³, and a family member of a core member. The L'Arche directors approached these individuals on my behalf to explain the study, to determine if they were interested in participating, and for permission to pass on their contact information to me so I could arrange with them a convenient interview time and location. In this way, the L'Arche directors were gatekeepers to interviewing other participants. However, based on the data collected, I do not believe their role in identifying and approaching potential participants had any detrimental impact on the variety and validity of the interview data. I made it clear to the directors that I did not want anyone to feel pressured in any way to participate in my research; particularly the core members. Everyone had the freedom and the right to refuse to participate.

With the exception of the community-based supervisor of an employee with an intellectual disability who worked at Stantec, I recruited the remainder my participants outside of L'Arche, by phone or by email after I located their contact information on their organization's website. As with L'Arche, I explained the study and sent them a letter along with a copy of the consent form to review in advance. If they were interested in participating we would then arrange for a convenient time and location for an interview. The community-based supervisor of an employee with an intellectual disability was recruited indirectly through Prescott Group (an Adult Service Centre) after I interviewed an employee there. One of their community employment services' counsellors approached one of their community employers to ask permission to forward their contact information to me. Once this permission was obtained, I followed up by phone and email to arrange the interview.

2.4.2 INTERVIEWING PARTICIPANTS

The interviews primarily occurred in a private office space at the participant's place of work, or in their home – wherever they were most comfortable. The majority of the interviews were conducted with only one individual at a time, but there were two dyads of participants that I interviewed at the same time. Being interviewed as a dyad was the choice of the participants. However, this form of interviewing proved to be productive as the participants built discussion around each other's interactions, which

³ In L'Arche communities the residents with intellectual disabilities are referred to as 'core members'.

offered new insights. On another occasion, when interviewing a person with an intellectual disability, the individual chose to have a support person in the room to assist him with understanding and communicating. The majority of interviews were about one hour, to one and a half hours long. Prior to the interview, all participants were forewarned that the interviews would be about one to two hours long and they were asked if they were comfortable being recorded with a digital audio recorder. Participants provided their signed consent to participate in the study and they were invited to ask me any questions they might have had about the research process. They were also informed that they were allowed to withdraw at any point during the interview itself, and up until four weeks following the interview, or up until two weeks after receiving a copy of the typed transcript to review if they had requested this opportunity on the consent form. The recorded interviews were then transcribed into Word documents in preparation for being coded and analyzed.

Although grounded theory adopts an open and relatively unstructured approach to interviewing that facilitates emergence, Charmaz (2014) recommends that researchers begin with a detailed, and yet flexible, interview guide. Without an interview guide and a list of questions or topics to cover, the researcher is at risk of “asking awkward, poorly timed, intrusive questions that [they] may fill with unexamined preconceptions” (p. 63). A good interview guide elicits important insights and perspectives from the participant without impeding the natural fluidity of the discussion. Following this advice, I began with a semi-structured interview guide, but maintained flexibility throughout by allowing the interview with the participant to develop naturally in different directions. As concepts and categories began to emerge, I revised the interview guide as needed, by removing and adding questions or topics as suggested by Charmaz (2014). Charmaz recommends utilizing what she refers to as ‘intensive interviewing’. She defines intensive interviewing as “a gently-guided, one-sided conversation” in contrast to the ‘standardized interviewing’ often used in quantitative research where the interview is wholly directed by the researcher with little flexibility because all the questions need to be asked the same way for consistency (p. 56). Charmaz also distinguishes intensive interviewing from other qualitative interviewing strategies that are ‘informational’ and ‘investigative’ in nature. Intensive interviewing is well suited to grounded theory methods because it is

“open-ended yet directed, shaped yet emergent, and paced yet unrestricted” (p. 85). As recommended by Charmaz, I followed up on unanticipated areas of inquiry that emerged in my interviews.

Although my original research design and methods evolved and I determined that my original *focus on L’Arche* was no longer relevant, I believe the eight interviews with participants associated with L’Arche communities continue to be a valuable contribution to this grounded theory study. In particular, I value these contributions because L’Arche communities place a strong emphasis on one of my paired social inclusion concepts; ‘friendship and belonging’. While these paired concepts emerged in all of my interviews to some extent, I appreciated the unique perspective of the L’Arche interviews which assisted me in explicating these concepts. During my data analysis the concept of friendship and belonging began to emerge with other participants as well. In an effort to engage in theoretical sampling and seek theoretical sufficiency, I interviewed an employee of Best Buddies in order to build on my understanding of friendship with people with intellectual disabilities. Since Special Olympics was emerging as a contentious topic in my interviews that I wanted to explore further, I continued my theoretical sampling by interviewing someone involved in Special Olympics in Halifax. Employment for people with intellectual disabilities, whether in a segregated or inclusive context, was also presenting as a contentious topic in my interviews, which prompted me to seek interviews with employees of Prescott Group and Stantec (see Section 2.3). I continuously evaluated the relevancy of my interview questions throughout this process and revised them as appropriate for different participants.

2.4.3 THEORETICAL SAMPLING

As previously mentioned, theoretical sampling is a strategy of grounded theory that is employed after theoretical and conceptual categories have begun to emerge. Theoretical sampling should not be mistaken for other types of research sampling such as sampling in order to reflect and represent population distributions, or ‘initial sampling’ which refers to the initial interviews and data collection that occur before analytic categories have emerged from the data (Charmaz, 2014). When the researcher is ready to begin theoretical sampling they revise their interview guide to focus data collection in the emerging areas as they gradually begin shifting from an inductive approach to a more

deductive, or even *abductive* approach in order to investigate and verify or refute their evolving new theory (Charmaz, 2014). Abduction is a type of creative reasoning that involves the researcher making inferences to explain surprising findings; creating imaginative hypotheses that can then be investigated and tested further by returning to empirical data collection and analysis (Charmaz, 2014). Grounded theory is iterative in that it involves simultaneously or cyclically moving between data collection and analysis. Theoretical sampling, consisting of deductive and abductive approaches, is the tool that bridges these two intertwined phases.

Following the emergence of tentative analytical and conceptual categories from my data, I began theoretical sampling by approaching four more people for interviews. Using abductive reasoning I made some conjectures about where I might find the data that would address the gaps in my theoretical categories. The four additional people I interviewed during this phase included individuals who were associated with Prescott Group, Best Buddies, Special Olympics, and community-based employment, as discussed previously. Sometimes, when they are doing theoretical sampling, researchers return to participants they have already interviewed in order to verify the developing theory (Charmaz, 2014). This did not occur during my study, but I did informally test my theory by analyzing other types of data in the form of academic literature, online blogs and newspapers, online chat forums and comments, promotional material from advocacy organizations, and my own observations. These forms of theoretical sampling and testing are supported by Glaser's (1998) well-known dictum, 'all is data'. Glaser (1998) states that grounded theory 'data' includes:

The briefest of comment to the lengthiest interview, written words in magazines, books and newspapers, documents, observations, biases of self and others, spurious variables or whatever else may come the researcher's way in his substantive area of research is data for grounded theory. (p. 8)

Luckerhoff and Guillemette (2011) also recommend that grounded theory researchers maintain an open mind when it comes to selecting data collection instruments for theoretical sampling and theory verification.

2.5 DATA ANALYSIS

2.5.1 CODING PHASES AND TECHNIQUES

The aim of data analysis in grounded theory research is to progress through four phases: theoretical plausibility, theoretical direction, theoretical centrality, and finally, theoretical adequacy (Charmaz, 2014). Ideas and relationships in the data begin to gain theoretical plausibility when they demonstrate that they can apply to multiple categories and across situations. Sometimes the researcher is alerted to the theoretical potential of an idea by even a single compelling quote that stands out (Charmaz, 2014). For me, I was alerted to a theoretical potential when I became so intrigued by the tensions I was discovering in the data. I was curious as to how and why these tensions existed. For example, how were people who professed commitment to the idea of social inclusion able to justify spatially segregated environments and activities? I began to investigate these tensions through the iterative process of analysis, data collection, and constant comparison. Eventually, using inductive, deductive, and abductive reasoning, I was able to form a hypothesis about why these tensions existed. A ‘theoretical direction’ began to emerge in my research process and my hypothesis gradually acquired ‘theoretical centrality’ after considerable analysis and more focused interviewing. Theoretical adequacy was established through theoretical sampling to ensure the robustness of the theoretical categories and their properties (Charmaz, 2014). If I had continued with my original research questions on L’Arche that I eventually dismissed, I may not have been open to the emergence of theoretical possibilities in the data. At each progressive step of my analysis I had the choice of whether or not to follow up on emerging ideas. A thorough analysis supported me in continuing to develop and raise emerging codes to “higher levels of abstraction” in order to produce a “dense grounded theory” that offers new insights (Charmaz, 2014, p. 204).

In order to successfully progress through the four phases described above, grounded theorists require ‘theoretical sensitivity’. Theoretical sensitivity is the “ability to sense the subtleties of the data” (Elliot & Higgins, 2012, p. 7) and to “understand and define phenomena in abstract terms and to demonstrate abstract relationships between studied phenomena” (Charmaz, 2014, p. 161). Skillful data coding contributes to the development of a researcher’s theoretical sensitivity. Through careful labelling,

categorizing and grouping of data fragments, implicit relationships and ideas can emerge as the researcher makes comparisons between coded segments. Using MAXQDA, a qualitative data analysis software program, I conducted ‘initial coding’ (also called ‘open coding’) by analyzing the data line-by-line and labeling every data segment with an appropriately descriptive gerund whenever possible. Charmaz (2014) strongly recommends coding the data with gerunds – “words that reflect action” and help you detect and study “processes” – rather than labels that are more static and topic oriented (p. 116; p. 124). Charmaz insists that utilizing *verbs* while coding can be very fruitful by facilitating theory construction through the analysis of human actions and social processes, rather than contributing to mere thematic description. Another essential strategy and skill for the grounded theorist, in addition to theoretical sensitivity, is the use of constant comparison. Through constantly comparing everything to each other – data fragments, whole interviews, categories and their properties, theoretical conceptualizations – I was able to observe the variations, similarities and differences (Charmaz, 2014). Constant comparison facilitates careful analysis and theory construction through identifying the many properties of emerging theoretical constructs.

Following ‘initial coding’, I entered the focused and selective coding phase to raise the most significant and frequent codes and their associated relationships to more abstract and conceptual levels of analysis. Focused coding assists the researcher in synthesizing, integrating, and organizing larger portions of data (Charmaz, 2014). Some grounded theorists advocate for another third phase of coding referred to as ‘axial coding’ (Strauss & Corbin, 1998). Axial coding is a procedural and systematic way of delineating all the properties, dimensions, and subcategories, that have relationships to the ‘axis’ of a major category (Charmaz, 2014). Charmaz (2014) is critical of a formal application of axial coding because she believes it risks forcing an analytic frame on to the data, coercing the integration of codes, and restricting grounded theory emergence. In her research Charmaz developed subcategories and demonstrated the relationships between the subcategories and the central categories, but she emphasizes that her approach was different from axial coding because her strategy was “emergent” rather than dependent on procedural applications of coding frameworks (p. 148). Charmaz recommends that those who prefer flexible guidelines and can tolerate ambiguity, to avoid axial coding. I

followed this advice by refraining from formally applying axial coding. However, as can be seen in Table 1, by the end of my data analysis my grounded theory was constituted as such that it easily fit into a theoretical framework similar to frameworks developed through axial coding, and yet the framework was *emergent* in the data rather than applied to the data.

| Table 1 <i>Theoretical framework</i> | |
|--|---|
| <i>Theoretical components</i> | <i>Description</i> |
| Research phenomenon (i.e. the ‘research problem’ and associated processes): | Participants expressed varied and conflicting opinions about spatially segregated environments and activities even though they all believed that social inclusion for people with intellectual disabilities was a goal society should aim for. |
| Concepts that categorize the phenomenon: | <ul style="list-style-type: none"> • Respect and equality • Opportunities and self determination • Friendship and belonging • Social inclusion • Spatial segregation |
| Relationships between the concepts: | <p>‘Respect and equality’, ‘opportunities and self-determination’, ‘friendship and belonging’ are three paired concepts that I identified in the various descriptions and examples of social inclusion expressed by participants.</p> <p>The concept of spatial segregation (e.g. people with disabilities congregated with other people with disabilities and separated from people without disabilities) had a varied relationship to the concept of social inclusion in the data. Sometimes it appeared as the opposite of social inclusion and other times, it appeared in the data as supporting social inclusion. For example, Special Olympics is a segregated sporting organization that was perceived by some participants to be a regressive step away from social inclusion, while it was seen by others as supporting social inclusion through the development of friendships and increased confidence.</p> |

| | |
|--|--|
| <p>Conditions under which the phenomenon emerges:</p> | <p>The phenomenon emerged when the following segregated environments or activities (and their alternatives) were discussed:</p> <ol style="list-style-type: none"> 1. Special care homes / alternative community-based living arrangements 2. Segregated education / inclusive education 3. Adult Service Centres / mainstream employment settings 4. Special Olympics / inclusive recreation and sports |
| <p>Cause of the phenomenon's emergence (i.e. the explanatory theory):</p> | <p>The cause of the phenomenon's emergence was that the participants were narrowly justifying their various opinions on the aforementioned topics by prioritizing one, two, or three of the paired concepts of social inclusion, while other participants prioritized a different set of defining concepts.</p> |
| <p>Consequences of the phenomenon:</p> | <p>The consequence of the phenomenon's emergence is that the lack of clarity and consensus around the meaning of social inclusion impedes progress in facilitating social inclusion for people with intellectual disabilities in Nova Scotia.</p> |
| <p>Framework for making predictions (i.e. the operational theory):</p> | <p>If all three of the paired concepts of social inclusion are simultaneously addressed and applied <i>holistically</i> when making policy and programming decisions, it is more likely a consensus around the definition of social inclusion can be achieved, which in turn, will support progress toward facilitating social inclusion for people with intellectual disabilities in Nova Scotia.</p> |

Table 1

Even when the formal procedure of axial coding is not used, there often is tension between “emergence and application” and a fine line between “interpreting data and imposing a pre-existing frame on it” (Charmaz, 2014, p. 151, p. 159). At all phases of coding there is the danger of theoretical *emergence* being co-opted and thwarted by pre-existing analytic frameworks, concepts and theories inherited from the researcher’s discipline, and the researcher’s own personal preconceptions. However, as a constructivist grounded theorist, Charmaz (2014) believes that to an extent this is inevitable because ultimately all codes, categories, and theories are co-constructed by the

researcher and the participants. She writes that although we may want to believe that our codes perfectly capture the empirical reality we are studying, it remains “our view: we choose the words that constitute our codes. Thus we define what we see as significant in the data and describe what we think is happening” (Charmaz, 2014, p. 115). I also retain this perspective as a constructivist grounded theorist, and yet I strive to minimize the interference of my preconceptions by practicing reflexivity. While being cognizant of the constructive and subjective nature of coding and constructing theories, Charmaz also reinforces what Glaser (1978) insisted upon; that all theoretical codes must be interrogated and “must earn their way” into the grounded theory (Charmaz, 2014, p. 153). She also advises that researchers avoid imposing forced frameworks on to the data, which axial coding can inadvertently encourage, and instead to allow the theoretical codes to “breathe through the analysis, not be applied to it” (Charmaz, 2014, p. 155). From the initial line-by-line coding to the more nuanced, focused and theoretical coding, fragmenting and reconnecting data in new ways enables researchers to gain new perspectives on their data. As Charmaz (2014) points out, “grounded theory coding is part work, but it is also part play” (p. 137). Rather than applying codes to the data in a rigid and procedural way, Charmaz (2014) advocates for a sense of theoretical playfulness which “allows us to try out ideas and see where they may lead” (p. 137). As has been already demonstrated by my description of some of the major design and methodological changes that occurred over the course of my research process, I embrace the open-mindedness, creative flexibility, and innovative potential that grounded theory offers.

2.5.2 WRITING MEMOS AND DRAFTS

Charmaz (2014) describes memo-writing as the “pivotal intermediate step between data collection and writing drafts of papers” in grounded theory (p. 162). Memos are notes that the researcher makes for themselves throughout the research process, using informal language for personal use (Charmaz, 2014). I recorded my memos in the data analysis software program I used (MAXQDA), as well as on paper using handwritten notes. Charmaz states that “writing successive memos throughout the research process keeps you involved in the analysis and helps you to increase the level of abstraction of your ideas” (Charmaz, 2014, p. 162). Memos can be used for a variety of purposes and

can include different types of information and reflections. Writing research memos in grounded theory is comparable to keeping a journal that records the process of theory construction by documenting what the researcher learns along the way. Incorporating regular memo-writing into the research process created the necessary informal space for me to describe and analyze the data, and engage in constant comparisons. Memo-writing was a key strategy that I used to catalyze the analysis process and facilitate theory construction. I also used memo-writing as a tool to record my “methodological dilemmas, directions and decisions” and to support my efforts to engage in reflexivity and monitor my preconceptions and their potential interference (Charmaz, 2014, p. 165).

When I was preparing to begin writing my first draft of my thesis, my collection of memos were essential to outlining the draft. In fact, both Charmaz (2014) and Glaser (2012) describe the process of writing the first draft as merely piecing together the various memos. Before writing Charmaz (2014) suggests that it is helpful to sort and organize the memos into different experimental arrangements, and to use various prewriting techniques such as diagramming the central concepts, processes, or categories on paper. I made many diagrams of my ideas by hand on paper, and I also developed a large diagram that encompassed all aspects of my grounded theory using Mindjet MindManager 9, a software program that facilitates brainstorming and the organization of freeform thinking using ‘mind maps’. As soon as theoretical adequacy and saturation is reached, and the document’s outline takes shape through a workable arrangement of sorted memos, Glaser (2012) advises that the researcher jump right into writing – even if the data collection is ongoing. Glaser believes that built into grounded theory methodology “is the readiness and moment to write a substantive theory”, and that the theory must be written “as it emerges” (p. 2). He warns that the moment of “readiness” when the theory should be written can easily be missed if the researcher is distracted by the requirement present in other forms of qualitative data analysis to achieve “full descriptive coverage” (p. 4), which can undermine the emergent grounded theory process. Aside from this grounded theory study, typically my writing process involves researching widely, and painstakingly creating a detailed outline before commencing the actual writing. When approaching the writing phase for this study I trusted in both Charmaz

(2014) and Glaser's (2012) description of the writing of drafts as being an extension of the analysis process. Charmaz (2014) writes:

The discovery process in grounded theory extends into the writing and rewriting stages. You will gain further insights and create more ideas about your data while you are writing. You will see clearer connections between categories and draw implications from them. Thus writing and rewriting become crucial phases of the *analytic* process. (p. 289)

I found this to be absolutely true. The first draft of this grounded theory study may have been the most disorganized first draft I have ever written. However, while immersed in the writing I was acutely aware that the process of writing was in itself, an analytic tool. As a result, the continued analytical work that occurred as I wrote the first draft catalyzed some significant changes to the thesis outline and the conceptual development of my grounded theory. Charmaz (2014) encourages grounded theorists to embrace the ambiguous process of writing up qualitative research and to trust in the emergent nature of the writing and analytic processes of grounded theory.

2.6 EVALUATING GROUNDED THEORY AND THE POTENTIAL FOR GENERALIZING THE RESULTS

Reliability and validity are common criteria used to evaluate quantitative research, but in qualitative research the relevance of these evaluative criteria is arguably less obvious (Bashir, Tanveer Afzal, & Azeem, 2008; Golafshani, 2003). However, I believe that the rigorous and systematic nature of grounded theory and grounded action support the researcher in achieving reliability and validity. I am explicitly transparent about my research process and demonstrate researcher reflexivity, which contributes to the validity, credibility, and trustworthiness of this study. The application of grounded theory strategies – such as the iterative process of data collection and analysis, constant comparative methods, memo-writing, and theoretical sampling – also all contribute to the study's validity. Furthermore, for those who had requested it, I mailed or emailed my participants their interview transcriptions to review with the option of revising or withdrawing any of the data they had provided to me. Incorporating this step into my research enabled me to seek confirmation that the data was an accurate representation of their views and opinions.

In terms of the criterion of reliability and the capacity of a study to be replicated and produce similar results, constructivist grounded theory (Charmaz 2014) asserts that data and theory are co-constructed between the participants and the researcher, and are thus localized to a particular context. Classic grounded theory, as articulated by Glaser (2014), is more confident of the potential to generalize grounded theory studies. Glaser (2014) argues that descriptive studies produced by other forms of qualitative data analysis do not obtain the same type of conceptual abstraction that grounded theory does, and thus they have limited applicability and generalizability – “they become stale data very quickly” (p. 49). In contrast, Glaser believes that grounded theory concepts are easily generalizable because they are abstract of time, place, and people. Similarly Raffanti (2005) states that the ability of grounded theory “to be generalized outside the initial unit of inquiry is a hallmark of grounded theory, setting the methodology apart from other naturalistic forms of inquiry that are descriptive rather than explanatory” (p. 74). Charmaz (2014) does not rule out the potential to generalize, but she insists that grounded theorists should not move too quickly in transitioning from the specific study embedded in a particular context, to generalizing at a broader level or across other substantive areas. As long as the grounded theory is rooted in a strong foundation of data and *gradually* moves to increasingly general levels with careful theorizing and additional data collection, generalizing grounded theories to other contexts is possible and permissible. Charmaz (2014) emphasizes that “generality emerges *from* the analytic process rather than as a prescribed goal *for* it” (p. 322).

I do not claim generality for this particular grounded theory study, but I believe the grounded theory of social inclusion that is explicated in this thesis has the potential to be verified in other locations (outside of Nova Scotia) and with other populations (other than people with intellectual disabilities). Generality cannot be claimed, however, until more data is collected and the explanatory and operational theories are tested in other substantive areas where it is apparent that the research or action problem defined in this study, is present. Furthermore, were these theories to be generalized to other areas, the categories related to the theory would need to be open to modification and revision when applied in new contexts (Charmaz, 2014). Similarly, with the extension of grounded action, Simmons and Gregory (2003) write that “although grounded action is generated in

a particular context for use in that context...it remains open to modification, application, and transformation in new settings” (p. 11). As previously mentioned, I have not completed the fourth and fifth steps of grounded action – ‘implementing the action plan’ and ‘transformative learning’, due to lack of resources and authority (Simmons, 2006). I wanted to extend my explanatory grounded theory in order to at least develop an operational theory and action plan with the hope that the action plan could be implemented, and the operational theory empirically tested, in the future. The operational theory would need to first be tested in the context of Nova Scotia with the action problem I am addressing, before being applied elsewhere.

2.7 ETHICAL CONSIDERATIONS

Dalhousie’s Social Sciences & Humanities Research Ethics Board approved this study in the fall of 2010, and again in the spring of 2011 when I submitted revisions following some of the changes I had made to my research design. The majority of participants provided me with permission, as indicated in the consent form, for the name of the organization they were associated with to be referenced, to be audio-recorded, and to be directly quoted in the thesis document. The exceptions to this were two participants of the same organization who declined to have the name of the organization referenced in the thesis document, and one participant who did not provided consent for their direct quotes to be incorporated into my thesis. In my consent forms I guaranteed my participants anonymity. In Appendix A I have included a list of all participants and their associated organizations when permitted. I have used first name pseudonyms for all participants. The first time I mention a participant in a paragraph, I will reference the organization they are associated with in parentheses, and then will omit this reference in repeated mentions within the same paragraph. When referencing lengthy organization names I will use the acronyms to represent the organization. Please refer to the abbreviation list at the beginning of this thesis or Appendix A to identify these acronyms.

There is a great deal of literature that discusses the challenges in ethically asking and obtaining informed consent from people with intellectual disabilities and I have reviewed this literature carefully (e.g. Cameron & Murphy, 2007; Griffin & Balandin, 2004; Lewis & Porter, 2004; Perry, 2004; Stalker, 1998). If the individual with the disability indicated they required assistance in reading the consent form, I read the

consent form out loud to them and explained any components of the form they may have been confused about. All three participants with intellectual disabilities were capable of providing signed consent. In one study on people with intellectual disabilities who had been diagnosed with cancer, researchers used a strategy called ‘process consent’ (Tuffrey-Wijne, Bernal, & Hollins, 2008). The researchers employed this strategy by continually observing the participant’s disposition and mannerisms in order to gauge if the participant seemed happy to interact with the researcher (Tuffrey-Wijne et al., 2008). If the participant showed signs of being uncomfortable with the interview process the researcher would bring the interview to a close, at least temporarily. In addition to the consent form that they signed, I also used ‘process consent’ throughout my interviews and I reminded them that they could end the interview if they desired to. I asked my interview questions in plain language as was necessary, to ensure that they understood what I was asking. Two of participants with disabilities I interviewed were able to respond to the questions independently without significant clarification. The third participant with an intellectual disability occasionally required the support of an assistant to understand the question or to communicate their response.

2.7.1 WHY THE MAJORITY OF PARTICIPANTS DO NOT HAVE INTELLECTUAL DISABILITIES

Among the 19 individuals I interviewed, only three of them lived with an intellectual disability. Two of these individuals were core members who lived in L’Arche communities, and the other individual was a representative of the self-advocacy organization; People First Nova Scotia. This may appear to be a disproportionate number for a study on social inclusion for people with intellectual disabilities. For example, when Abbott and McConkey (2006) undertook research on experiences of, and barriers to, social inclusion, they chose to only collect qualitative data from people with intellectual disabilities through focus groups. They made this methodological decision because they believed “the voice of the person with intellectual disability has often been missing from debates as to how greater social inclusion can become a reality for them” (Abbott & McConkey, 2006, p. 276). Abbott and McConkey (2006) have made a significant contribution to the literature with this micro-level study focused on individual experiences. The meso and macro levels, or the spheres of action where social inclusion /

exclusion occur, include the individual's immediate community and the broader societal structures respectively (Taket et al., 2009). Each of the three levels influences the others.

My study attempts to investigate social inclusion from the micro to the macro level by interviewing a diverse group of participants. Hall and Kearns (2001) suggest that although the agency of people with intellectual disabilities to facilitate their own social inclusion is certainly not negated, "the community's willingness to accept intellectually disabled people may be more important than any individual's capacity to seek out such acceptance" (p. 242). They point out that meso and macro level factors may be a "more potent determinant of inclusion" than individual agency in this situation (Halls & Kearns, 2001, p. 242). For example, if the people who are making, influencing, implementing and responding to programming and policy decisions have not reached a consensus regarding the meaning of social inclusion, its desired outcomes and how we should achieve these outcomes, then this remains a significant barrier to enacting social inclusion for people with intellectual disabilities. Therefore, because the aim of this study is to contribute to policy and programming change and a more inclusive province, interviewing people within all three spheres of action, the micro to the macro, was preferable in contrast to undertaking a study that focused solely on the perspectives and experiences of people with intellectual disabilities.

The other reason for the small number of participants with intellectual disabilities in this study is that many people with intellectual disabilities experience significant communication challenges that make it exceedingly difficult to engage with and interview them (Carlsson, Paterson, Scott-Findlay, Ehnfors, & Ehrenberg, 2007). Intellectual disability can range from 'mild' to 'profound' or 'severe'. I am highly cognizant of the fact that people with *profound* intellectual disabilities are rarely included as research participants (Kiernan, 1999; Koltz, 2004). Many people with profound intellectual disabilities cannot communicate through written or spoken words, or even symbols (Thurman, Jones, & Tarleton, 2005). They tend to communicate through more individualized and idiosyncratic behaviors and sound, which necessitates that in order to understand them, the researcher must engage in long-term field work to sensitize themselves to the individual's range of responses and learn how to discern the meaning of their responses (Koltz, 2004; Porter, Ouvry, Morgan, & Downs, 2001). Unfortunately I

did not have the time or resources to pursue this type of long-term fieldwork with this project and the three individuals with intellectual disabilities in my study would like be considered to have a *mild* or *moderate* disability. Yet, throughout the course of my research, during both data collecting and analysis, it was vitally important to me to consider how the grounded theory I was developing *might apply* to people with profound intellectual disabilities. Existing communication challenges should not be a reason to wholly exclude their needs and desires from research, but as Halls and Kearns (2001) point out, “their inclusion may need to be filtered through the views of family members, other caregivers, or service providers” (p. 243). I achieved this through my interviews with participants who cared and supported people with more profound intellectual disabilities.

I do not assume to have captured the perspectives of people with profound intellectual disabilities in this study, but neither do I believe that I would have been able to accurately include their voices if I had chosen to *only* interview people living with *mild* intellectual disabilities while excluding other community members. Kiernan (1999) points out that family members and caregivers may be just as capable as, or even more capable, than people with *mild or moderate* disabilities in speaking accurately on behalf of people with *profound* disabilities. I interviewed a wide variety of people that included family members of people with intellectual disabilities, service-providers, employers, volunteers, and three people with mild intellectual disabilities. As a non-disabled researcher researching within the disability field, I am aware that the decisions I made during the research process regarding the participation of people with intellectual disabilities relate to ongoing ethical issues. Historically, the voices of people with disabilities, particularly those with intellectual disabilities, have been excluded from objectifying research that was conducted ‘about’ them (Boxall, Carson, & Docherty, 2004; Charlton, 1998; Kiernan, 1999). I thoroughly appreciate, and I am keenly cognizant, of the risks of producing misguided research as a non-disabled researcher without substantial input from people with intellectual disabilities. However, at present, while recognizing the limited agency of many people with intellectual disabilities in Nova Scotia due to the social barriers they face, the aim of this study is to remove some of the programming and policy related barriers that are perpetuated by a lack of

consensus around the concept of social inclusion. Again, as Hall and Kearns (2001) point out, meso and macro level factors may be a “more potent determinant of inclusion” than individual agency in this situation (Halls & Kearns, 2001, p. 242). Therefore, I sought to engage a variety of community members in this research in addition to people with intellectual disabilities. Although I readily admit that a limitation of this study is its lack of participants with intellectual disabilities, I believe the results of the study, grounded firmly in data collected from a variety of participants, have significant potential to contribute to a more inclusive province.

CHAPTER 3: CONTEXTUALIZING ‘SOCIAL INCLUSION’

3.1 INTRODUCTION

In this chapter, I provide a comprehensive rationale for my study based on a thorough analysis of the literature. First, in Section 3.2, I demonstrate how people with intellectual disabilities have been subjected to a long history of social exclusion, which has had a detrimental impact on this population. This appalling historical trajectory highlights the necessity of moving toward social inclusion in order to increase the quality of life for people with intellectual disabilities. The institutions that housed people with intellectual disabilities began closing in the 1970s and many people have returned to their communities (Johnson, Walmsley, & Wolfe, 2010). Yet, as I point out in Section 3.2.3, people with intellectual disabilities often remain isolated and excluded even though they are in closer spatial proximity to other members of society (without disabilities) (Amado et al., 2013). This global phenomenon is related to the *action problem* I identified in Nova Scotia – despite the government’s stated intention to progress toward an inclusive society for all; in general, people with intellectual disabilities have not been effectively integrated into society to the extent hoped for by advocates (Barken 2013; Devet, 2014; Encol & Orrell, 2013; Wicks 2010). After commencing my grounded study, the *research problem* that emerged was that my participants had varied and conflicting opinions about four different types of *spatially segregated* environments and activities, even though they all believed that social inclusion for people with intellectual disabilities was a goal society should aim for. I also encountered a similar array of varied opinions in the literature – some authors spoke of the value and benefits of segregated environments (e.g. Hall, 2010), while some authors perceived these segregated environments and activities as regressing toward greater social exclusion (e.g. Gill, 2005). These opinions, presented in Section 3.3, confirm the importance of investigating these disagreements in order to seek clarity and consensus around the concept of social inclusion. However, I found that no other study has comprehensively examined the debates regarding the *four* different types of segregated environments and activities that I address in my research.

The process of deinstitutionalization and the efforts made toward inclusion have been guided by a progression of multiple theories – older theories are replaced by new theories when they are perceived to be outdated and no longer relevant. In Section 3.4, I

review, *and highlight the limitations of*, theories and approaches that have been integral to deinstitutionalization and the disability movement, such as normalization theory, social role valorization and the social model of disability (Nirje, 1969; Wolfensberger, 1998; Oliver, 1996). The concept of ‘social inclusion’ has been recently positioned to replace these theories and approaches as the newest theoretical tool that will be capable of propelling progress toward a higher quality of life and integration for people with intellectual disabilities (e.g. Cobigo et al., 2012). However, as will be discussed in Section 3.5, when academics have attempted to adopt the concept of social inclusion for use with people with intellectual disabilities, their definitions are often unclear, unduly influenced by outdated theories, or heavily weighted with value-laden ideas that they inherited from the original definition of social inclusion, which are not always beneficial or useful for this population (Cobigo et al., 2012). My research addresses this theoretical and practice deficit by advancing a definition of social inclusion for people with intellectual disabilities in Nova Scotia through my *operational theory* (see Chapter Eight). I believe my definition of social inclusion, based on the common values that emerged among my participants’ varied perspectives, is less narrow, inflexible, and value-laden than other definitions, and therefore, is potentially more relevant and useful.

Although this literature analysis chapter is positioned *before* my discussion of my data in this thesis document, in terms of my actual research process, an intensive literature analysis was undertaken only *after* my data had been collected, analyzed, and my grounded theory had been developed. Before commencing my data collection, I completed an *initial* literature review to orientate myself to the field (Luckerhoff & Guillemette, 2011), to develop theoretical sensitivity (Charmaz, 1990; Dunne, 2010), and to identify knowledge gaps in the literature (Dunne, 2010; Elliott & Higgins, 2012). However, only *after* my data collection and analysis was completed and the majority of my other chapters had been written, did I engage in a more intensive and thorough literature analysis. This is in accordance with the advice of many grounded theorists who recommend avoiding a thorough analysis of the literature until *after* the research is completed and the explanatory theory is developed (Elliott & Higgins, 2012; Glaser, 1998). The expectation is that by delaying a thorough literature analysis this minimizes the researcher’s biases and preconceptions, which could otherwise interfere with data

analysis and theory development. Although I completed this literature analysis at the end of the research project, I have decided to present this in-depth literature analysis in Chapter Three *before* discussing my research results, because of its value in contextualizing the study for the reader (Dunne, 2010).

3.2 PEOPLE WITH INTELLECTUAL DISABILITIES: A LONG HISTORY OF BEING EXCLUDED

3.2.1 SPATIALLY EXCLUDED IN INSTITUTIONS

People with intellectual disabilities have long been perceived by society as humans whose lives have lesser value than others (Reinders, 2008). Yates (1999) used the term “devalued people” to refer to those who are “relegated to low social status”, “cast into subhuman and nonhuman roles” and denied their “personhood” (p. 135, 136). Goffman (1963) used the term “stigmatized” to refer to those possessing discrediting attributes that render them social outcasts. Throughout history, people with intellectual disabilities have often been perceived as devalued and stigmatized people. As referenced in the introduction to this thesis, before acquiring the label ‘people with intellectual disabilities’, they were classified as – idiots, imbeciles, feeble-minded persons, and moral imbeciles, according to Britain’s Mental Deficiency Act of 1913 (Mental Deficiency Act, 1913). These labels were reflective of society’s attitudes toward people with intellectual disabilities at the time (Reinders, 2008). The medical model, which has heavily influenced public opinion throughout history, defines disability exclusively as a medical ‘problem’ and frames disabled people as faulty, defective human beings (Brisenden, 1986). Within the medical model, people with disabilities are perceived only as their diagnosis; “as non-people with non-abilities; not as people who can construct a life out of... different abilities, but as helpless individuals who have to be forced into a life that is constructed for them” (Brisenden, 1986, p. 175). Brisenden (1986) blames the influence of the medical model for the exclusion of people with disabilities from all aspects of social life. Influenced by both the medical model and the eugenics movement, in an effort to ‘protect’ society from their perceived flaws and deficits and to ‘treat’ their ‘condition’, people with intellectual disabilities were often congregated together in institutions where they lived, segregated from the rest of society (Chappell, 1998; Joffe, 2010; Johnson et al., 2010).

Canada began opening its first institutions in the late 19th century. Parallel with these developments, governments often took additional eugenic action against people with intellectual disabilities: “By 1931, thirty-seven U.S. states had passed sterilization laws, with similar Acts passed in Alberta (in 1928) and British Columbia (1933)” (Neufeldt, 2003, p. 30). In addition to these injustices, the physical, sexual, and psychological abuse of the residents in institutions was rampant (Cambridge, 1999; Joffe, 2010; Williston, 1971). Although historically, institutions were typically large buildings that housed numerous people with intellectual disabilities, People First of Canada’s definition of an institution makes it clear that institutions are defined by more than their size:

An institution is any place in which people who have been labelled as having an intellectual disability are *isolated, segregated and/or congregated*. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and their day to day decisions. (n. d.b., para. 3)

Institutionalizing people with intellectual disabilities is a form of *spatial* exclusion. Authors such as Gabel et al. (2013) and Hall and Kearns (2001) argue that spatial exclusion and segregation of people with intellectual disabilities continues today in various forms, often under the guise of labels such as ‘special’ (e.g. ‘special education’). Although the majority of Canada’s large institutions have closed, there are some that remain – particularly in Nova Scotia (Barken, 2013), where unfortunately, abuse continues to be reported (e.g. Canadian Press, 2009; Canadian Press, 2011). This situation calls for immediate progress toward a more inclusive society where people are treated with the respect and equality they deserve.

3.2.2 DEINSTITUTIONALIZATION

In the past forty years there has been a significant shift in how society perceives people with disabilities, at both a national and international level (Roehrer Institute, 1996), and this has resulted in the closing of large institutional residential centers across Canada (Canadian Healthcare Association, 2009). Hennen (2006) reports that in the early 1970s there was “an increasing awareness that institutional placement was not the way for societies to manage this vulnerable population, that their quality of life could be better, that they should be integrated into general community life” (p.3). Deinstitutionalization

now constitutes “a policy goal in many western societies” (Overmars-Marx, Thomese, Verdonschot, & Meininger, 2014, p. 269). The shift toward deinstitutionalizing people with intellectual disabilities was catalyzed by several historical and theoretical developments. Historical developments include the end of World War II and the emergence of rehabilitation and community services for injured war veterans, as well as Canada’s transition to being a ‘welfare state’ and its provision of universal healthcare coverage (Neufeldt, 2003). Another major historical development that changed the way people perceived institutions and people with disabilities was the proliferation of social rights-based movements that occurred during the second half of the 20th century (Neufeldt, 2003; Driedger, 1989). In 1989, Driedger writes:

Many disabled people view their rights movement as the last in a long series of movements for rights – labor, blacks, colonized peoples, poor people, women – and now people with disabilities. Indeed, it appears that disabled people are some of the last people to be engaged in this historical sweep of the struggle for human rights. (p. 1)

Carried forward by a wave of other rights-based advocacy work, the 1980s were a period of great progress and achievement for people with disabilities (Neufeldt, 2003). In 1982, “Canada became the first industrialized country to include a constitutional clause according disabled people equality before and under the law and to equal protection and benefit of the law without discrimination” (Neufeldt, 2003, p. 59). These historical events began to shift the public perception of disability from being seen as “a health and service issue to one of citizenship and human rights” (Neufeldt, 2003, p. 58).

In addition to the historical events and developments described above, there were also theoretical developments that contributed to the deinstitutionalization of people with intellectual disabilities; primarily normalization theory and social role valorization (Johnson et al., 2010). Hennen (2006) states that “the adoption of ‘normalization’ as the rallying cry for the advocates of people with intellectual disabilities was the primary force behind the promotion and implementation of the deinstitutionalization process” (p. 18). Flynn and Lemay (1999) believe ‘normalization’ and its reincarnation as ‘social role valorization’ (SRV) to be “one of the most significant human-service reform movements of the last-quarter-century” (p. 4). Normalization/SRV provided the necessary theoretical

rationale to support the shift to community living for people with intellectual disabilities (Neufeldt, 2003). In institutions residents had very little agency and were subjected to abnormal patterns of day-to-day living that looked very different to the typical lifestyles led by most non-disabled people outside of institutions (Joffe, 2010). Acting on the basis of the normalization principles would require making available to everyone with intellectual disabilities “those patterns of life and conditions of everyday living that are as close as possible to, or indeed the same as, the regular circumstances and ways of life of their communities and culture” (Nirje, 1999, p. 17). SRV asserts that people assess and interact with other people according to their ‘position’ or ‘role’ in society and that these positions or roles can be either valued or devalued (Yates, 1999). SRV aims to shift the role of someone with a disability from being one that was devalued to one that is valued (Yates, 1999), thus supporting inclusion rather than exclusion and marginalization. Prompted by historical and theoretical developments, closing institutions and bringing people with intellectual disabilities back into the community has been a positive progression, and yet people with intellectual disabilities continue to be “among the most disadvantaged and socially excluded in society” (Bigby, 2012, p. 360). There is still work to be done in order to achieve social inclusion for this population.

3.2.3 OBTAINING COMMUNITY ‘PRESENCE’, BUT NOT ‘INCLUSION’

As a result of the deinstitutionalization movement, catalyzed by the aforementioned historical events as well as normalization/SRV theories, segregating and congregating people in institutions came to be perceived as the “antithesis” of what “is now seen as desirable” (Cummins & Lau, 2003, p. 145). Consequently, the more that people with intellectual disabilities *are visible and present* in their communities, the more *desirable* their lifestyle is perceived to be (Cummins & Lau, 2003, p. 146). As I will discuss in the next section (3.3), segregated environments, such as special education, sheltered employment, and any other environment where they are surrounded by people with similar disabilities, are often perceived to be *undesirable* in the same way that institutions are undesirable (Cummins & Lau, 2003). However, while the detrimental impacts of living in institutions are widely acknowledged (Cambridge, 1999; Hennen, 2006; Joffe, 2010; Williston, 1971), progressing toward more community-based, residential models has not been a seamless, problem free development. Johnson et al.

(2010) observe that the initial perception was that after people were released from institutions into the community, “magic would be wrought” and social inclusion would naturally occur (p. 93). Unfortunately, this premise was “deeply flawed” (Johnson et al., 2010, p. 93). Transitioning from an institutional approach to a community-based approach for people with disabilities is not simply a matter of logistics. In fact, “closing an institution is a complex process of social change” because it “represents a challenge to policy-makers, service providers and community developers” (Roehrer Institute, 1996, p.32). The current reality in the twenty-first century is that despite deinstitutionalization, people with intellectual disabilities continue to experience *social exclusion* (Bigby & Clement, 2009). Cushing (2002) points out that “real social and economic integration has eluded most ex-residents [of institutions]. Neglect and abuse have continued in their new locales but on a smaller, less detectable scale” (p. 65). Cushing criticizes the “overtly positive language of independence, community care, family values, and consumer choice” for obscuring the reality of social exclusion in this post-deinstitutionalization era (p. 65).

Following the closure of institutions it soon became obvious that simply achieving *physical presence* in a mainstream community environment, did not equate with, or naturally progress to, achieving genuine inclusion (Bigby, 2008; Bigby & Clement, 2009). The most widely cited *benefit* to achieving physical presence in the community is that it is a *necessary precursor to inclusion* (Bigby & Wiesel, 2011; Simplican, Leader, Kosciulek, & Leahy, 2015). Thorn, Pittman, Myers, and Slaughter (2009) acknowledge that “although simple presence in the community is not considered the gold standard, it was the preliminary implementation focus as it serves as the foundation for a larger community involvement continuum” (p. 895). Another cited benefit of simple presence is that when people with intellectual disabilities are physically present in their communities, non-disabled people have an opportunity to become more familiar with manifestations of cognitive difference, thereby quelling their “psychological unease” and potentially rendering them more welcoming to people with intellectual disabilities (Hall, 2010, p. 53). Unfortunately, people with intellectual disabilities often remain stalled at the level of ‘physical presence’ in the community, without ever

achieving true integration and community connectedness through inclusion (Johnson et al., 2010).

Johnson et al.'s (2010) writing, explores the philosophical question of 'the good life' and what 'the good life' means to a person with an intellectual disability. Furthermore they ask: what does social inclusion mean for someone with an intellectual disability? What would it look like? These are pertinent and vital questions to ask at a time with the majority of research in this area is focused on questions that are designed to be addressed using objective, quantitative measures (Amado et al., 2013; Bigby, 2012; Cummins & Lau, 2003). Bigby (2012) assessed common measurements of inclusion utilized in current research and found them to be limiting and inadequate. Bigby notes that empirical studies focused predominantly on two key elements: "the nature of personal networks such as size, relationships and frequency of contact, and the frequency a person left their home and places visited" (p. 369). Cummins and Lau (2003) provide a ranked list of what they found to be the most common variables measured in studies examining the social inclusion of people with intellectual disabilities. This list of variables includes "the *number* of activities undertaken within the community... the *number* or objective character of personal relationships... *frequency* of access to community resources... the *number* of leisure activities..." (Cummins & Lau, 2003, p. 152, emphasis added). This focus on measuring inclusion through the use of objective and quantitative scales unfortunately "creates a heavily biased literature which misrepresents community exposure as integration because it fails to address the realm of personal experience" (Cummins & Lau, 2003, p. 152). Cummins and Lau found an "almost exclusive orientation of the literature to *physical integration* within the general community of non-disabled people" (p. 145). The reliance on quantitative measures in this area of research can be partially blamed for the lack of progress toward social inclusion. A high quantitative score can disguise mere physical presence in the community and present it as full inclusion, thereby hiding the issues and barriers that need to be addressed.

Gradually it has become apparent to researchers that although people with intellectual disabilities may be now "*in* their communities, there was still a gap with people being *of* their communities... although people might physically live in a

community home or participate in community activities, they experience little sense of belonging and membership and few meaningful relationships with nondisabled community members” (Amado et al., 2013, p. 360). For example, Bigby and Clement’s (2009) study indicates that after leaving institutions and securing residential placements in communities, people with intellectual disabilities made trips outside their home with increased frequency, to a greater variety of locations, than they had when they lived in institutions. However, many of these public outings involved destinations, such as shopping centres and parks, or activities, such as bowling and swimming, where the individuals remained anonymous (Bigby & Clement, 2009, p. 34). Bigby and Clement (2009) observed that even though people with intellectual disabilities were physically closer to non-disabled people in these settings, the nature of the activities were “unlikely to lead to the formation of new friendships of even acquaintances with other community members” (p. 34). Cummins and Lau (2003) also point out that “simply bringing people together for some recreational purpose may not generate social connectedness” (p. 153). When there is opportunity for interaction with the non-disabled public in these community settings, Clement and Bigby (2009) note that it is “likely to be mundane, impersonal and fleeting, characterized at best by casual acquaintances rather than friendships” (p. 264). Despite this reality, the caregiving staff interviewed in Bigby and Clement’s (2009) study insisted that social inclusion occurred when their residents “conform to social norms, visit public facilities, use commercial outlets such as shops and restaurants, or participate in social groups established for people with disabilities that operated from a base in local communities” (p. 35). However, according to Thorn et al.’s (2009) levels of community involvement, these activities indicate mere ‘community presence’ rather than inclusion. Sherwin (2010) believes that through misuse and misapplication, the concept of social inclusion has been “co-opted” (p.87).

Cummins & Lau (2003) found it noteworthy that none of the studies they reviewed “measured the extent to which people *desire* community integration, or indeed the nature of the community into which people desire to integrate” (p. 152, emphasis added). The measurements that were used in the majority of the studies reviewed by Cummins and Lau, neglected to measure the more subjective and interpersonal aspects of social inclusion. Bigby (2012) asserts that physical presence or activity in the community

is “of little value unless referenced to an individual’s preferences” (p. 368). Policy developers, as well as service providers and researchers, are prone to utilizing a narrow definition of social inclusion for people with intellectual disabilities, because they are often preoccupied with “‘community inclusion’ *as an end in itself*” (Ramcharan, 2009, p. 19, emphasis added). This preoccupation may produce increased community presence and visible ‘lifestyle changes’ that can be *objectively measured*, but this approach rarely succeeds in having a significant impact on individual well-being (Cummins & Lau, 2003; Milner & Kelly, 2009; Ramcharan, 2009). Cummins and Lau (2003) point out that “the issue at hand is *not* whether people should be accommodated in institutions. That battle has been fought and won. The question now is *how to optimize the life quality of people living in community settings*” (p. 146, emphasis added).

Social inclusion is commonly included as one of the domains and indicators of quality of life (QOL) measures (Amado et al., 2013; Brown, Cobigo, & Taylor, 2015). Cummins and Lau (2003) point out that although it is implicitly assumed by service-providers and policy makers that an *increase* in community-based activities and community outings must always be objectively superior, this cannot be true for everyone’s quality of life. Cummins and Lau believe that the potential benefits of increased presence and visibility in the community will depend on multiple factors and in particular, the unique preferences and needs of the individuals themselves. Not only can increased community presence fail to be beneficial, but according to Cummins and Lau, it can even be *harmful*. For example, “a frenetic lifestyle of socially integrated activities would leave no time for other aspects of life” (Cummins and Lau, 2003, p. 149). In particular, increasing community exposure without the development of *meaningful social relationships* can be detrimental. Because many people with intellectual disabilities want to establish social relationships, but find this difficult (Amado et al., 2013; Bigby & Clement, 2009; Milner & Kelly, 2009), “the consequences of an overly enthusiastic program of integration for such people has more potential to be more stressful than beneficial” (Cummins & Lau, 2003, p. 145). Milner & Kelly (2009) also critique the policy lens that gauges quality of life by measuring the degree of visibility a person has within mainstream settings, in order to locate them along an “exclusion-inclusion continuum” that does not take into account interpersonal relationships (p.53). Therefore,

community presence or inclusion should not be pursued as “an end in itself” without consideration of the individual’s preferences and what is best for their overall wellbeing (Ramcharan, 2009, p. 19).

Inclusion, perceived ‘as an end in itself’, can be conveniently measured using quantitative scales, and in a cyclical fashion, high quantitative *outcomes* can reinforce the goal of inclusion *as an end in itself*. However, the focus of research needs to be re-centred on individual preferences using subjective, qualitative methods, framed within *a broader quality of life perspective*. Bigby (2012) urges research to move “beyond an approach that tends to equate social inclusion with simple counts of how many times a person goes out their front door to visit the community” (p. 369). It should be clear by now that simply closing institutions and securing increased community presence and exposure for people with intellectual disabilities has *not* resulted in genuine social inclusion. Community presence and exposure *alone* do not necessarily lead to a higher quality of life. This conclusion certainly does not indicate that we should return to more segregated options, but that we need a new approach to facilitating and building social inclusion. According to Amado et al. (2013) research has gradually been shifting away from a focus on physical integration and mere community presence/exposure, to a more genuine, deeper social inclusion. However, as I will continue to highlight in this chapter, there remains a need for qualitative research that probes subjective accounts of social inclusion framed within a broader quality of life discourse that seeks to achieve ‘the good life’ (Johnson et al., 2010) rather than community presence or inclusion *as an end in itself* (Ramcharan, 2009, p. 19). Martin & Cobigo (2011) state:

Until there is a clear understanding of what social inclusion is, there can be no ‘gold standard’ for its evaluation. Therefore, future studies need to focus on the development of a conceptual framework for understanding the many aspects of social inclusion, and then come to a consensus on the indicators that can be used to measure those aspects. (p. 281)

My qualitative research study seeks to contribute to the development of a conceptual framework or definition of social inclusion that is rooted in the responses of my participants and bypasses the trappings of physical integration versus social

connectedness debates and segregation versus inclusion arguments, by extending beyond them.

3.3 DIVERSE PERSPECTIVES ON SEGREGATED ENVIRONMENTS AND ACTIVITIES: BENEFICIAL OR REGRESSIVE?

The *research problem* that emerged in my grounded study was that my participants had varied and conflicting opinions about four different types of *spatially segregated* environments and activities, even though they all believed that social inclusion for people with intellectual disabilities was a goal society should aim for. My literature analysis demonstrated that this was a common global phenomenon. As stated earlier in this chapter, I encountered a similar array of varied opinions in the literature. The majority of authors perceived these segregated environments and activities as regressing toward greater social exclusion and they advocated for people with intellectual disabilities to be involved in mainstream, mixed-ability environments and activities (e.g. Gill, 2005). In the era of post-deinstitutionalization, there is a noticeable concern about being perceived as stating anything that might be interpreted as suggesting that we resurrect the age of institutionalization (e.g. Johnson et al., 2010, p. 729). However, some authors, such as Hall (2010), spoke of the value and benefits of segregated environments and called for them to be “reimagined as ‘safe havens’ and ‘oases’” (p. 52). Whereas belonging and friendship is not always found within mainstream environments, it is often more easily accessed in certain spatially segregated environments. Hall (2005) writes, “Within places of seeming exclusion – care homes and non-paid work – can be found spaces of inclusion, and within apparent contexts of inclusion – independent living and paid employment – exclusion is commonly experienced” (p. 113). The four different types of spatially segregated environments and activities that emerged most frequently in my interviews as contentious topics, included: special care homes, segregated education, Adult Service Centres, and Special Olympics. In this section I will provide a brief overview of the varied perspectives I found in the literature as related to these four segregated environments and activities.

3.3.1 DIVERSE PERSPECTIVES ON LIVING ENVIRONMENTS

The majority of the literature I reviewed criticized the congregate living model of group homes and institutional care. A 2006 study by the Canadian Mortgage and Housing

Corporation, asserts that “adults, including those with intellectual disabilities, usually want to live independently” (p. 2). Their research identified the independent living model, co-op type housing arrangements, home ownership, the L’Arche model, and living in a senior’s complex as “favoured housing models” (p. 3). Crawford’s (2008) literature review identified semi-independent living and supported living as best practice models for people with intellectual disabilities, whereas options like the ‘group home model’ were noted to be inadequate. Both semi-independent and supported living models involve the individual living in a home of their choosing, while receiving tailored and person-centred support services that are often provided from an external source unrelated to their housing situation and are controlled by the individual (Crawford, 2008). When Stancliffe and Keane (2000) conducted a comparative study of two matched groups of people with intellectual disabilities, one group living in a group home and the other, semi-independently, they found that people who lived semi-independently experienced better outcomes in certain areas. The more favourable outcomes for semi-independent living included: increased satisfaction with social lives; more frequent use of community facilities; more participation in domestic tasks; and a greater sense of empowerment. Stancliffe and Keane (2000) emphasized that the findings should not be interpreted as indicative that everyone who lives in a group home (with moderate to low support needs) “*must* live semi-independently”, but rather that they should have the “opportunity and support to live semi-independently *if they choose*” (p. 303). This position affirms Article 19 of the *United Nations’ Convention on the Rights of Persons with Disabilities* (ratified by Canada in 2010), which stipulates that “persons with disabilities have the opportunity to *choose* their place of residence and where and with whom they live on an equal basis with others and *are not obligated* to live in a particular living arrangement” (United Nations Human Rights, 2006, emphasis added).

LaVigna et al. (1994) write that although initially, small group homes were eagerly welcomed as a superior replacement to the state institution, now “group homes are considered passé” (p. 256). Despite the persistence of agencies in championing the group home model, LaVigna et al. believe that “the supported living service model now is seen as more capable of meeting consumer needs and having the potential of providing a better quality of life”, and that therefore, the outdated group home model should be

retired (p. 256). However, Clement and Bigby (2010) express explicit disagreement with this perspective. They argue that for pragmatic reasons, which include limited economic resources and the practical tasks of addressing the high care needs of people with *severe and profound* intellectual disabilities, congregate living in group home environments will, and should, remain part of the intellectual disability service landscape. For people with severe and profound intellectual disabilities, who are significantly limited in their ability to live independently; to communicate personal preferences; and choose their own lifestyle; Clement and Bigby argue that “‘supported living’ is not likely to be a guarantee of a better life” (p. 12). They blame underperforming service delivery for poor outcomes, and insist that *if* a group home is well-managed, it can achieve high quality outcomes for people with intellectual disabilities. Felce, Perry, and Kerr (2011) compare the quality of life and activity levels of adults with intellectual disabilities who live in their family home to those of people who live in supported accommodations beyond the family home. Although they present their results with caution, aware of the limitations of their quantitative activity scales in measuring quality of life, they indicate that people who remain in their family homes may have *fewer* opportunities for community activity and engagement – to be involved in “certain aspects of daily living” – than those who live in staffed and supported housing (Felce et al., 2011, p. 425). Oldman (2003) also presents a critique of how the independent living model is upheld as a ‘universal good’, and points out that not everyone desires to live independently in their own homes. Finally, Barken (2013) discusses divergent attitudes among implicated community members in Nova Scotia “regarding the purpose and necessity of institutions, as well as policies and practices in community-based group homes” (p. 3). While some community members in Barken’s study believed that congregated institutional environments were beneficial for ‘rehabilitating’ people with intellectual disabilities or for providing ‘long-term care’ for those with severe disabilities, others indicated that rehabilitation was unnecessary and that a ‘long-term care’ perspective was inappropriate.

3.3.2 DIVERSE PERSPECTIVES ON EDUCATION

The Canadian Council on Learning (2007) indicates that in Canada, the majority of school-age children with disabilities attend school, and among this group, 87% attend regular schools (rather than specialized segregated schools). It is the new accepted norm

to include children with disabilities in classes with their non-disabled peers. This is in accordance with Article 24 of the *United Nation's Convention on the Rights of Persons with Disabilities* (2006), which indicates that people with disabilities should receive the necessary supports and reasonable accommodations *within* the general education system, and should not be excluded because of their disability. The vision of inclusive education has been heavily championed by the Canadian Association for Community Living (CACL). Porter, a contributor to CACL's Education Watch newsletter (2011), admits that unfortunately the *practice* of inclusive education is often inadequate and does not measure up to the theoretical vision of inclusive education. However, Porter (2011) believes there are plenty of examples of how inclusive education has been implemented successfully, and that full inclusive education *is* realistic, it is a right, and it is a worthy, necessary aim. Obiakor, Harris, Mutua, Rotatori, and Algozzine (2012) also admit that the *practicality* of full inclusive education is often debated. However, Obiakor et al. (2012) argue that while more reforms and supports are necessary, inclusion in the general education classroom "signifies that these students are not only members within the classroom and school community, but also are *valued* members within that community" (p. 487, emphasis added). The results of a comparative study conducted by Dessemontet, Bless, and Morin (2012), indicate that students with intellectual disabilities who were placed in general education classrooms experienced improved literacy skills in contrast to those who were segregated in special schools.

Unfortunately about one third of children with disabilities in Canada and their families experience difficulty accessing necessary aids, devices and other supports to enable them to take full advantage of educational opportunities (Canadian Council on Learning, 2007; Kohen, Uppal, Khan, & Visentin, n.d.). Several authors believe that the inclusive classroom can be improved upon by training teachers how to provide differentiated instruction that is responsive to all students' varying needs, and furthermore, by cultivating relationships, a sense of belonging and a supportive community in the classroom environment (Anderson, 2006; Bender, 2008; Prince & Hadwin, 2012). Other authors argue that even with improved supports, 'full inclusion' (having *all* students in the general education classroom throughout the entire duration of the school day) may be a radical, unrealistic, and unbeneficial option for some students

with disabilities (Borthwick-Duffy, Palmer, & Lane, 1996; Hornby, 1999). Hornby (1999) believes that inclusion into general classrooms *or* segregation into special classes is only defensible if it fulfills what he perceives to be the two essential rights of all students: “the right to an appropriate education and the right to be fully integrated into the community to which they belong when they are adults” (p. 157). Facilitating these rights for some children *may* involve receiving tailored supports in a segregated classroom in order that they may be better able to maximize their inclusion into the broader society when they graduate (Hornby, 1999). Rimland (1995), the parent of an autistic child, writes that inclusive education in the general classroom may be right for *some* children, but not for all – including his own son who has thrived in special segregated classes while receiving specialized and tailored instruction. Rimland disagrees with those who believe that full inclusion and mainstreaming (for children with disabilities) should be the *only* option, and that it is universally *the right choice for everyone*. Zwaagstra, Clifton, and Long (2010) also criticize the way that the principle of full inclusion has been uncritically applied as a “reigning ideology”, “prescriptive norm”, and “misplaced egalitarianism”, which ignores what is best for students and ignores “what is reasonable to expect from teachers” (p. 58, 55, 54). Zwaagstra et al. (2010) argue that “to ask classroom teachers to design and implement engaging and effective programs of instruction for twenty-five to thirty students with widely different levels of ability and performance... is more problematic than many administrators and parents seem to realize” (p. 54). Even with the help of teaching assistants they believe this request is unrealistic and that at least *some* students would benefit from receiving tailored supports in specialized classrooms for at least *a portion* of the day.

3.3.3 DIVERSE PERSPECTIVES ON WORK CONTEXTS

Among the perspectives regarding work environments, Gill (2005) makes a strong case against segregated ‘sheltered workshops’⁴. He refers to sheltered workshops as locations of “isolation and forced docility” where people with intellectual disabilities are

⁴ Sheltered workshops are spatially segregated spaces (often subsidized by the government) that operate on typically weekly work schedule and engage people with intellectual disabilities in simple tasks in exchange for a small monetary reimbursement. Segregated workshops are also referred to as vocational centres or Adult Service Centres (see Chapter Four for more information).

not only paid less than minimum wage, but are also cemented to “a lifelong servitude to the workshop” that has a “a built-in incentive to retain the most productive and dependable clients”, and thus discourages their potential transition to mainstream employment (Gill, 2005, p. 619, 613, 618). Kober and Eggleton’s (2005) study found that people working in mainstream open employment had a higher quality of life than those working in sheltered workshops. Cimera (2008) highlights the cost-effectiveness of providing supported (paid) employment in the community in contrast to subsidizing sheltered workshops, and Burge, Ouellette-Kuntz and Lysaght (2007) report that the majority of Canadian public appear to support integrated, mainstream employment opportunities for people with intellectual disabilities. However, there are also researchers who identify a lack of belonging, acceptance and reciprocal social relationships within mainstream employment environments for people with intellectual disabilities (Butcher & Wilton, 2008; Jahoda, Kemp, Riddell, & Banks, 2008; Lysaght, Cobigo, & Hamilton, 2012). Cohen Hall and Kramer (2009) point out that although community-based mainstream employment may not immediately increase a person’s social network; there are greater *opportunities* and *potential* for people to develop relationships in mainstream employment settings than in sheltered workshop environments, when they are provided with appropriate supports in this area.

Migliore et al.’s (2008) study investigates the reasons *why* individuals with intellectual disabilities continue to work within segregated sheltered workshops. According to individuals and their families, the reasons included: increased safety; reliable long-term placements; the ability to retain disability benefits; the social environment; and the opportunity to acquire work skills (Migliore et al., 2008). Although these are undeniable benefits, it is notable that among the survey participants nearly half of them reported that no one had even encouraged the individuals to find mainstream community-based employment beyond the workshop (Migliore et al., 2008). Butcher and Wilton (2008) also highlight how the decisions of mothers of youth with intellectual disabilities to place their children in sheltered workshop settings were “made in a context where more mainstream alternatives were not readily apparent” (p. 1086). Whitehead (1987) and Li (1998) both emphasize the need for sheltered workshops to support workers to transition to community-based employment if they desire to. This would

support their right “to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities” as enshrined in the *United Nations Convention on the Rights of Persons with Disabilities* (United Nations Human Rights, 2006, Article 27). However, several authors make an argument for spatially segregated work environments being a legitimate and potentially meaningful option for people with intellectual disabilities, rather than simply being a transitional space (Butcher & Wilton, 2008; Hall & Wilton, 2011; Hall, 2005). Hall and Wilton (2011) believe that “despite the importance of paid work as a route to social inclusion, mainstream employment in capitalistic economies continues to perpetuate the marginalization and oppression of disabled people” (p. 876). They argue that people with intellectual disabilities may have more success with achieving inclusion within “alternative spaces of employment”, such as sheltered workshops that are transformed into places that are at least partially run by people with disabilities (p. 872). Hall (2005) points out that although securing a paid job is commonly considered a key pathway to ‘social inclusion’ for people with intellectual disabilities, “the experience of [mainstream] work can be extremely variable – for some a positive inclusionary experience, for many a *difficult exclusionary combination of low-waged and low-skilled employment*” (p. 108, emphasis added). Arguably, according to the literature, the greatest benefits of the segregated sheltered workshops are the social relationships and acceptance by peers with disabilities (Butcher & Wilton, 2008; Cohen Hall & Kramer, 2009).

3.3.4 DIVERSE PERSPECTIVES ON SPECIAL OLYMPICS

Special Olympics provides sporting opportunities to athletes with intellectual disabilities. For over 45 years, Special Olympics Canada has been effectively acting on its mission, which is to: “enrich the lives of Canadians with an intellectual disability through sport” (Special Olympics Canada: Our Mission, n.d., para. 2). Special Olympics, on a global scale offers many different types of programming, but its primary programming is segregated – only people with intellectual disabilities are allowed to participate as athletes. In recent years Special Olympics has been subjected to criticism (Counsell & Agran, 2012; Storey, 2008). When Special Olympics Canada first launched in 1969, it likely would have been considered progressive, but Counsell and Agran (2012) argue that now Special Olympics’ “antiquated lifeworld view of people with

disabilities has largely resulted in outdated program practices... that run counter to today's emerging proactive lifeworld view of empowerment" (p. 253). Storey (2008) provides many points of criticism against Special Olympics regarding its outdated programming, reinforcement of negative stereotypes, paternalistic attitudes, and the lack of opportunity to choose another recreational option. Storey states that "like all segregated programs, the Special Olympics is unable to deliver important quality-of-life outcomes for people with severe disabilities and often diminishes the possibility of achieving those outcomes" (p. 140). Storey believes firmly that there is no point to trying to *reform* Special Olympics; rather it needs to be *replaced* with "integrated recreational services" (p. 140). Authors, such as DePauw and Doll-Tepper (2000), and Donnelly and Coakley (2002), speak to the benefits of integrated physical recreation and sports, and of the necessity to progress toward this inclusive goal. To move *away* from inclusive and integrated physical education, for example, would be a "step backward not only in terms of social justice and equity access for all but especially in terms of the international attention and forthcoming emphasis on physical education as a right of all" (DePauw & Doll-Tepper, p. 140).

In contrast, other authors and researchers praise Special Olympics as an organization for their progressive achievements and because of the way that their athletes have benefited from their involvement (Dykens & Cohen, 1996; Eidelman, 2011; Harada, Siperstein, Parker & Lenox, 2011; Ozer et al., 2012; Weiss, Diamond, Demark, & Lovald, 2003). Pedrinelli, Brandao, Shapiro, Fugita, and Gomes (2012) studied the motivations of athletes with intellectual disabilities involved in Special Olympics Brazil. They identified four key motivations to participate in Special Olympics: "1) to get ribbons and medals, 2) to play with other people from the team, 3) to go to new and different places, and 4) to feel like an important person" (p. 1005). Several of these motivations and benefits were reinforced in other literature. For example, Dykens and Cohen (1996) demonstrated how involvement in Special Olympics successfully improved social competence of the athletes and increased their self-esteem. Weiss et al. (2003) indicated that Special Olympics athletes developed a more positive perception of themselves, a sense of greater social acceptance, and increased self-worth through their involvement. Harada et al. (2011) also spoke to the capacity of Special Olympics to

improve self-esteem, social and physical competence, and to provide their athletes with “opportunities to develop social relationships with their teammates which often carry over into their lives off the playing field” (p. 1135). Harada et al. praise Special Olympics for providing athletes with intellectual disabilities with a “normative life experience” and comments that “the importance of Special Olympics is perhaps most salient in those communities where there may be few other services or opportunities for people with intellectual disabilities” (p. 1142).

Unlike Storey (2008) who advocates for *replacing* Special Olympics, Eidelman (2011) believes that “Special Olympics is a program we need now perhaps more than ever” (p. 403). In his article, Eidelman reviews a wide variety of diverse programs and projects that Special Olympics has launched, which extend far beyond its primary segregated programming. Eidelman commends Special Olympics for the depth of their leadership and for its progressive stance in “embracing new ideas and promoting the value of people with intellectual disability” (p. 405). One of Special Olympics most recently developed programs is ‘Youth Unified Sports’, which offers mixed-ability sporting opportunities that aims to bring people with and without disabilities together in an inclusive context (McConkey, Dowling, Hassan & Menke, 2013). Although this programming is not yet as widespread as Special Olympics’ segregated programming, research suggests that non-disabled youth have positive attitudes about such programming (Townsend & Hassall, 2007).

3.3.5 THIS STUDY ADDRESSES A GAP IN THE LITERATURE BY EXAMINING PERSPECTIVES ON ALL FOUR TOPICS

As these diverse perspectives demonstrate, moving forward toward social inclusion in the era of post-deinstitutionalization is complex. Hall (2005) writes that “far from being *absolute positions*, social inclusion and exclusion are fragmentary and *relational*, ‘entangled’ within each other in particular ways and in particular contexts” (p. 108). This describes the *research problem* I encountered in the data I collected from participants in Nova Scotia. Although other researchers have investigated the segregated environments and activities described above, I am not aware of any other study that has examined all four topics at once. Focusing on only one segregated or environment at a time conceivably could hinder a researcher’s ability to theorize beyond one example and

produce insights based on an analysis of the commonalities and differences among multiple types of spatially segregated environments and activities. By comprehensively investigating the varied perspectives on special care homes, segregated education, Adult Service Centres, and Special Olympics, this study addresses a gap in the literature by identifying the common values underlying the diverse opinions associated with all four of these segregated environments/ activities (see my explanatory theory, Chapters Five, Six, and Seven).

3.4 REACHING THE LIMITS OF WHAT WE CAN ACHIEVE WITH CURRENT THEORETICAL TOOLS

Underlying every policy, program, and individual attitude toward people with intellectual disabilities, are the particular values, cultural conceptions, theoretical models and ideologies that shape them (Prince, 2009; Reinders, 2008). As Shore and Wright (1997) point out, for example, no policy is “ideologically neutral” (p. 6). Despite being hidden beneath the guise of seemingly objective and logical-rational idioms, “policies codify social norms and values, and articulate fundamental organizing principles of society” (p. 7). Rioux and Valentine (2006) confirm that “theory *does* matter” when developing effective “laws, policies and practices” because theoretical concepts, although often latent, directly influence our ability to advance an inclusive society (p. 1). It is vital to examine and address detrimental or limiting ideologies and theoretical approaches to disability if we want to be able to move forward beyond ‘mere community presence’ toward inclusion. The impact of values, theories, and ideologies are more obvious when we look at those that support outdated models of service provision. Institutions, for example, as previously discussed, were founded on *eugenic theories* that promoted the idea that people with intellectual disabilities were morally dangerous and flawed – a risk to society (Johnson et al., 2010; Joffe, 2010). Therefore, isolating them against their will seemed like the rational decision that followed from this belief. The *medical model*, when applied to people with intellectual disabilities, framed them as humans with biomedical disadvantages and defects who needed to be treated, trained and taught how to contribute to society in some way (Brisenden, 1986; Joffe, 2010). The *personal tragedy* and *charity model* positioned people with intellectual disabilities as objects of pity; deserving of social protection, and yet not *entitled* to rights and resources as equal citizens (Swain &

French, 2000; Tsai & Ho, 2010). Although these theories and models may still shape policies and practice, they are generally considered to be outdated in the disability field and have been replaced by normalization/SRV theory and rights-based approaches as encapsulated in the social model (Hall & Kearns, 2001; Rioux & Valentine, 2006).

Normalization and SRV theory, which were first introduced in Section 3.2.2, represent two of the most dominant and well-known approaches within the disability field, particularly in regards to people with intellectual disabilities (Johnson et al., 2010, p. 67). Normalization/SRV developed specifically for people with this type of disability at a time when the majority were living in large institutions, and became the “rallying cry” of deinstitutionalization efforts (Hennen, 2006, p. 18). By helping people with intellectual disabilities increase their social value by changing their environments and societal contexts, adjusting their behaviors and appearance, and encouraging them to “engage in a constant process of self-regulation” (Tregaskis, 2004, p. 15), normalization/SRV aimed to change the way people relate to people with intellectual disabilities (Yates, 1999). The theories of normalization / SRV underlie the ‘readiness model’ (Kinsella, 1993), where people are expected to work toward ‘graduating’ to social inclusion. For example, Clement and Bigby (2009) found that staff members of a group home they studied, perceived their role as getting the residents [with intellectual disabilities] “‘ready’ for community participation in the distant future” (p. 270). This approach to facilitating inclusion is limiting and restrictive, particularly for those with more severe intellectual disabilities who may never ‘qualify’ for inclusion because they may not be able to demonstrate that they can meet or conform to the minimum expectations of normality that society demands. There is the assumption that by working on getting them ‘ready’, at some point in the distant future “people with intellectual disabilities will graduate to ‘real’ housing and ‘real lives’” (Ramcharan, 2009, p. 22). However, Ramacharan (2009) notes that “many people with intellectual disabilities never graduate. Instead they are caught in a lifetime of segregated services with the ‘promised land’ always that vital step away” (p. 22). Normalization / SRV theory, with its focus on establishing normal living conditions and normal behaviors to enable people to ‘fit in’ to society by adopting valued roles, lends its support to this ‘readiness model’ of social inclusion. Social role valorization (SRV), the closely-related offshoot of normalization

theory, aims to assist people with disabilities in adopting and developing valued roles in society (Wolfensberger, 1998). However, it is ultimately other society members who maintain the power to dictate what social roles will be 'valued' (Wolfensberger, 1998). Therefore, Cobigo et al. (2012) write that "conceptions of social inclusion generally reflect dominant societal values and lifestyles, leading to moralistic judgements if people reject or cannot achieve the dominant norms" (p. 79). Normalization / SRV, as theoretical resources, are clearly limited in their capability to facilitate radical social inclusion where 'difference' is deeply valued and respected and everyone is treated as an equal (Burt, 2007).

Normalization/SRV was followed by the development of the social model of disability. The social model of disability (which serves as the foundation of the 'sociology of disability' and 'disability studies'), has been described by Chappell (1997) as "one of the most significant intellectual and political developments of the last 10 years [1987-1997]. It has transformed the meaning of disability, at a personal, intellectual and political level, for many people" (p. 58). According to Oliver (1996), the social model asserts that while people with disabilities may live with certain impairments, it is not their bodies and minds that disable them, but society who *disables* and oppresses them by not providing appropriate services and accommodating their needs. The social model is grounded on the view of people with disabilities as full citizens who share equal rights with the rest of the population and are thus entitled to have societal barriers removed so that they can participate in society to the same degree as anyone else (Oliver, 1996). Oliver (1999) believes that normalization "as a social theory is inadequate" and insinuates that the motivations of Wolfensberger and Nirje (the original creators of normalization theory) are less than honorable by trying to make disabled people 'normal' (Oliver, 1999, p.170). Neither does Oliver place much value on social role valorization (SRV), the offshoot theory of normalization theory. He views the concept of SRV as having little potential to effectively contribute to the political materialist struggle for political change that he envisions as necessary to create a more inclusive society (Oliver, 1999). Prince (2009) seems to agree with him when he writes that "disability mainstreaming techniques" may serve as supplementary tools, but they will not "radically transform the role of the state" and "advance the inclusion of Canadians with disabilities"

(p. 109), which is what the social model aims to do. Not only does Oliver (1999) blame normalization/SRV for *prioritizing the value of social normality instead of diversity*, but he also argues that it fails to truly challenge the root causes of why people with intellectual disabilities are excluded in the first place – what he interprets to be oppressive societal barriers and discrimination.

However, similar to normalization/SRV, the social model of disability is also limited in its capacity to support the full inclusion of people with intellectual disabilities, despite being sometimes perceived as a progressive step forward from normalization theory (Chappell, 1997). Corker and Shakespeare (2002) argue that the social model “seeks to explain disability universally, and ends up creating totalizing, meta-historical narratives that exclude important dimensions of disabled people’s lives” (p. 15). In particular, the social model of disability has been accused of excluding people with intellectual disabilities, while focusing primarily on the concerns of people with physical and sensory impairments (e.g. Chappell, 1998; Chappell, Goodley, & Lawthom, 2001; Goodley, 2001; Rapley, 2004). Central to the social model, is the separation of impairment and disability (Race, Boxall, & Carson, 2005). While ‘impairment’ is still framed as a component of an individual’s condition, according to the social model a person is *disabled* not by their impairment, but by economic, political and cultural barriers in society (Race, Boxall, & Carson, 2005). However, social model theorists (e.g. Oliver, 1999) have been criticized for several reasons – one of which is their perceived dismissal of the *experience* of impairment, whether cognitive or physical (Race, Boxall, & Carson, 2005, p. 514). It also has been noted people with intellectual disabilities pose a dilemma for social model theorists who appear hesitant to attribute their limitations to societal barriers in the same way that they would with people with physical and sensory disabilities (Chappell, 1998; Rapley, 2004). When physical and sensory impairments are deconstructed and perceived as socially constructed, they can be framed, for example, as simply an example of human diversity that should be accommodated like all other types of diversity. In contrast, if cognitive impairments are perceived as essentialized, naturalized, ‘real’ impairments, then the danger is that it will still be possible to justify the continued exclusion of people with intellectual disabilities on these grounds (Goodley, 2001). In light of this risk, Goodley (2001) states that “the place of (some)

people with [intellectual disabilities] in the context of the social model of disability is decidedly shaky” (p. 213).

Race, Boxall, and Carson (2005) suggest that another reason why some social model theorists struggle to encompass people with intellectual disabilities within their model, is because the social model asserts that “individuals must transform themselves through collective action, not be transformed by others who know what’s best for them or what’s best for society” (Oliver, 1999, p. 170). However, those with profound intellectual disabilities may not be able to act independently, and “without the support of other people to ‘act on them’ or on their behalf, they may be ‘unable’ to transform their own lives or the society in which they live” (Race, Boxall, & Carson, 2005, p. 516). Although Reinders (2008) supports the continued use of the social model, he expresses concern that the potential inclusion of people with disabilities within the model is “entirely dependent on their capacity for self-representation and self-affirmation” (p.85). As a result, many people with intellectual disabilities (particularly profound disabilities) “remain marginalized within the broader disability political movement” (Hall, 2005, p. 113). Furthermore, as Reinders (2008) points out, “rights cannot open up spaces of intimacy, which are kinds of spaces where humans have their need for belonging fulfilled. Put simply, disability rights are not going to make me your friend” (p. 43). Studies have indicated that friendships between people with and without disabilities did not automatically increase after deinstitutionalization (e.g. Bigby, 2008), and yet many authors have spoken of the central value of friendship to people with intellectual disabilities and in facilitating inclusion (e.g. Milner & Kelly, 2009; Reinders, 2008; Thorn et al., 2009). Frazee (2005), for example, writes that in her research with youth with intellectual disabilities, her findings indicate that “friendship is the distinctive and defining feature of inclusion” (p. 111).

Johnson et al. (2010) have interpreted the past 35 years of the history of people with intellectual disabilities as occurring in three phases. The first they identify as being about normalization theory, deinstitutionalization, and community presence. They perceive the second phase as being about the social model of disability, rights-based advocacy, and person-centred planning. Finally, the third and current phase, according to

Johnson et al. (2010), emphasizes “the importance of personal relationships and emotional well-being” (p. 134). They write that

rights and citizenship [i.e. the social model] are argued to be necessary prerequisites, but not sufficient, for the development of meaningful relationships between people. Similarly, having varied and valued social roles [i.e. normalization/SRV] sets the scene for varied social relationships, but does not ensure friendship and belonging. (Johnson et al., 2010, p. 134).

Race et al. (2005) remind us that although normalization/SRV and the social model have their differences, “*both* approaches have *similar aims* in relation to people with learning difficulties – promoting, supporting and sustaining their inclusion in mainstream society” (p. 508, emphasis added). The overall goal continues to be ‘inclusion’, and yet neither approach has effectively facilitated an inclusive society for people with intellectual disabilities. Despite the historical achievements of normalization/SRV and the social model of disability, Cushing (2002) asserts that they are *both* ultimately limited in their ability to offer the public a vision of a truly inclusive society. To develop a strong theoretical foundation to support social change and move beyond mere community presence (Section 3.2.3), Culham (2003) believes that we need to challenge dominant disability theories and *deconstruct* them in order to rebuild what Corker and Shakespeare (2002) refer to as a “new theoretical toolbox” (p. 15). Unfortunately current debates and discussion regarding disability theory are “dominated by the binaries of institution/deinstitutionalization, isolation/integration and success/failure” (Hall & Kearns, 2001, p. 244). We need to move beyond simple dichotomous binaries to a more nuanced and sophisticated understanding in order to build a theoretical foundation that is capable of responding to the complexity of the current reality and understands “social inclusion and exclusion [as] fragmentary and *relational*, ‘entangled’ within each other in particular ways and in particular contexts” (Hall, 2005, p. 108). It has been one of the aims of this chapter and literature analysis to *deconstruct* dominant theories and models to prepare a clean slate for the following chapters that will contribute to the design of a new theoretical toolbox.

There has been a call among disability researchers “for new ways of thinking about social inclusion beyond those derived from normalization 30 years ago” (Bigby &

Wiesal, 2011, p. 264). Culham (2003) makes a strong argument that normalization / SRV has served its purpose in history by catalyzing the deinstitutionalization movement, but agrees with other critics of normalization theory (Mesibov, 1976; Shaddock & Zilber, 1991) that its use has expired. Johnson et al. (2010) argue that “institutions were not the only problem, nor is deinstitutionalization the only answer; and that *normalization/social role valorization and the social model may have taken us as far as they can*” (p. 82, emphasis added). Culham (2003) believes that it is now time to “embrace a new guiding philosophy that is not exclusive to people with an intellectual disability” (p. 72), and he argues that ‘social inclusion’ is well suited to this role. Prince (2009) points out that “social inclusion is a *flagship concept* in disability politics, associated with the active participation of persons with disabilities in all life domains” (p. 91, emphasis added). ‘Social inclusion’ has been framed as the theoretical successor of the twenty-first century; poised to replace older theoretical models and approaches to disability (Culham, 2003). These statements further validate the relevance and pertinence of studying the social inclusion of people with intellectual disabilities at this time in history.

3.5 RECENT EFFORTS TO DEFINE SOCIAL INCLUSION FOR PEOPLE WITH INTELLECTUAL DISABILITIES

There are three major challenges with utilizing the concept of social inclusion: 1) it has been shaped by dominant ideas that emphasize economic participation in the labour market and hegemonic social norms (Levitas, 2003; Peace, 2001); 2) when translated into a new context, social inclusion risks being merged with older outdated theories (e.g. normalization theory) (Culham; 2003); and 3) therefore, because of these external influences, the concept of social inclusion suffers from a lack of clarity within the disability field (Kendrick & Sullivan, 2009).

The concept of social exclusion first originated in France in the 1970s to promote social cohesion and solidarity at a time of turmoil, which threatened to undermine the state (Burchardt, Le Grand, & Piachaud, 2002). It was adopted in the policy discourse of the European Union in the 1980s because addressing ‘social exclusion’ seemed like a more palatable way to discuss ‘anti-poverty’ strategies with member states (Guildford, 2000; Peace, 2001; Rose, Caiches, & Potier, 2012). Finally, Britain’s Labour Government incorporated the term into policy documents in 1997 (Guildford, 2000).

Within Britain and the European Union, the emphasis was on transitioning people from exclusion to inclusion through employment and labour force attachment (Levitas, 2003; Peace, 2001). The concept of social inclusion was first championed in Canada and within the disability field in (primarily) the late 1990s and early 2000s (Sin & Chung Yan, 2003; Culham, 2003).

When the term ‘social inclusion’ entered disability field, it was accompanied by the concept’s historical focus on poverty and the labour market, as well as the concept’s traditional dismissal of power relations, diversity, and agency (Buckmaster & Thomas, 2009; Sherwin, 2010; Taket et al., 2009). Even beyond the disability field, the concept of social exclusion and inclusion has been criticized widely for its limited scope, and for its promotion of dominant societal values and lifestyles; a coercive set of standards and norms against which marginalized people are judged by (Buckmaster & Thomas 2009; Mitchell & Shillington, 2005; Pereira & Whiteford, 2013; Rose, Caiches, & Potier, 2012; Shakir, 2005). Socially excluded people (the targets of social inclusion policies) who *voluntarily* decline to abide by these societal norms risk being considered non-conforming social deviants whose exclusion is justified (Goffman, 1963; Peace, 2001). Therefore, people with intellectual disabilities who indicate a preference that goes against societal norms and values (such as choosing not to be employed or spending time with other people with disabilities) also risk this societal fate (Culham, 2003; Cummins & Lau, 2003; Johnson et al., 2010; Hall, 2005). Johnson et al. (2010) point out that within the dominant model of social inclusion, “inclusion is a one-way process – people with intellectual disabilities must travel into the communities of ordinary life, populated by non-disabled people... No one travels the other way” (p. 136). Cobigo et al. (2012) indicate that when social inclusion becomes an inflexible and narrow ideology that is “mainly defined as the acceptance and achievement of the dominant societal values and lifestyle”, it can result in harm for people with intellectual disabilities (p. 75).

Johnson et al. (2010) blame the influence of traditional understandings of social inclusion, for promoting an uncritical acceptance of ‘paid work’ as the ideal goal for people with intellectual disabilities within the disability field. Johnson et al. (2010) criticize this ideal goal as supporting “work on society’s terms”, as “a policy of insertion rather than inclusion”, and they question whether paid work as a policy goal, will

necessarily contribute to an increased quality of life for people with intellectual disabilities (p. 106). This is one example of how the historical and conceptual baggage of ‘social inclusion’ has impacted people with disabilities after it was adopted in the disability field. Long-standing theories in the disability field can also have a continued impact on shaping social inclusion approaches. For examples, Culham (2003) believes the legacy of normalization / SRV “has left practitioners thinking that difference is not something to be valued, while conformity is” (p. 71). This has led to promoting assimilation strategies and prescribed normality for people with intellectual disabilities (Culham, 2003). Cummins and Lau (2003) challenge their readers to reflect on who actually benefits from a social inclusion agenda that is measured by socially normative criterion. For example, they point out that policy makers and service providers benefit because they “can obtain satisfaction from knowing that they are successfully implementing the dominant philosophy” (p. 146). But what about people with intellectual disabilities – do they benefit? Simplican et al. (2015) argue,

Social inclusion is for all of us: an individual with an intellectual or developmental disability; for people with intellectual and developmental disabilities as a group; for members of society who will benefit from their inclusion; and for nation states who can benefit from the participation of people with all levels of abilities. If social inclusion is to accomplish all this, then we need a clear and accessible definition. (p. 22)

The advantages of using the concept of ‘social inclusion’ include its open-ended conceptual flexibility (Simplican et al., 2015) as well as its accepted legitimacy and familiarity in political, economic, social and academic realms (Cushing, 2003; Kendrick & Sullivan, 2009; Standing Senate Committee on Social Affairs, Science and Technology, 2013). However, the concept of social inclusion, as applied to people with intellectual disabilities, demands a clearer definition or else inclusive progress with this population will stagnate or regress due to a lack of conceptual consensus, or misguided direction (Clement & Bigby, 2009; Cobigo et al., 2012; Bigby & Fyffe, 2009; Kendrick & Sullivan, 2009; Martin & Cobigo, 2011).

3.6 THIS STUDY'S CONTRIBUTION TO THE THEORETICAL AND PRACTICE DEFICIT

In recent years, other academics in the disability field have identified the lack of conceptual clarity around social inclusion as an issue that needs to be addressed (Bigby & Fyffe, 2009; Cobigo et al., 2012; Hall, 2009). There are two definitions of social inclusion that are worth discussing here and contrasting with my definition. Both of these definitions were developed recently, specifically for people with intellectual disabilities. The first was developed after careful research by the MAPS research program in Ontario, which was launched to inform and guide the enactment of *Ontario's Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*, and in doing so, to reach "a consensus on the definition of social inclusion" (MAPS, n.d.a., para. 1). They have made progress on achieving their aim, and yet they emphasize that "further work is required to develop a consensus on the meaning of social inclusion and its measurement" (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012, p. 82). They recommend defining social inclusion as:

A series of complex interactions between environmental factors and personal characteristics that provide opportunities to:

- (1) Access public goods and services, [*opportunities*]
- (2) Experience valued and expected social roles of one's choosing based on his/her age, gender and culture, [*belonging, and self-determination?*]
- (3) Be recognized as a competent individual and trusted to perform social roles in the community [*respect and equality*]
- (4) Belong to a social network within which one receives and contributes support. [*friendship and belonging*] (Cobigo, 2012, p. 2, emphasis added)

In brackets and italics, I have highlighted where there appears to be some overlap between my definition and theirs. Their definition is more specific and concrete, and mine is more intangible and abstract. The importance of self-determination is referenced in the corresponding list of 'principles' that accompany social inclusion (Cobigo, 2012, p. 2), but I would have included the need for choice and self-determination more prominently and explicitly in the actual definition as a key component. I believe their definition is useful, and can be used alongside my definition. However, I argue that in

contrast to the MAPs definition, the intangible, abstract nature of the three paired concepts provides my definition of social inclusion with a greater flexibility and transferability to different contexts.

The second definition that is worthwhile to highlight is the *ecological model of social networks and community participation*, which was recently developed by researchers in the United States and Ireland (Simplican et al., 2015). Their definition focuses on the two interacting life domains of *interpersonal relationships* and *community participation*. Simplican et al. (2015) indicate that each domain has three characteristics, which they refer to as category, structure, and function or degree of involvement (Simplican et al., 2015). The characteristic of ‘category’ within the domain of ‘interpersonal relationships’ may include “family members, friends, staff members, partners, children, acquaintances” (Simplican et al., 2015, p. 23). The characteristic of ‘structure’ within the domain of ‘community participation’ may include “segregated, semi-segregated, and mainstream” (Simplican et al., 2015, p. 23). All domains and characteristics in their model are neutral; they can be either disabling or enabling. The benefit of this model is that it can be utilized alongside other definitions, such as the one I present, and is useful for highlighting a diverse range of contexts and situations that can be evaluated and targeted. Therefore, when contrasted with other recently developed definitions of social inclusion for people with intellectual disabilities, my definition of social inclusion either has a certain advantage, due to its intangible and abstract nature which lends a more holistic and balanced perspective, or it can be utilized in tandem with other definitions and models.

My research also has the potential to make a practical contribution to disability policy and programming in Nova Scotia. In June 2013, following extensive research and consultations, the NS Advisory Committee submitted a landmark document with recommendations to the Minister of Community Services who manages the province’s SPD program. The report is titled: *Choice, equality and good lives in inclusive communities: A roadmap for transforming the Nova Scotia Services to Persons with Disabilities Program*. It outlines a clear five year plan for the transformation of Nova Scotia’s disability services that is supported by many of Nova Scotia’s disability advocacy groups (Nova Scotia Hansard Reporting Services, 2014a). Unfortunately the

progress on these recommendations has been slower than hoped for (Devet, 2014; Nova Scotia Hansard Reporting Services, 2014b). However, this “roadmap” document remains a significant contribution to the development of a socially inclusive province. It is a straightforward guide that includes many specific and well-thought out recommendations that are organized according to three goals: 1) to increase people with disabilities’ self-direction, choice and control in life (e.g. through individualized funding mechanisms and supported decision making), 2) to modernize the delivery system of supports and services (e.g. reducing reliance on institutions and increasing access to community-based employment), and 3) to make generic community systems more inclusive to people with disabilities (e.g. equal access to housing) (NS Advisory Committee, 2013). In light of my definition of social inclusion, I believe the recommendations neglect the paired concepts of friendship and belonging while solely emphasizing the paired concepts of respect and equality, opportunities and self-determination. Furthermore, although the NS Advisory Committee’s (2013) efforts were guided by a foundational vision – “Nova Scotians will enjoy good lives of their choosing in inclusive and welcoming communities” (p. 1) – the report lacked an explicit and comprehensive definition of social inclusion. I believe the report contains many important recommendations that aim to remove barriers to opportunities for people with intellectual disabilities in Nova Scotia. I also believe the application of the recommendations would benefit from the definition of social inclusion that has been produced through my research. The action plan recommendations outlined in Chapter Eight are not intended to replace the recommendations in the roadmap document, but rather, to complement them.

I believe my definition of social inclusion, grounded in the common values that emerged among my participants’ varied perspectives, is less narrow and value-laden than other definitions, and therefore, is potentially more relevant and useful for people with intellectual disabilities in Nova Scotia. The definition of social inclusion presented in my operational theory is applicable, yet abstract enough, to avoid the limitations of socially normative, concrete and specific indicators that are influenced by outdated theories. Authors, such as Brown et al. (2015), Cobigo et al. (2012), and Johnson et al. (2010), indicate that in order to safeguard social inclusion efforts from being misguided and causing harm, they need to be applied within a quality of life framework that prioritizes

the person's own unique perception of 'the good life' and their psychological well-being. Based on the three paired concepts of respect and equality, opportunities and self-determination, and friendship and belonging, my definition of social inclusion is balanced, holistic and person-centred. Due to its abstract flexibility, the definition of social inclusion presented in this thesis can contribute to achieving individual well-being and quality of life for people with intellectual disabilities in Nova Scotia.

CHAPTER 4: THE RESEARCH PROBLEM

4.1 FOUR CONTENTIOUS TOPICS

The *research problem* that emerged during the data analysis, was that although all the research participants I interviewed expressed the belief that social inclusion for people with intellectual disabilities was a goal that we should aim for, they held varying opinions about what it should look like and how it should be brought about. The different perspectives held by the participants were most acutely apparent when four examples of segregated environments and activities (and their alternatives) were discussed during my interviews. These four examples are as follows: special care homes, segregated education, Adult Service Centres, and Special Olympics. In this chapter, I will explore each of these four contentious topics to demonstrate the various tensions and opposing viewpoints that emerged during my interviews. Sometimes participants expressed a perspective that differed from another participant's perspective, and other times the participants seemed internally conflicted with their own opinions in relation to each of the four topics. Whereas this chapter *describes the nature of the research problem* I discovered, the following chapters (Chapters Five, Six, and Seven) will explicate my explanatory theory and how I *resolve* the research problem. It should also be noted that when I reference an example of something a participant said as being either for or against a segregated environment or activity, it does not necessarily indicate that the participant firmly held this opinion, but the example highlights the diversity of perspectives and issues in relation to the four contentious topics.

4.2 SPECIAL CARE HOMES VERSUS ALTERNATIVE COMMUNITY-BASED LIVING ARRANGEMENTS

4.2.1 TERMINOLOGY AND DEFINITIONS

In this thesis, I will use the term 'special care homes' or 'homes for special care', as defined by Nova Scotia's Homes for Special Care Regulations (2012), to denote various types of homes and facilities where paid staff offer different types of care services to people with intellectual disabilities. Special care homes include small option homes (SOHs), group homes, residential care facilities (RCFs), adult residential centres (ARCs), and regional rehabilitation centres (RRCs) (Homes for Special Care Regulations, 2012; Nova Scotia Department of Community Services: Services for Persons with

Disabilities [NSDCSPD], n. d.). I have chosen to use the term ‘special care homes’ in the subsequent discussion because it is the only provincially legislated term that encompasses *the range of congregated living options available to people with intellectual disabilities*. RCFs, ARCs, and RRCs are residential options that house the largest numbers of residents in their facilities – these three different models are commonly referred to as ‘institutions’ (NS Advisory Committee, 2013; Wicks, 2010). However, it should be noted again that some groups, such as the People First of Canada advocacy group, do not define institutions merely by its size. The website of People First of Canada (n. d.b.) states:

An institution is any place in which people who have been labelled as having an intellectual disability are *isolated, segregated and/or congregated*. An institution is any place in which people do not have, or are *not allowed to exercise control over their lives* and their day to day decisions. (para. 3, emphasis added)

Regardless of their differences, all of the options denoted by the term ‘special care home’ imply a house or facility where people with intellectual disabilities are *congregated* together, rather than a home that offers a more typical residential arrangement (e.g. living independently in an apartment, living with friends of one’s choosing, living with family). It is debatable and dependent on multiple factors whether all the different types of special care homes can be considered institutions. I will clarify the differences between the various types of special care homes when necessary, but otherwise I will simply use the term ‘special care homes’ (or ‘homes for special care’) to refer to government funded and regulated congregated living arrangements. I will utilize the term ‘alternative community-based living arrangements’ to refer to living arrangements that resemble more typical homes lived in by the general public.

4.2.2 ARGUMENTS AGAINST LIVING IN SPECIAL CARE HOMES

Participants highlighted four key reasons why special care homes were not ideal living arrangements for people with intellectual disabilities, and were not capable of facilitating inclusion. These reasons referenced provincial zoning rules and a moratorium on building new small option homes (SOHs) as barriers to opening special care homes in family neighborhoods; a crisis-driven system and a shortage of vacancies in special care homes that forced people to live far away from family and friends; congregation and

isolation in special care homes that facilitated abuse; and a lack of autonomy in special care homes that could contribute to behavioral issues.

Peter (a special care home agency) described how the city's zoning rules prevent new homes for people with intellectual disabilities to be opened in typical residential neighborhoods. First of all, because of the moratorium on opening new SOHs, which house fewer than four people, residential service providers are forced to open special care homes that house four or more people. What makes the situation worse is that some city by-laws do not permit special care homes that house four or more persons to open in residential neighborhoods that are zoned R-1 (e.g. Halifax Regional Municipality's Dartmouth Land Use By-Law, 2014, section 22, 32). As a result of these policies, people with intellectual disabilities end up living in special care homes that are more likely to be located on the outskirts of the city, and they are less likely to live in typical family-oriented subdivisions and neighborhoods where there is greater potential for social inclusion. Peter emphasized that these zoning by-laws are not inclusive; they are a human rights issue. With the moratorium on new SOHs and restrictive zoning by-laws, special care homes can be limited in their capacity to even achieve 'community presence'; much less 'social inclusion' (Cummins & Lau, 2003; Thorn et al., 2009). This current reality stands as an argument *against* special care homes and their ability to facilitate inclusion.

Furthermore, according to Peter, because of the shortage of available vacancies in special care homes, people with intellectual disabilities are frequently admitted into facilities that are far away from their families in order to obtain the support they need. Sometimes this is a result of a crisis occurring, which the family is unprepared for (such as the death of parents). When a crisis occurs, people with intellectual disabilities may be abruptly placed in a distant special care home without consideration of their preferences. According to Allen (RRSS), unfortunately there are few transitional supports that ease the move from a family home to a special care home. This can make it difficult for the individual to adjust to the new situation. Of course, one of the alternatives to living in a group home is to continue living with family members (a community-based living arrangement). These views highlight how the special care home system, as it currently exists, works against social inclusion. When I asked Melissa (Best Buddies) how she envisions a 'social inclusion utopia', Melissa expressed that she wants to see more people

with disabilities being able to live with their families. Melissa acknowledged the support that people obtain in a special care home and she indicated that she understood how oftentimes families are unable to care for the person with a disability (even with the in-home supports offered by the government). However, ultimately Melissa would prefer to see familial relationships strengthened by people being able to remain in their communities and their family homes. Melissa perceives social inclusion through family relationships as being more likely flourish when people remain in the homes they grew up in, rather than in special care homes.

One of the central reasons why institutions have a bad reputation is because of the well-documented, rampant abuse that has occurred in institutional environments (e.g. Joffe, 2010; Canadian Press, 2009; Canadian Press, 2011; Williston, 1971). Kate (L'Arche) discussed a recent situation where a person with an intellectual disability had died in a large institution in Nova Scotia. Although the death was ruled accidental, she was deeply saddened by it and felt that the way the situation was handled made her feel that the client's life "didn't seem to hold a lot of value". She believed the death could have been easily prevented. Kate readily admitted that "abuse can happen anywhere". However, for her, it was *not* the size or the number of people living in a congregate facility; it was the *isolation* that enabled the abuse to happen. However, while ensuring that people with intellectual disabilities are not living in isolated areas mitigates the risk of abuse occurring, the *congregated settings* of special care homes can still potentially heighten the risk of abuse according to Donna (NSACL). The increased likelihood of abuse is an argument against the potential of special care homes to provide safe environments that support social inclusion.

Donna (NSACL) does not see there being any need for institutions. She described how institutional environments create difficult behaviors that are often blamed as the reason for why these individuals had to be put in institutions in the first place. However, she has witnessed a significant decrease in these behaviors when these individuals were living in the community and were able to exercise greater self-determination and autonomy in their lives. She told me:

A lot of people that came out of the institutions in New Brunswick a number of years ago had incredible behaviors and needed one-on-one support all the time,

but once they got their own bedroom and could go to the kitchen whenever they wanted – cause they wanted a piece of cheese or a glass of whatever – behaviors that were astronomically ridiculous, diminished... [In the institution] they would be in their forties and they'd have to be in bed at eight o'clock because that was the institution's rule. They're in their forties and they can watch TV – until midnight if they wish as long as they got up the next morning to do whatever [when living outside an institution].

Donna (NSACL) acknowledged that some people with a dual diagnosis (living with an intellectual disability in addition to a mental health issue) may need greater supports than other individuals, but she firmly believed that everyone should be able to live in communities, in a living arrangement of their choice, with the right supports. Institutions and congregated living situations tend to be predisposed to undermining people's autonomy and right to self-determination because of the strict rules they often enforce to 'manage' the larger numbers of residents. When autonomy is undermined and there is no viable way for people to control their own living situation and make choices, Donna argued that it was understandable that residents in special care homes may react with various physical behaviors and responses that may be interpreted as 'difficult'. The four arguments provided in this section highlight the issues with special care homes and how living in a special care home can interfere with social inclusion. Participants, such as Melissa (Best Buddies) and Donna (NSACL) argued instead for other alternative community-based living arrangements such as living with family or in an apartment of one's choosing.

4.2.3 ARGUMENTS IN FAVOUR OF LIVING IN SPECIAL CARE HOMES

In contrast, participants also stated four arguments *in favour* of special care homes and demonstrated how, despite being congregated and spatially segregated living environments, special care homes were not necessarily barriers to social inclusion and neither did they detract from quality of life. They argued that although special care homes are sometimes limited by government policies (e.g. zoning by-laws) many agencies strive to create comfortable and inclusive living environments. Participants also highlighted how some special care homes are able to encourage people's independence while still

offering access to necessary specialized services and care, and that furthermore, the congregated setting of special care homes can increase opportunities for socializing.

Allen (RRSS) told me of his desire to create safe, small, comfortable living environments for RRSS clients. His agency has been working on significantly downsizing their homes so that residents can have more privacy and personal space. The agency is moving toward ensuring private single bedrooms for all their clients, despite the economically-driven pressure from the government to fit as many people as possible into their homes. Service providers, such as L'Arche Halifax, have used creativity in order to prevent regulations and policies from negatively influencing the type of community and environment they want to cultivate. L'Arche Halifax decided to build an eight-bed group home that allowed them access to higher levels of funding, but they built the group home as two separate duplexes with an indoor connection in order to create a more home-like living environment with only four residents (plus their assistants) in each duplex. These examples indicate that although the agencies are currently providing congregated living environments to people with intellectual disabilities, many agencies have good intentions and are striving to provide a safe and comfortable home environment for their residents that will facilitate social inclusion.

Homes for special care are thus named because of the 'special care' and support they provide. Allen (RRSS) admitted, "we're a necessary evil I guess, to people who are much more dependent on our support - [those who are] saying I need you more. And trying to accommodate all of the philosophical issues that go along with that, [as well as] the practical issues. It's a constant dance I guess". Allen admitted that more intensive service provision, such as the services that are provided in special care homes, may be *necessary* for some people. However, as a service provider with progressive ideas about autonomy and independence, Allen referred to the work that they do as a *constant dance*; trying to provide just the right amount of support without undermining autonomy. Peter (a special care home agency) also admitted that "at the end of the day there are some people who may need that as an interim thing – they need that kind of support [as found in more institutionalized special care homes]". For Linda (NSDCS), even the most ideal, socially inclusive society does not preclude the existence of institutions and special care homes. Linda believed that "in a lot of situations that's what people need and want". She

recounted a story of a client who experienced psychosis, and lived in an institution. The client wrote her parents to tell them that living there made her feel “like a princess in a castle”. For this client, the structure, routine, and security in this controlled environment made her feel safe. Linda argued that at this point in time, with the client’s current condition, the ideal living situation for her was in an institutional environment. Implied in these statements is the belief that the intensive supports and services that are necessary for some people with high needs may not be readily available in alternative community-based living arrangements as they are in a special care homes. The views expressed here are in favour of special care homes because of the support they provide.

Another reason that people with intellectual disabilities leave their family homes and move into special care homes is to *gain independence*. Although Ann (L’Arche) had access to great supports for her son while he lived at home, she wanted him to have the opportunity to gain more life skills and become more independent. She believed this was more likely to happen in a special care home like L’Arche, rather than while her son was living at home. At RRSS, Lindsay and Allen told me about how they have created resident councils of about twenty client representatives in an effort to empower clients and provide them with greater authority within the agency. Allen was excited because through the council he has seen that “people are really discovering their voice”. Staff meet with the council about five times a year and discuss the agency operations and what they would like to do differently, as well as what sort of community outreach they would like to see. Allen was pleased to see members becoming bolder and more confident in stating that they do not like something or that they want to see change within RRSS. This holds the agency and the staff accountable to its clients. These are arguments in favour of special care homes because they identify potential benefits of these environments, such as opportunity for increased autonomy and independence.

Linda (NSDCS) highlighted that another *potential* benefit of moving away from the family home to live in a special care home is the increased opportunities for social interaction. Since special care homes are congregated living arrangements, there are multiple people sharing the same living space. For people with intellectual disabilities who remain living with their parents, it can be difficult for them as their parents grow older, and their extended family members move or pass away. Consequently their

network of family supports may dwindle and they may find themselves stuck at home with little stimulation, social interaction, or appropriate supports. Linda insisted that in addition to being able to learn life skills in a special care home, residents have access to plenty of opportunities to engage in recreation and social activities with other people that they may not have had when they were living with their family. Claire (L'Arche) told me that "one of the benefits of a group home setting is that we don't need to leave the home to have a social experience". The residents and their assistants still make many excursions outside the group home, but even when they are at home, there is an accessible social environment just outside their bedroom door where they can interact with peers and friends. While Claire acknowledged that living with a group of people is not for everyone and it can be difficult for some people, she highlighted the accessible social environment as one of the benefits of the congregated living environments of special care homes.

Jane (L'Arche) described how everyone in L'Arche ends up feeling like family and friends, rather than simply housemates, assistants, or clients. Ann (L'Arche) told me they always wished that their son had an extended family that he could spend time with, and now she feels that he has acquired that extended family by living at L'Arche. L'Arche communities are well known for their focus on building friendships and cultivating a sense of belonging and inclusion (e.g. Cushing & Lewis, 2002; Pottie & Sumarah, 2004; Vanier, 1997; Wolfensberger, 1973). Jane (L'Arche) enjoys her work at L'Arche because she does not think of her time there as a "work shift", but she experiences it as living together as a community; like a family. Jane argued that this focus on community living "brings a different feel to [a L'Arche] house", in contrast to other special care homes. Alison (L'Arche) said that unlike other special care homes, L'Arche places a big emphasis on being *with* core members and not doing things *for* them – doing things *together* within the context of a relationship. When I interviewed one of the core members (who had recently moved out of his family home), and asked him what he liked best about L'Arche, he quickly replied, "having more friends".

All the people I interviewed were familiar with L'Arche in some capacity. For example, Donna (NSACL) referenced the inspiration of Jean Vanier, the founder of L'Arche, and his vision of everyone living as equals within a community of

interdependent relationships. Chris (Special Olympics) referred to L'Arche communities as "truly inclusive". However, L'Arche certainly is not the only service provider to cultivate friendships among residents and staff. Linda (NSDCS) told me how staff members of one group home supported two clients in achieving their dream of going to Disney World. The staff team committed to raising funds for clients' trip, and then they decided to go *with* the clients (paying their own way) along with their own families. Linda knew of staff members of various agencies who will invite clients to their home outside of work hours for special occasions and holidays. This allows clients to interact with the staff person's extended family and broader network. After years go by, the client may begin to feel like they are a part of that extended family. Linda credited this phenomenon to the type of supervisor in each home and what sort of role modeling they provide. Increased autonomy and opportunities for social interaction, along with comfortable and inclusive living environments and access to specialized care services, are four *potential* benefits that make some special care homes an appealing living arrangement when contrasted with other community-based living arrangements, such as living independently or with family.

As a form of congregate living, can special care homes for people with intellectual disabilities contribute to social inclusion and an increased quality of life? Or do they prevent inclusive progress? It appears that based on the responses of my participants, special care homes can do either – it depends on a variety of factors. I have demonstrated how arguments against and in favour of special care homes can be justified in various different ways. What about alternative community-based living arrangements? Are more 'typical' living situations more capable of facilitating social inclusion and quality of life for people with intellectual disabilities if they are provided with the necessary supports? Jane (L'Arche) pointed out that even though living independently in your own apartment may be society's idea of success, it is possible for someone to live alone and be unhappy, lonely, and not experience social inclusion in their community. In Chapter Five, Six and Seven, I will use my explanatory theory to bring increased clarity to the concept of social inclusion and to offer a more insightful explanation of how my participants were able to justify their various arguments for and against special care homes.

4.3 SEGREGATED EDUCATION VERSUS INCLUSIVE EDUCATION

4.3.1 METHODOLOGICAL SCOPE, TERMINOLOGY AND DEFINITIONS

The topic of segregated or inclusive education was the second topic area that provoked differing opinions among my participants. Initially I was not planning to explore this topic because at the outset of this study I focused primarily on *adults* with intellectual disabilities and those who provided them with support and services. However, the topic of segregated and inclusive education began to emerge unprompted during my initial interviews. Therefore, utilizing the flexible approach of grounded action, I began to follow up on this emerging topic with successive interviews. No one I interviewed was *currently* involved in the grade school education system as either a student, or as a teacher or education program assistant (EPA). However, all of my participants had filled one or both of these roles at some point in their lives, and nearly all the participants had an opinion related to inclusive or segregated education for people with intellectual disabilities.

‘Inclusive education’ is generally understood as having children with intellectual disabilities spatially included in the same classroom among other children without disabilities, where they have access to the same educational programming and resources. Nova Scotia’s *Special Education Policy* (2008) defines the right to inclusive education as that which “embodies the beliefs, attitudes, and values that promote ‘the basic right of all students to receive appropriate and quality educational programming and services *in the company of their peers*’” (Nova Scotia Department of Education, 2008, p. 5, emphasis added). When children with disabilities are provided with a tailored education in separate classrooms away from children without disabilities, they are receiving ‘segregated education’. In this section I explore the arguments my participants provided both against and in favour of segregated education.

4.3.2 ARGUMENTS AGAINST SEGREGATED EDUCATION

Participants highlighted three key reasons why segregated education was not beneficial. Segregated education may prevent young people with disabilities from learning life skills and engaging in social interaction with a wide range of peers. Segregated education also limits the opportunities for youth *without* disabilities to be able to interact with their peers *with* disabilities, and as a consequence spatial segregation may

contribute to increased fear and prejudice toward people with disability. Finally, although there were identified issues with inclusive education *as it is practiced right now*; participants argued that it had great *potential* to be more fully inclusive *in the future*.

For Ann (L'Arche), inclusive education was not so much about the academic components that are taught in the school system, but rather it was more about learning life skills and engaging in social interaction with peers. She was thrilled that during her son's grade school education, everyone at the school knew him and was friendly with him. Although Ann expressed some hesitation about the extent to which someone with an intellectual disability should be in an inclusive classroom, she believed that at some point every day a young person with an intellectual disability should be with their peers in an integrated environment. Participants also identified long-term benefits to inclusive classrooms. The social interaction that occurs within an inclusive education system not only benefits students with intellectual disabilities, but it is also beneficial for students *without* disabilities. Chris (Special Olympics) emphasized that the youths who share classrooms with people with disabilities will eventually grow up and potentially be in positions to support social inclusion that is even broader in scope – as employers and community leaders, for example. Positive exposure and interaction with disability in grade school, has the power to influence their beliefs and perspectives about the potential of people with intellectual disabilities. Peter (a special care home agency), Claire (L'Arche), Linda (NSDCS), and Donna (NSACL) all expressed the hopeful belief that today's children and youth are growing up with less fear and prejudice toward people with intellectual disabilities because people with disabilities have a greater visible presence in their schools and communities than they have had in the past when segregation was the norm.

Despite some of the issues with the current state of inclusive education in Nova Scotia, Donna (NSACL) believed that inclusive education has a lot of improvement potential. She has worked with schools that are really dedicated to inclusive education and are willing to use a bit of creativity and problem-solving in order to fully include people with intellectual disabilities in different school activities. For example, whereas at some schools children are excluded from class trips unless one of their parents can accompany them, other schools are better at planning and accommodating so everyone

can be included without being dependent on the assistance of their parents (Donna). Although participants had many criticisms regarding the *current practice* of inclusive education in the province, like Donna, other participants also spoke to the *potential* of inclusive education for increasing social interaction, life skills, and confidence among people with intellectual disabilities, and for fostering more inclusive attitudes among their peers. Many participants wanted to see more effort invested into improving inclusive education, rather than a return to a completely segregated model of education.

4.3.3 ARGUMENTS IN FAVOUR SEGREGATED EDUCATION

However, participants also made arguments in favour of segregated education. The majority of the arguments in favour of segregated education consisted of the belief that it would be of greater long-term benefit for people with intellectual disabilities if they had access to specialized and tailored education that would adequately prepare them to act on realistic future opportunities – such as job skill training. Several participants pointed out that students with disabilities were a distraction to other students in inclusive classrooms if their behavior was disruptive. Participants also noted that young people with intellectual disabilities sometimes found greater acceptance among other students with similar disabilities in a segregated classroom, and that it could be difficult to graduate from an inclusive classroom only to watch nondisabled peers move forward in ways that were inaccessible to high school graduates with intellectual disabilities.

Jane (L'Arche) had an academic background in education. Although she was not currently practicing as a teacher, she aspired to return to teaching in the future. She described how the term 'inclusive education' was so prevalent throughout her teacher training and how it was presented as something that should never be questioned. During her teacher training she observed issues with the inclusive education model, but she never felt comfortable enough to question the model publically. Although there were EPAs in the classroom to provide extra support, Jane still believed that many of the students with intellectual disabilities would have benefited from being removed from the inclusive classroom setting, and instead, provided with specialized and tailored supports in a separate classroom. She ended up teaching a lot of kids who were placed in grade seven because of their age, and yet they were still doing grade two math sheets. For many of these kids it was unrealistic to expect them to academically progress to the point where

they could qualify for post-secondary education, and thus this continued persistence on teaching them advanced academic subjects seemed like a waste of their time. This was an argument in favour of segregated education.

Jane (L'Arche) believed inclusive education was more beneficial in elementary school to build confidence levels and increase social interaction, but in the older grades, although some students with intellectual disabilities would do just fine with an Individualized Program Plan⁵ (IPP) and an EPA, she observed that many young people required even greater supports to achieve their potential. She argued that it would be more helpful for these particular individuals to have access to the provision of an alternative education, even if only part-time, where they could develop the life skills and job skills that would assist them in securing suitable employment in the future. Jane believed that in the bigger picture, participating in an alternative, more individually tailored education program, would contribute to greater social inclusion that would extend beyond their time spent within the grade school education system:

It just struck me as so weird, so weird that [development centres / alternative special education] was seen as a thing to run in the opposite direction from because that's not inclusion. But it's really working towards a better inclusion for them in their lives. If they have more job skills and communication skills and these things that they're going to need to hopefully do their jobs, then they'll be included in society.

However, Jane was aware that expressing a preference for an alternative and spatially segregated education for people with intellectual disabilities outside the regular classroom setting was going against the common perception of progressive and inclusive education. She admitted:

If you speak out about it, well I would imagine in my head cause I never did, it seems like you'd be sounding like this really awful person that wants them in a separate classroom... but I think really to not acknowledge that these people are different and will learn in different ways, and that that's beautiful that they can be

⁵ “An IPP is a statement of annual individualized outcomes and specific individualized outcomes based on the student’s strengths and needs that is developed and implemented for every student for whom Nova Scotia’s public school programs curriculum outcomes are not applicable and/or attainable” (Nova Scotia Department of Education, 2006, p. 5)

contributing, as much contributing as we are, but possibly in a different way... just as valuable a way.

For those whose goal it is to secure employment, Allen (RRSS) expressed that the current education system with its primary focus on academics, was inadequate to prepare students for career opportunities. He believed that many people with intellectual disabilities have not had the opportunity to learn necessary job skills such as writing resumes, looking for employment, and going to interviews. Allen wanted to see people's education tailored to build on their strengths and to support their future goals – that is what he defined as inclusive education. Allison (L'Arche) expressed the same. While some people with intellectual disabilities have the capacity to pursue some form of higher education after high school, Allison told me, "I don't pretend to think that the majority of people could go to a regular community college or university". For Allison, people with intellectual disabilities will have a greater chance of experiencing increased social inclusion and success in pursuing their goals, if they are supported and trained to pursue future opportunities that they are capable of engaging in.

Claire (L'Arche) echoed many these opinions about inclusive education. She answered my question about inclusive education not as a spokesperson for L'Arche, but as someone who has had experience working as an EPA in the school system. She was not a proponent of an "all or nothing" approach where it is "100% inclusion or 100% segregation", but rather preferred an approach to education that is person-centred and is guided by questions such as: "What does this person require to be healthy and happy and educated to the best of their ability?" If an individual's needs can be met in an inclusive math classroom with other children, then as Claire said, "That's wonderful". However, if this is not meeting their needs, perhaps they should, for example, have physiotherapy or an alternative education class, as part of their school day instead of math class if that is what they need. As both a mother of someone with an intellectual disability and as a volunteer in the school system, Ann (L'Arche) was hesitant about the idea of people with intellectual disabilities being fully integrated because inclusive education may not be the best for them personally, and because of the disruption they can sometimes cause in the classroom for the teacher and other students.

Although some participants spoke positively about the opportunities for friendship and social interaction within an inclusive classroom setting, other participants questioned the benefits of social interaction in this context and perceived it to be limited. Linda (NSDCS) described how teachers may attempt to create inclusive environments in the classroom, but the child with the intellectual disability may still end up feeling excluded because their needs have not been fully taken into account. Linda pointed out that being in classes with other youth who can do things better than you, is “like a slap in the face” and can lead to being ridiculed. In contrast, Linda believed “if you went to a class with other kids who had similar issues, you might be able to stand out and be pro at something and get recognized for it”. She said that although inclusive education may look good from the outside, many of her clients have admitted that the shared classroom setting made it more difficult for them after high school when their peers graduated and went on to college or university and they were not able to do the same. Linda told me that many of her clients did not actually have a strong connection or friendship with the kids they went to school with, and if they were able to create friendships in the school system, they rarely persisted beyond high school. Linda said her clients have told her that “they would rather have gone to school with people like them so that they have an opportunity to develop friendships with people like them [with intellectual disabilities]”. Claire (L’Arche) and Ann (L’Arche) had also observed that whether or not youth with intellectual disabilities established friendship during grade school, after graduation those without disabilities sought out jobs, went away to university, or simply moved away. In contrast, the person with the disability is, as Claire stated, often “back home with mom and dad and they have nowhere to go” and as Kate (L’Arche) said, “in front of the TV”. These examples challenge the long-term benefits and sustainability of social interaction and friendships within the inclusive classroom setting.

In summary, I pose the question: does the current inclusive education model contribute to social inclusion? What does social inclusion mean for young people with intellectual disabilities in the school system? Participant perspectives on these questions were divergent. In Section 4.3.2, inclusive education was praised by some participants as increasing social interaction among people with intellectual disabilities and their peers. In Section 4.3.3, the benefits of social interaction within the inclusive education model were

seen as limited. Although many participants recognized that the *current practice* of inclusive education was not ideal, they believed it had great potential for improvement. However, many other participants indicated that a return to spatially segregated specialized classrooms was more beneficial – at least for a portion of the school day – for students with intellectual disabilities who needed additional supports, because it would contribute to their social inclusion in the long-term. In the next three chapters I will present my explanatory theory, which will explain further, how my research participants were able to justify divergent perspectives while maintaining a belief in the value of social inclusion.

4.4 ADULT SERVICE CENTRES VERSUS MAINSTREAM EMPLOYMENT

4.4.1 TERMINOLOGY AND DEFINITIONS

Adult Service Centres (ASCs) are segregated alternatives to community-based mainstream employment. ASCs reference both ‘vocational programs’ and ‘adult day programs’ (NSDCSSPD, 2008b). Both adult day programs and vocational programs (sometimes referred to as ‘sheltered workshops’), are government funded programs for people with (primarily) intellectual disabilities. ASCs are segregated environments where people with varying types of disabilities are congregated together and work at different tasks according to their ability. When participating in vocational programming members contribute to providing services and products to the public for a fee. For example, at the Prescott Group centre in Halifax, a member might work in the Fireside Kitchen to prepare food for Prescott’s catering business, or they might stuff envelopes for Prescott Mailing Services. ASCs typically operate according to a regular work week schedule, Monday through to Friday, and members are paid a small wage, or honorarium for their efforts (considerably less than the provincial minimum hourly wage). In the 1980’s and 1990’s, the number of ASCs increased in response to the closure of large institutions, because they provided a place for people with intellectual disabilities to go during the day (NSDCSSPD, 2008b). There are currently about 30 ASCs in Nova Scotia, funded by the SPD Program (Nova Scotia Joint Advisory Community-Government Committee, 2013).

4.4.2 ARGUMENTS AGAINST ADULT SERVICE CENTRES

Participants expressed six reasons why ASCs have a detrimental impact on the quality of life and social inclusion of people with intellectual disabilities. In contrast to

previous generations, the current generation of young people with intellectual disabilities (and their families) have higher expectations for their futures after they graduate from inclusive classrooms, which do not include working in ASCs. Participants referenced how mainstream employment provides the employed individual with a sense of pride and accomplishment, and also influences the members of the public who interact with them in these settings and can observe what they are capable of. They argued that even people with high support needs can engage in mainstream employment settings with the right supports in place, and how people with intellectual disabilities can make new friends through mainstream employment. ASCs were also criticized for discouraging people with intellectual disabilities from seeking mainstream employment.

Although it is still the norm for many young adults with intellectual disabilities to be placed in an ASC after they complete their education, this is gradually changing. Donna (NSACL) pointed out that because the younger generations have grown up experiencing inclusive education, both young adults with disabilities and their parents have higher expectations and may not want to follow the well-trodden route of applying for a placement at an ASC. Donna believed that many of this generation's young adults with disabilities want to be out in the community working. Even if they are only able to do part-time work a few hours a day - if it is meaningful work and they are getting paid for it, this can be satisfying for them (Donna). Donna emphasized that for younger parents in particular, an ASC is not part of their dream for their child's future. They want to see their children out in the community working.

Being employed in general, has great value for many people with intellectual disabilities, as it does for other members of society. Jane (L'Arche) pointed out that employment in the community benefits both the individual with the disability who feels pride in having a job to do, and the broader public who identifies them as a contributing member of society. Claire (L'Arche) said that in her experience "most people get a great sense of pride and accomplishment and satisfaction from knowing they have a job". She listed off many people she knew who had jobs in the community and how this allowed them to interact with and get to know more people. Allison (L'Arche) referred to people with intellectual disabilities as an "untapped resource". She believed that there are many jobs out there that they would be more than capable of doing in the community. Catherine

(Stantec) spoke highly of the strong work ethic of the employee with the intellectual disability whom she supervises. When I asked about the employee's dependability, she replied, "Oh my god yes, she's early normally... she doesn't like to miss work for anything". Edward (People First) also spoke to how dependable and motivated employees with disabilities are. He believed that they were "less likely to miss time off work due to sick days". Edward said that even if they cannot manage working a full 40-hour week, they are dedicated to working the hours assigned to them.

Even for those who need greater supports throughout the day, community-based employment can still be a viable option. Peter and Lorraine (a special care home agency) told me about a young client of theirs who has been really embraced by his co-workers at the retail outlet where he works. He is clearly considered an asset and has been working there for many years. This particular client has support staff who accompany him throughout the day while he works at his job. Peter credits the agency's wonderful support staff as part of the reason this employment situation has worked out so well. Peter told me that the support staff are involved with "laying the groundwork" and communicating with everyone at the place of employment. This contributes to everyone feeling more at ease and comfortable. According to Lorraine, "they don't do his job for him. They sort of stand back and support him if it's necessary". The support staff also have the opportunity while they are there, to demonstrate a respectful and appropriate way of interacting with the employee with the disability. Peter and Lorraine feel that this role-modeling "rubs off" on other employees.

Donna (NSACL) told me about someone she had known for many years in another province who had an intellectual disability and worked in an ASC as a wood worker. He was apparently one of the top producers at the centre and his wood working skills were excellent. However, he continuously expressed great interest in having a job in the community. The centre had outlined goals for him to work on each year. The centre decreed that if he achieved these goals he may be allowed to get a job in the community. One of the goals he was given was to learn how to not talk to himself while he worked, which he did frequently. Learning how to not talk to oneself may have been more important to achieve if the goal was to work in customer service, but Donna believed it would not have really bothered anyone if he had talked to himself when involved in

woodworking tasks in a machinery room. The individual was never able to stop talking to himself while he worked, and thus was not supported by the centre in finding community employment. However, Donna suspected that another reason he was not supported in finding community employment was because he was one of their top producers and they did not want to let him go and potentially lose money. At the time of my interview with Donna, the man would have been over 45 years old and had been at the sheltered workshop since the age of 21. Years later when Donna asked him about his employment goals he told her: “I gave up on that dream because I’m too old to make friends and I want to stay with the friends that I have”. While she understood that oftentimes people choose to stay at a sheltered workshop because they want to continue the friendships they have there, she also worried that no one has really explained to these individuals that they can make new friends in the community and still maintain the friendships they have at the ASC. Donna has highlighted an argument against ASCs – they may act more out of self-interest, than in the interest of the client, and may fail to thoroughly support a client in achieving their goals.

Edward (People First), Linda (NSDCS), and Catherine (Stantec) provided me with examples that indicated the potential of establishing strong friendships and social connections in a community-based employment setting. Edward commented how someone he knows with an intellectual disability had been working at Tim Horton’s for about 20 years, and was invited to every work-related Christmas party, because the job is “not just going to make coffee and Timbits; it’s being a part of the culture of work”. Linda (NSDCS) told me about the clients she has who work at a law firm. She said that whenever the firm’s staff members go away for a retreat they invite the clients with intellectual disabilities to come as well. These clients are fully supported during the retreat weekend and receive all the same perks as everyone else (i.e. jackets, bags). Linda told me that “just because they only work in the mailroom and they’re not a lawyer, doesn’t mean that they get treated any differently... that’s about the most inclusive I’ve seen”. Catherine, the supervisor of an employee with an intellectual disability, spoke to the social inclusiveness of her work environment:

she’s [the employee with the disability] such a part of this office... You know all employees think of her... her birthday is such a big deal every year. She tells

everybody and people show up with presents and we have cake. Like she's just such a part of this office. And even like our former CEO, at a Christmas party, he won a gift certificate and he just, he didn't think anything of it and gave it to [the employee with the disability]. She was just beside herself! ...even though they're way up there... that doesn't faze them to stop and say that she's doing a really good job and to her like wow, it's like the best compliment you could pay her, like she's a hard worker.

These examples indicate that a person with an intellectual disability does not have to forfeit friendships, involvement in social networks, and a sense of belonging, in order to accept the other benefits of community-based employment (e.g. income, independence). Catherine told me "I can't imagine how it couldn't be that way all over". From her point of view, she did not see any reason why other employment environments could not facilitate the same social inclusion that was occurring at Stantec.

4.4.3 ARGUMENTS IN FAVOUR OF ADULT SERVICE CENTRES

Arguments that were made in favour of people with intellectual disabilities working in ASCs instead of community-based employment included the following: many people with intellectual disabilities were more comfortable at ASCs where they enjoyed long-term friendships and fun activities along with a sense of stability and security in these settings; ASCs were still capable of providing workers with a sense of accomplishment through meaningful work; in contrast to for-profit businesses ASCs were better able to support people with intellectual disabilities with trained staff; and finally the low hourly wage of the ASCs allowed members to participate in a full week of work without losing their healthcare benefits or having their income taken away – as would occur, according to income assistance rules, if they earned over \$150 a month at a community-based employment setting where they were paid at least minimum wage.

Heather (Prescott) admitted that although the *community employment services* associated with the Prescott Group ASC successfully placed some people in the community with job positions, the majority of new clients who applied to Prescott Group were seeking full-time participation within the agency's spatially segregated ASC. Peter (a special care home agency) has had several clients who worked at an ASC. One of their residents used to have a regular job in the community, but Peter said the client "did not

feel effective so she does prefer working at [the ASC]. It's not inclusion and it's just everybody there has an intellectual disability and she feels more comfortable". Other participants also referenced people they knew who left their community-based jobs and returned to an ASC because they felt more comfortable there. Claire (L'Arche) commented on the sense of familiarity that can be found at an ASC. She described how one of their core members had been at an ASC for years. Even though other factors in his life had changed (such as his living situation), he continued to have a sense of stability, security, and a network of long-term friendships at the ASC.

One of the major arguments in favour of ASCs is that they provide an opportunity for people with intellectual disabilities to develop long-term friendships and socialize on a daily basis. Participants indicated that it can be harder to cultivate friendships in community-based jobs than it can be to establish friendships in ASCs with other people who also have disabilities. For Ann (L'Arche), an ASC proved to be a welcome diversion from her son's post-high school boredom and depression. The period after high school can be difficult for young adults with intellectual disabilities because they are no longer surrounded by other people and can be stuck at home without much stimulation. The ASC environment provided the social and mental engagement that Ann's son was missing in his life at that time. Ann told me that her son "likes to be around people that have their disabilities". When I asked Ann's son about his work at the ASC, he told me that his favourite thing was to "hang out" with the people there, and the only thing he did not like was "having too much work". The social benefits at the ASC were clearly prominent for him, and his mother confirmed this. The ASC also incorporated games and other social programming into their workday for their clients, which some argued created a more social and fun environment than could be found in a mainstream community-based job.

Even though ASCs are segregated environments, Ann (L'Arche) said she had observed that everyone there was treated with respect. She commented that even though the environment was spatially segregated away from the general public, there was a sense of inclusion within the centre that was fostered by the social interactions between staff and clients, as well as the inclusion that occurred among the clients with disabilities. When I asked her for her opinions on community-based employment she wondered:

Why would we put them out there [in the community] for them to fail with they can go somewhere like [a ASC] and they're included and they've got people trained to work with them?... I mean sure, I would love to see [my son] work in a lawyer's office or be a doctor or something like that, but that's not going to happen. So I want him to have the best life that he can have, and that [means] including him in things that work.

Since ASCs often accept outside service and production orders from businesses and agencies in the community, Ann commented that her son “doesn't look at everyone there as disabled; he looks at it as he is giving back [to the community]”. Although Jane (L'Arche) believed that there was room for improvement as there is with everything, she perceived ASCs as positive environments for the following reasons: depending on the type of work they were involved in, ASCs could provide clients with a sense of accomplishment; ASCs provided the support that many clients required; working at an ASC was better than being isolated at home and not being able to contribute at all; and she also commented on the value of the long-term friendships and social networks that clients have developed while working at an ASC.

In the previous section I described how some participants emphasized the motivation and reliability of a person with an intellectual disability, and how these traits were assets when working in the community. However, in contrast, Daniel (L'Arche) expressed concern that for-profit employers were looking for productive workers who were going to contribute to their business in a tangible way, and he did not believe that people with intellectual disabilities were generally perceived to be highly productive members of society. Daniel (L'Arche), a parent of two men with intellectual disabilities, identified this as a major barrier to community-based employment. Daniel recounted stories of employers of people with intellectual disabilities who eventually say, “I can't

really justify this anymore” and who feel that the employee is “more trouble than he is worth”. Daniel told me about when his own son was hired by a landscaping company. The crew did not have the patience or skill to teach him how to do the job properly, and it was easier for them to direct Daniel’s son to just sit in the truck so he did not get in the way. Thus Daniel considered the job “a failure”, but acknowledges that “it’s better than the alternative which is for him to sit at home, looking out a window”. Now his son works in one of L’Arche’s vocational programs. Daniel believed this is a more successful work arrangement for his son because unlike for-profit employers that are focused primarily on monetary gain, the staff at L’Arche have a different worldview and a different set of values. In contrast to L’Arche, Daniel pointed out that for-profit employers outside the realm of disability services have no “vested interest in making [the employment] arrangement successful”. This is an argument in favour of ASCs.

Prescott Group is the only ASC I approached for an interview, but L’Arche Homefires also operates an ASC (or sheltered workshop) for their residents and other people living in the broader community who have intellectual disabilities. The centre is referred to as ‘Applewicks’ and includes a public storefront for customers. I received a lot of comments about how much the core members at L’Arche Homefires in Wolfville enjoy their work there. Jane (L’Arche) considered the work that they do there very meaningful. Candle making is a key component of the Applewicks enterprise. Jane commented how inclusive the work environment was at Applewicks. For example, she said that if Applewicks receives a large order for candles (i.e. for a wedding or for Christmas) they begin working on the order early, so that the core members can continue to be thoroughly engaged in the work without being rushed. When I interviewed a core member who worked at Applewicks, she talked about being very happy with her job there and told me proudly that she was a “very fast weaver”.

Finally, for many individuals with intellectual disabilities, there is often no financial incentive to seek community employment because if they earn more than \$150 a month while they are on income assistance, the majority of their additional earnings are collected by the government to go toward paying for their living expenses (Nova Scotia Department of Community Services, n.d.). Many people with intellectual disabilities are not able to work enough hours at a sustainable wage that would allow them to step away

from income assistance. Edward (People First) told me that if they are able to achieve this, they are worried about losing the health benefits that accompany their income assistance. Furthermore, they worry about facing challenges in re-applying for income assistance if they find themselves in a situation where they need it again. Edward said he has never met anyone who says they do not want to work, but said he has met many people who say “I can’t work because I’ll lose my supports”. Allen (RRSS) would love to see everyone “have the opportunity to work at least for minimum wage at a job that makes sense to them whether it’s five days a week or three hours a week” without risking the loss of their additional income or supports. These examples highlight the negative aspects of seeking community-based employment.

In this section, I reviewed the arguments *in favour* of ASCs and those against community-based employment. In the previous section, I reviewed the arguments *against* ASCs and in favour of community-based employment. Clearly my participants had mixed feelings and divergent opinions on this topic. Should ASCs co-exist alongside community-based employment? Are they necessary? Can they contribute to social inclusion despite being spatially segregated environments? Is community-based employment necessary for social inclusion? Based on the data collected from my participants, the answers to these questions are not always straightforward. In Chapter Five, Six and Seven I will present my explanatory theory, which will explain further, how my research participants were able to justify different perspectives while maintaining a belief in the value of social inclusion.

4.5 SPECIAL OLYMPICS VERSUS MAINSTREAM RECREATION AND SPORTING OPPORTUNITIES

4.5.1 TERMINOLOGY AND DEFINITIONS

Special Olympics is an international sporting movement that was founded in 1968 in Chicago, and was first introduced to Canada in 1969. For over 45 years, Special Olympics Canada has been effectively acting on its mission, which is to: “enrich the lives of Canadians with an intellectual disability through sport” (Special Olympics Canada: Our Mission, n.d., para. 2). Whereas Paralympics provides opportunities for athletes with *physical disabilities* to play sports and compete, Special Olympics provides sporting opportunities to athletes with intellectual disabilities – though it should be noted that

some of the athletes with intellectual disabilities may also have a physical disability. Special Olympics Nova Scotia offers different types of year-long sporting activities and programming for athletes aged two and upward, ranging from bowling, to power lifting, to softball (Special Olympics Nova Scotia: About Us, n.d.). Through Special Olympics, athletes have the opportunity to compete at local, provincial, national, and even international levels.

4.5.2 ARGUMENTS AGAINST SPECIAL OLYMPICS

Participants expressed a number of arguments against Special Olympics, which they perceived as providing primarily segregated sporting opportunities for people with intellectual disabilities. They emphasized that people with intellectual disabilities do not necessarily want to be grouped with people ‘like them’, despite opinions that indicated otherwise. Some participants perceived that the athletes were not always treated with respect by some of the volunteers who spoke to them condescendingly. Some emphasized that their main issue with Special Olympics was that it was often positioned as the *only* available sporting and recreational opportunity for people with intellectual disabilities, while others presented examples of other mainstream recreational opportunities.

When I asked Kate (L’Arche) what an inclusive society would look like, she told me, “there would not be any ‘special’ because the world would run in such a way that different needs would be met. There would not be a ‘special door’”. It would then follow from this statement that *Special Olympics* implies a separate door; it implies difference and segregation. Some individuals would rather not be part of a segregated group of people with intellectual disabilities. For example, Kate told me that they encouraged one of their core members to get involved with People First (a self-advocacy group for people with intellectual disabilities) because they thought he would enjoy it. He checked it out, but Kate said that he did not want to attend their meetings because in his words according to her: “they’re all handicapped”. Kate told me, “I just thought it would be a great place for him to make friends but he didn’t want to be a in a group which wasn’t open”. Similarly, it is possible that people with intellectual disabilities would not want to be a part of Special Olympics for the same reason.

One parent told me that when she goes to Special Olympic events she did not feel comfortable. While some participants had described the positive and respectful

interactions that occurred on the Special Olympics field, others had a less favorable opinion of Special Olympics. Helen felt the athletes (which included her daughter) were treated like children sometimes. Chris (Special Olympics) admitted that sometimes athletes were not treated with the respect they deserve – they were not always treated as ‘athletes’. Some of the volunteer coaches have been involved in Special Olympics for many years – which is great, as Chris pointed out, but unfortunately sometimes these longtime volunteers have outdated perspectives on disability and this influences their interactions with the athletes. Chris perceived these volunteers as “our biggest struggle and our biggest asset”. Chris indicated how much he appreciated their dedication to the Special Olympics organization throughout the years. Nevertheless, the older volunteers have a greater tendency, in contrast to the younger volunteers, to treat the athletes (who are all adults) as “kids”. Chris said, “Oh yah that comes out all the time, all the time – ‘the kids’. The kids are older than you!”

Finally, even among the participants who recognized the benefits of Special Olympics, many wanted to see the creation of other less segregated sporting and recreational *options*. Donna (NSACL) admitted, “Special Olympics is great”, but she would like it better if it was an program that anyone could participate in. When she works with families she always tries to highlight an array of options – not just Special Olympics. She suggests walking clubs, bike clubs, sporting teams that anyone can join, and she recommends people look in the newspaper to discover free or inexpensive social events they can attend. Donna provides as much information as she can so the individual with the disability and their family can make informed decisions about what to participate in. She hopes that they choose the option they are most comfortable with. If people choose to be involved with Special Olympics because their friends are involved, Donna told me:

Who am I to say that they can’t be with their friends?... I know that people just love Special Olympics and I am not going to ever condemn it because people want to have fun, and so if that’s where they want it that’s fine, but they can have fun in other places. So I just try and explore all the options.

Donna believed that if Special Olympics simply did not exist, then people who wanted to be involved in sporting activities “*would* find something in their community that would

fulfill that need”. She called this perspective “radical”. Although Donna said that she would not want to take Special Olympics *away from people*, if it simply did not exist, she believed people would find other sports and recreation opportunities to engage in.

Ann (L’Arche) provided examples of how her son, who has never been involved in Special Olympics, found inclusion in non-competitive, recreational activities such as bowling and swimming. When he attended the open senior swims at a local pool, Ann told me that the seniors “couldn’t wait for Jeff to come... and they’d have races and you know if he did anything extra in the water they just cheered for him and that kind of stuff, so he loved it”. Ann also told me about the physical rehabilitation program at the YMCA that her son participated in. The program was offered to people with a wide range of disabilities, not just intellectual disabilities. In this setting, her son experienced cross-disability inclusion. Ann spoke enthusiastically of the program and of the sense of community he found there. This is another example of social inclusion found outside Special Olympics, and yet centred around physical activity. The arguments in this section highlight the reality that Special Olympics’ primary programming is *segregated*, and that there are other viable recreational and sporting options accessible to diverse participants that render Special Olympics programming potentially unnecessary.

4.5.3 ARGUMENTS IN FAVOUR OF SPECIAL OLYMPICS

Participants also identified that there were apparent benefits from engaging in Special Olympics programming. They highlighted that people enjoyed the opportunities to socialize with other athletes, as well as with nondisabled family members and volunteer coaches at Special Olympics sporting practices, competitions and events. Participants emphasized that engagement in Special Olympics developed the confidence, self-esteem, and independence of the athletes, which encouraged them to become involved with society in other ways. Furthermore, participants attested that nondisabled people who were associated with Special Olympics as volunteers or funders experienced attitude shifts toward people with intellectual disabilities when they saw what the athletes were capable of through sports. Finally, a participant pointed out that although Special Olympics’ primary programming is segregated, Special Olympics is engaged with other projects that contribute to broader social inclusion.

Linda (NSDCS) emphasized that for her clients, Special Olympics was not so

much about the opportunity to play sports, but it was about spending time with peers and “people that they consider to be like them”. For example, when she spoke to her clients after a Special Olympics bowling tournament it was clear they did not care whether they got three strikes or missed every pin. As one client told her, the tournament was great because: “I get to hang out with Beverly. I never get to see her. Cause she lives in another group home in Dartmouth and... I can't get there by myself”. Special Olympics was instrumental in bringing together these friends. Allen (RRSS) also pointed out that Special Olympics is “not inclusion as such, but it's a lovely social opportunity for people where people make good friends”. Claire (L'Arche) readily admitted: “We love the Special Olympics”, because her and other L'Arche staff have witnessed the enjoyment that many of their core members derive from it. They look forward each week to attending Special Olympics training events and competitions, they are proud when they win a trophy or a medal, and for many of them, Special Olympics is a community that they have belonged to for many years. The people there are like family to them. Jane (L'Arche) told me that although Special Olympics is segregated, it is hard for her to think it is “a bad thing” when she sees how much people enjoy it and “how big a part of some people's lives it is”.

Even though regular Special Olympics programming is only offered to people with intellectual disabilities in Nova Scotia, it also involves the athletes' families, as well as the coaches and assistants. Chris (Special Olympics) described some spontaneous mixed interaction between people with and without disabilities that occurred on the field when a young person with Down's syndrome for example, would come to a practice event with his younger brother and sister. Chris told me “they'll come out and practice with us [even though] they wouldn't be able to go and compete”. Chris guessed that there were probably just as many volunteers without disabilities as people with intellectual disabilities who were involved in Special Olympics. Chris commented that the majority of their volunteers “fall in love” with Special Olympics immediately, and the hope is that the attitude shifts that occur among volunteers on the field will “translate into other parts of the community”. As Allen (RRSS) and Chris pointed out, many of the athletes develop great relationships with the coaches. The coaches will often take them out for dinner or to a movie even after the season has finished. Thus, through Special Olympics, friendships

are created across varying types of ability even though the actual Special Olympics programming is segregated. According to participants such as Chris, Special Olympics contributes to increased social inclusion in the community by changing attitudes – both those of the athletes and of community members.

According to many of my participants, not only does Special Olympics encourage friendships, but it also contributes to increased confidence, self-esteem and independence for people who may have otherwise had their confidence undermined in other mainstream sporting opportunities. Daniel's (L'Arche) son went bowling regularly with other L'Arche members and when I asked if his son might want to bowl with a mixed, non-segregated group, Daniel told me, "I don't think he looks down the bowling alley lanes at the group somewhere down there, and says 'gee, I wish I could be bowling with them'". He believed that because of the inherent competitive nature of mainstream sporting activities, no matter how recreational they are designed to be, mainstream sporting activities are still essentially competitive and that defining characteristic was likely to exclude people with intellectual disabilities from truly participating. For a mixed sporting opportunity to be successful and genuinely inclusive, Daniel argued that there needed to be commitment among all participants *to ensure* that it was genuinely inclusive and successful, or else the participants with intellectual disabilities may be technically included, but actually marginalized within the group (e.g. being part of the team, but sitting on the bench without a chance to play). In contrast to the sense of failure and discouragement Daniel feared people with intellectual disabilities would experience if they engaged in mainstream sporting opportunities, my research participants highlighted how Special Olympics athletes experienced an increase in confidence and self-esteem as they developed their sport-playing skills, athletic abilities and accomplished things that they did not initially believe they would be able to. Although, as mentioned previously, some research participants believed otherwise, Jane (L'Arche) commented how Special Olympic participants are always addressed respectfully by coaches and staff. For example, she highlighted how participants in Special Olympics are generally always referred to as "athletes". Chris spoke about the weekend competitions where Special Olympic athletes travel to regional, provincial, and national sporting competitions. These events, which they often attend without their parents, offered them the "opportunities that

they never thought they'd have and their families never thought they'd have. Getting to see them kind of go through those is quite remarkable”.

As athletes grow in confidence through Special Olympics, they begin to identify other opportunities that they want to pursue. Allen (RRSS) told me that when people start participating in Special Olympics, “it’s seeing the athletes kind of recognize they do have purpose all of a sudden and you know they can have the same things that they see other people having. It’s that social, the real social connection and having the confidence and esteem to go out there and pursue it”. Chris (Special Olympics) told me that it gives the athletes the “courage to kind of get out there into the community and try something that they typically wouldn’t do – not work at the work shelter, but try to get a job in a regular kind of business environment”. The confidence that people gain through social connection and sporting opportunities in Special Olympics can be a stepping stone toward other pursuits and goals. Chris has witnessed how Special Olympics has also changed the attitudes of volunteers and sponsors. Chris said, “it does open [the eyes of volunteers and sponsors] more to ‘I never thought they’d be able to do that. If they can do this, well then why can’t they push our mail from the mailroom? Why can’t they do this? Why can’t...’ so it does open up a lot more doors”. Consequently, Special Olympics has indirectly facilitated the creation of community-based jobs for people with intellectual disabilities.

Special Olympics contributes to social inclusion in additional ways, beyond their regular programming. According to Chris (Special Olympics), they have recently launched an *Athletes Leadership Program* where Special Olympics recruited some of their athletes and trained them in public speaking and speech writing. They now support their athletes in speaking to university classes and corporate events about Special Olympics and their own experiences with the organization. This raises awareness among the public of the capabilities of people with intellectual disabilities, which ultimately has the potential to contribute to social inclusion by changing people’s attitudes. Chris clarified that when a Special Olympics representative has the opportunity to give a speech; it is not just about building awareness about Special Olympics as an organization. Chris told me that when they go to schools to talk about Special Olympics, their main message is: “We’re providing sporting opportunities for these people and you guys

should be doing kind of the same within your school to make sure they're included in kind". So although Chris readily admitted that Special Olympics' primary programming is not inclusive because it involves only athletes with disabilities competing against other athletes with disabilities, he said that Special Olympics as an organization is "out there and trying to create more opportunities for our athletes, promoting social inclusion... we're doing everything we can to make sure they're accepted in our local society". Chris insisted that even though the programming is segregated, Special Olympics as an organization is progressive. Chris emphasized, "We're not trying to hide in the back room, and do things on our own. We're doing it because it's the most effective way that [Special Olympics] found how to do it and then we're using the skills and our successes to kind of push it back into the community".

As with the other three contentious topics, the topic of Special Olympics provoked differing opinions among my research participants. Participants pointed out that the popularity of Special Olympics may be due in part to the reality that it is often presented as *the only default option* for people with intellectual disabilities who want to be involved in sports. Is Donna (NSACL) correct in thinking that "if there were no Special Olympics, then the people who wanted to be active in sports would find something in their community that would fulfill that need"? Or alternatively, does Special Olympics serve an important purpose in the lives of its athletes with intellectual disabilities by cultivating a validating, safe and friendly environment while simultaneously promoting broader social inclusion indirectly? Participants were clearly conflicted about whether Special Olympics hindered or contributed to, social inclusion.

4.6 CONCLUSION

In this chapter I have highlighted the conflicting and divergent perspectives that emerged when my research participants discussed four different spatially segregated environments or activities and their alternatives: special care homes versus alternative community-based living arrangements; segregated versus inclusive education; ASCs versus mainstream community-based employment settings; and Special Olympics versus inclusive recreation and sporting opportunities. All of my participants supported the concept of 'social inclusion' in theory, and yet many of them presented arguments in favour of segregated activities and environments. In the next three chapters, I will present

the grounded, explanatory theory I developed, which will explain in greater detail how my research participants were able to defend their various opinions while continuing to uphold the ideal of social inclusion. For many participants it was not about whether segregated environments and activities were ‘good’ or ‘bad’ in themselves, but rather it was more important that certain elements were present in whatever environment or activity people were engaging with. They justified their various arguments by prioritizing one or more of the following three paired conceptual elements of social inclusion: *respect and equality*; *opportunities and self-determination*; and *friendship and belonging*. By combining all three of these paired concepts in the concluding chapter (Chapter Eight), I will establish a cohesive and clear definition of social inclusion, which I hope will facilitate conceptual clarity and consensus, and progress toward a more inclusive province for people with intellectual disabilities.

CHAPTER 5: THE EXPLANATORY THEORY (RESPECT AND EQUALITY)

5.1 INTRODUCTION

In the previous chapter, I discussed the conflicting and divergent opinions that emerged when my participants discussed four different types of segregated environments and activities. These conflicting and divergent opinions, related to the concept of ‘social inclusion’, indicated a research problem. If all of my participants upheld the concept of social *inclusion* as an ideal, how were they then able to justify their support both in favour of, and against, *segregated* environments and activities for people with intellectual disabilities? In this chapter, I describe the first part of the explanatory theory I developed to answer this question and create a usable definition of social inclusion. My explanatory theory states that the differing perspectives of participants stemmed from their prioritization of one or more of the following three paired concepts: respect and equality; opportunities and self-determination; and friendship and belonging. In this chapter, I will describe how participants utilized the paired concepts of *respect and equality*. First I will explain my reasons for selecting the words ‘respect’ and ‘equality’ to label the concepts that emerged in the interview data. Then in Section 5.2, I will demonstrate how participants utilized the paired concepts of respect and equality to make arguments against, or in favour of, the four different types of segregated environments and activities discussed in Chapter Four. In the remainder of this chapter, I elaborate on the meaning and the implications of applying the concepts of respect and equality to bring about social inclusion, as described by my participants. In Section 5.3, I write about how participants were able to identify when respect and equality were present and when the concepts were absent. In Section 5.4 and 5.5, I discuss how participants believed in order to enact respect and equality it was important to both recognize our shared humanity and similarities, and to value differences.

I have paired the concept of ‘respect’ with the concept of ‘equality’, because respect refers to how one behaves and interacts with a person with an intellectual disability when the concept of equality is manifest. Genuinely respectful behavior and interactions, which protects and honours the human dignity, contributes to creating a society of equals. I have chosen to use the concept ‘equality’ to refer the ideas that

emerged in the data, for reasons which I will outline here. The concept of equality is closely related to the idea of human rights, as first enshrined in Universal Declaration of Human Rights signed by the United Nations General Assembly in 1948 and again in the Canadian Charter of Rights of Freedoms (1982). In 2008, on the 60th anniversary of the adoption of the Universal Declaration of Human Rights, the United Kingdom's Equal Rights Trust facilitated a consensus among international human rights and equality experts around the meaning and implication of the 'right to equality'. The group of experts agreed on *27 Principles of Equality* with the hope that these principles would "serve as a compass to orient legislative, judicial, and policy efforts towards a more progressive set of equality norms and policies in the 21st century" (Equal Rights Trust, 2008, p. 2). The second principle, "Equal Treatment", is defined as an *aspect of equality*, but one that "is not equivalent to identical treatment" (Equal Rights Trust, 2008, p. 5). They emphasize that "to realise full and effective equality it is necessary to treat people differently according to their different circumstances, to assert *their equal worth* and to enhance their capabilities to participate in society *as equals*" (Equal Rights Trust, 2008, p. 5, emphasis added). The concept of 'equity' is evident in this principle of equality. In a commentary on the *Principles of Equality*, written by Petrova, the Executive Director of the Equal Rights Trust, Petrova (2008) confirmed that this principle of "Equal Treatment" departs from a framework of what she refers to as *formal equality*, "whereby individuals would be treated in identical ways regardless of their relative capabilities for participation" (p. 61). Petrova asserts that "non-identical treatment is justifiable and indeed necessary" to the pursuit of equal participation and to realise "full and effective equality" (p. 61). Equality and equity are *not* fundamentally opposed concepts. On the contrary, depending on how they are interpreted, they can be complimentary.

In this thesis, when I refer to the concept of 'equality' I am not referring to 'formal equality' or to 'identical treatment', but to an equality that encompasses equity, as defined by the Equal Rights Trust in their *Declaration of Principles of Equality* (2008). I have chosen to utilize the concept of 'equality' instead of the concept of 'equity', because although my participants certainly discussed issues of equity and inequity, I believe that the broader concept of 'equality' is better able to encompass the

many statements and examples participants discussed in relation to this topic. This chapter is premised on the belief that *all* human beings, including people with intellectual disabilities, have the right to be “*equal* in dignity, to be treated with *respect* and consideration and to participate on an equal basis with others in any area of economic, social, political, cultural or civil life” (Equal Rights Trust, 2008, p. 5, emphasis added). It is my interpretation that the concepts of respect and equality that were referenced by my participants throughout the examples they provided, are aligned with this principle.

5.2 APPLYING ‘RESPECT AND EQUALITY’ TO THE FOUR CONTENTIOUS TOPICS

5.2.1 ‘RESPECT AND EQUALITY’ IN LIVING ENVIRONMENTS

In Chapter Four, participants used the concepts of rights and equality to highlight the issues with special care homes, and they also referenced these concepts when identifying the positive aspects of special care home living. Peter and Lorraine (a special care home agency) discussed how some zoning by-laws in Nova Scotia and the moratorium on new SOHs were encouraging a trend toward large special care homes being opened far away from residential neighborhoods, they highlighted a policy issue that they did not agree with. Peter pointed out that zoning by-laws which prevent special care homes from opening in family neighborhoods was a “human rights issue”. In making this assertion, Peter highlighted how this situation was a violation of the paired concepts of respect and equality. The abuse that sometimes occurs in special care homes, which was highlighted by Donna (NSACL) and Kate (L’Arche), also indicates a deficit of respect and equality. In response to a recent death at an institution in Nova Scotia, Kate said that the way the situation was handled made her feel that the client’s life “didn’t seem to hold a lot of value”. This lack of perceived value Kate referred to, underscored a lack of respect and equality. In contrast, when the respect and equality of people with intellectual disabilities are enacted in a special care home context, the result is that people with intellectual disabilities become more empowered and self-confident. Kate acknowledged that there is the potential for abuse to occur in a L’Arche community, just like there is the potential for it to occur within any special care home environment. However, she believed that any type of abuse would not stay hidden for long because the

core members were aware of their rights and knew that they deserved respect as equals. They knew that they could call Kate if something happened that they did not like, whereas “for many years people with intellectual disabilities could not get permission to say what they didn’t like” (Kate, L’Arche). She believed that this was one of the most effective ways to ensuring that people with intellectual disabilities do not become victims of abuse – address their perceived vulnerability by empowering them to communicate what they need and what they do not like. Empowered, confident people and a reduced possibility of abuse is an outcome of enacting the paired concepts of respect and equality.

Allen told me how they have been working on downsizing their homes so that residents have more privacy and personal space, and how they decided to create resident councils to empower their clients. According to Allen, RRSS also focuses on anger *management* with their clients, effective communication, and eliminating the environmental antecedents to anger, rather than treating demonstrations of aggression as a personal flaw and trying to restrain the aggression only when it manifested. In these examples, Allen was emphasizing his agency’s efforts to enact the paired concepts of respect and equality. Linda (NSDCS) attested to the impact that staff education and training can have on increasing respect and equality of perception for people with intellectual disabilities. Linda believed that if the leadership within an agency was strong, and the director and management staff were committed to the principles of respect and equality, then it was likely that all staff members would be equipped with the education and training to promote a culture of deep respect and equality within special care homes. Some agency directors have such a strong philosophical approach and distinctive leadership style in promoting respect and equality that Linda said she could easily identify staff members who have been trained by them, which she thought was “awesome”. It was a testament to the power of education in facilitating respect and equality.

5.2.2 ‘RESPECT AND EQUALITY’ IN EDUCATION

When discussing arguments against segregated education and those in favour of the inclusive education model, some participants pointed out that if nondisabled students had the opportunity to be in classes with people with intellectual disabilities, they would be more likely to grow up to become future employers and leaders that would help create

a world where people with intellectual disabilities are treated with respect, as equal human beings. This scenario was described by participants as being in contrast with the experiences of previous generations who had little exposure to people with intellectual disabilities and thus grew up being fearful and prejudiced against them, and less likely to treat them with respect as equals. Although there were issues with the current practice of inclusive education, Donna (NSACL) believed that there was great potential for improving inclusive education in the province as it strove to enact a key principle of Nova Scotia's *Special Education Policy* (2008) – the 'Right to Inclusive Education'.

However, in contrast, Jane (L'Arche) also utilized the concepts of respect and equality to justify her hesitation to embrace the inclusive education model, by highlighting the importance of respecting and valuing *difference*. Jane believed that many students with intellectual disabilities needed the more specialized supports, which could be more effectively provided in a segregated classroom. She told me: "I think really, to not acknowledge that these people are different and will learn in different ways; [it is denying that it can be] beautiful that they can be contributing, as much contributing as we are, but possibly in a different way... just as valuable a way". Furthermore, the lack of resources and supports, such the reduction in EPAs due to education funding cut-backs, were identified by participants as a barrier to inclusive education. Not providing students with the supports they need to succeed represents *a lack of respect and equality* for people with intellectual disabilities.

5.2.3 'RESPECT AND EQUALITY' IN WORK CONTEXTS

The concepts of respect and equality were also present when participants discussed arguments for and against ASCs. Donna (NSACL) told me that the new generation of young adults with intellectual disabilities (and their families) have grown up with the inclusive education model expect greater respect and equality in life, and thus many do not want to work in an ASC. Jane and Claire (L'Arche) commented on the pride and sense of satisfaction people experience when they have jobs in the community. This is indicative that people with intellectual disabilities may experience higher levels of confidence in situations where they feel like their rights to employment opportunities are enacted. Furthermore, according to Jane, when people with intellectual disabilities are working in the community, the broader public is also more inclined to perceive them as

contributing members of society; as equals. When Catherine (Stantec) and Edward (People First) spoke of the motivation and dependability of people with intellectual disabilities in an employment setting, they highlighted the value of the contributions that people with intellectual disabilities can make to labour market and thus underscored concepts of respect and equality. Even if someone requires greater supervisory support in their employment setting, such as Peter and Lorraine's (a special care home agency) client, they are still capable of being a valuable employee. In Chapter Four, Peter and Lorraine noted that placing the individual in a community employment setting supported by the agency's staff throughout the day, promoted respect and equality for people with intellectual disabilities in the way that the agency's staff members were able to model respectful interactions with the individual. This had the potential to encourage other employees to behave similarly.

The concepts of respect and equality were also used to justify arguments in favour of working in an ASC rather than in the community. Ann (L'Arche) noted that even though the ASCs are segregated environments, the clients were still involved in meaningful work *for* community businesses or individuals, and they demonstrated pride in their efforts and contributions. In Chapter Four, Daniel (L'Arche) spoke of his concern that people with intellectual disabilities may lack the skills to be gainfully employed in a competitive work environment and he referenced the experiences of his son in an unsuccessful community job placement. He told me that he believed for-profit employers outside the disability world have no "vested interest in making [the employment] arrangement successful". Daniel found the community employment environment to be lacking in respect and equality for people who may learn differently and may have a different type of contribution to make in the work environment. In contrast, he believed that L'Arche's Applewicks ASC operated according to a different set of values that caused them to be more accommodating to people with intellectual disabilities. Other L'Arche staff and core members spoke of the meaning and enjoyment that their members derived from working in Applewicks, L'Arche's ASC, because their work was valued and they were treated with respect.

Kate (L'Arche) admitted that when people define a person's value by the degree to which they participate in the labour market as a 'productive member of society', this

perspective tends to reduce the value of people with intellectual disabilities because they cannot always meet society's definition of productivity. Kate provided the example of a core member in the community who did not speak an understandable language and was quadriplegic, and yet had "the most incredible gift of welcome and... you will never be welcomed as greatly as you will be by this woman". Kate was aware that according to an economically-based definition of productivity, this woman's gift of welcome would not be valued highly. Instead of valuing people based on their 'productivity', L'Arche emphasizes the unique 'gifts' that everyone has to share with others. From this gift-based perspective, many different types of contributions to community life can be honoured. Alison (L'Arche) told me how L'Arche communities are intentional and deliberate about identifying and naming people's gifts. Daniel (L'Arche) told me about attending a L'Arche community social event. There was dancing and food, and during the event they gave out awards. He described what happened next:

Everybody in that room got an award. For this person it might have been he was 'the greatest dancer' because he was a good dancer. For somebody else it was 'the greatest helper'... For somebody it might have been because she has a beautiful smile. There's always something to celebrate and [L'Arche] always bring that to the front.

Appreciating and celebrating people's different gifts is built into the very fabric of L'Arche where the concepts of respect and equality are upheld and enacted throughout the different aspects of a L'Arche community, including in the ASCs they operate, such as Applewicks.

5.2.4 'RESPECT AND EQUALITY' IN SPORTS

The concepts of respect and equality emerged when participants discussed Special Olympics. As discussed in Chapter Four, Helen (a parent) expressed concern that sometimes the athletes were treated and interacted with condescendingly as if they were children, rather than adults. Chris (Special Olympics) was also aware that the older generation of Special Olympics coaches and volunteers have a greater tendency than the younger volunteers to refer to people with intellectual disabilities as 'kids', and to treat them as such. He recounted an experience of watching an older Special Olympics coach (in their late sixties) "babying" the athletes at an event. Regardless of their level of

capacity and function, Chris said he would rather error on the other side by giving the athletes complete freedom to do what they want until something occurred that was against the rules or inappropriate. This coach acted like a babysitter, making all the athletes report to her continuously and not trusting them to be independent. In conversation with him, Chris supported the athlete in agreeing that the coach's behavior was inappropriate, although she likely had good intentions. It can be difficult to address the attitudinal barriers in this context since the older volunteers have been around for a long time and have invested and dedicated countless hours of their lives to supporting the athletes in Special Olympics. The new generation of Special Olympics coaches tended to be younger than thirty, and less likely to talk to people with intellectual disabilities as if they were children. Chris was optimistic that over time inappropriate and condescending behavior will become a thing of the past.

While the aforementioned examples indicate a *lack* of respect and equality on the Special Olympics field, other participants, like Jane (L'Arche), believed that athletes were treated with respect during Special Olympics events and activities. In Chapter Four, Chris told me how Special Olympics has even indirectly facilitated the creation of community-based jobs for people with intellectual disabilities. Special Olympics coaches, volunteers, and sponsors have begun to see people with intellectual disabilities differently; with a newfound respect for them. The Special Olympics' *Athletes Leadership Program* that Chris told me about, also enacts the concepts of respect and equality. The leadership program, which supports athletes in speaking to university classes and at corporate events, raises awareness among the public of the capabilities and potential of people with intellectual disabilities. Participants, such as Chris (Special Olympics) and Allen (RRSS), also spoke highly of the increased confidence, self-esteem and independence that athletes acquired through their experience with Special Olympics. Due to this increased confidence, participants noted that Special Olympics athletes were more likely to begin pursuing other goals.

In summary, in this section I demonstrated how my participants applied and utilized the paired concepts of respect and equality to make arguments against or in favour of, four different types of segregated environments and activities: special care homes, segregated education, ASCs and Special Olympics. Regardless of their differing

opinions and perspectives of segregated environments, the concepts of respect and equality were clearly central to participants' understanding of social inclusion. Respect and equality were more important determinants of social inclusion than whether or not the setting or activity was considered spatially segregated or not. This set of paired concepts composes the first part of my explanatory theory; the two other paired sets of social inclusion concepts (opportunities and self-determination; friendship and belonging) will be discussed in Chapters Six and Seven.

5.3 WHAT IT LOOKS LIKE WHEN RESPECT AND EQUALITY ARE PRESENT OR ABSENT

Since respect and equality are be abstract and intangible concepts by themselves, I have used the data from participants to elaborate and elaborate further on the meaning of these paired concepts (how they understood them), in order to render the concepts more applicable to concrete situations. When the concepts of respect and equality are present, people have the freedom to embrace their true selves and to be who they are. Kate admitted that even for her, as a leader at L'Arche, L'Arche has helped her claim the freedom to be who she is. She expressed this as realizing "that I don't have to pretend to be something that I'm not... for me L'Arche is really about freedom... that you can be who you are and be accepted and be loved". Allison (L'Arche) also expressed that L'Arche is about giving people the freedom to be who they are and celebrating people's unique strengths. For example, birthdays are significant events at L'Arche and they are always celebrated. It is customary at L'Arche that during the birthday party all the guests take turns saying what they appreciate about the person whose birthday it is. This is an opportunity for individual strengths and unique personalities to be recognized and affirmed. This verbal and direct affirmation of a person's value and their unique gifts is an outcome of achieving respect and equality. According to Edward (People First), people with intellectual disabilities need to have at least one person that believes in them and their potential. He told me a story of a friend of his who, when he was younger, had been told that he would not amount to anything. This friend used to listen to the radio all the time and was able to identify a wide selection of songs after only hearing a few notes. After a conversation with a man running a radio booth at a mall, Edward's friend was told by the man that he should be in the radio business, and he believed him. His friend

went on to work in radio for many years. Edward emphasizes that in his experience “people who succeeded the best have people who believed in them the most, and saw them as a person first and not the disability”. This is an example of respect and equality enacted. When people believe in the potential of someone, they are demonstrating respect for the person and a belief in the person’s value and worth.

When people do not experience respect and equality, they experience judgement, discrimination, and stigma. The experience of being stigmatized and discriminated against can have a detrimental impact on one’s confidence and sense of self-worth. For example, the word ‘retarded’ has often been used as a derogatory and stigmatizing label for people with intellectual disabilities (Greenspan, 2010; Social Security Administration, 2013). Claire (L’Arche) emphasized that the word should no longer be used anymore “because it’s too hurtful; it’s too harmful”. Alison (L’Arche) agreed that this word can be very painful for people with intellectual disabilities. As previously mentioned, another common, but also hurtful term, is to refer to adults with intellectual disabilities as “kids”. Allison (L’Arche) told me about a “nice lady” at the bank who always asks, “How are the L’Arche kids doing?” When she tries to correct people they often respond by saying, “Oh yah, I know, but I think of them as kids”. Perceiving people with intellectual disabilities as permanent children does not foster respect and equality. Kate (L’Arche) expressed her belief that it is convenient for society to think of people with intellectual disabilities as children, because it means that society does not feel as obligated to respect them as equals and to respect their desire for self-determination to the same degree if they felt they were dealing with an adult. Lindsay (RRSS) believed that language has improved over time. She remembered how her father would ask her: “How are the kids that you work with?” Lindsay said that now she only hears the older generation refer to them as “kids”, and she is hopeful that attitudes are evolving over time. Linda (NSDCS) had also noticed that older generations were more likely to treat people with intellectual disabilities as children. She commented on how people will take her clients by the hand and she has to point out, “No, he’s 50, you can’t do that”. Linda blamed these attitudes on how segregated people with intellectual disabilities were in the past. The older generation did not have the same opportunities and exposure that young people have now, to become more comfortable with intellectual disability as a form of diversity.

Alison (L'Arche) shared with me that about six years ago someone spray-painted offensive disability-related labels around the town. She remembered calling authorities to have it removed, but it took a long time for them to get rid of it. This is an overt example of what can occur when there is a lack of respect and equality for people with intellectual disabilities. Aside from this graffiti incident Allison had not witnessed any blatant and aggressive discrimination, although she was aware of many less visible discriminatory incidents and interactions that occurred on a regular basis. Jane (L'Arche) was aware that they were stared at when she was out in public with a core member. Sometimes people gave them dirty looks if core members were having trouble controlling the volume of their voice in public. Jane told me she gets frustrated when she accompanies a core member to the doctor and the doctor directs all their questions to her, rather than to the core member sitting beside her who would be the most knowledgeable in regards to how they are feeling. When waiting in store line-ups, Jane has noticed how the cashier will look at her for the payment, rather than the core member who is prepared to make a purchase. These are all examples of what it looks like when the paired concepts of respect and equality are *not* fully enacted. Ann (L'Arche) noted that although some people with intellectual disabilities may take longer to process information and to articulate a response, they should still be given the same respect that would be given anyone else. Her son told her that he feels like sometimes he asks a question, but no one waits for him to answer. His speech can be slow, but it is very disrespectful to not wait for a response. Ann appreciated that at L'Arche that they talk *to* the core members, rather than *at* them, which meant a lot to her as it indicated that they were being respected as equals in that environment.

Jane (L'Arche) said that when people find out that she works at L'Arche she often gets reactions from people such as:

'Oh aren't you doing a good thing... you must be really sweet to do this kind of work' ... in saying that it's really kind of *devaluing* the people with disabilities. Like, 'oh only a special type of really nice person could work with him'. So I kind of, I hate when I hear that, because you never really know. It's hard to respond to because they don't mean it in a malicious way, but it really shows what their feelings are about [people with intellectual disabilities].

Alison (L'Arche) also experienced frustration when people expressed the attitude that working at L'Arche was 'a burden'. People have said to her, "'Wow you work so hard, it must be hard to do that', or 'I could never do that'... I have to point out the fact that they're so charming, we have so much fun together". These types of responses from the public imply that they believe people with intellectual disabilities are difficult to work with and it reduces the value of the reciprocal relationships between Jane and Allison and the core members. People who make these comments may appear to be 'nice people', but as Jane pointed out, the comments they make reveal that they do not perceive people with intellectual disabilities as true equals. Instead their comments indicate that they see them as charity cases and as burdens for their caregivers.

Participants indicated that the stigma and discrimination that is experienced when there is a deficit of respect and equality can cause people with intellectual disabilities to not want to be associated with other people who also have intellectual disabilities. Heather (Prescott) said that many of their clients recognize that they have intellectual disabilities, but they resist being associated with Prescott although they may work there regularly. Melissa (Best Buddies) said that they sometimes have a hard time recruiting people to participate in the Best Buddies friendship program. Their issue is not with recruiting non-disabled student participants, but rather they sometimes have difficulties recruiting people with intellectual disabilities. For example, Melissa told me that someone who has high functioning autism may look at the Best Buddies brochure and see someone with a more apparent disability, and then decide that they do not want to be a part of Best Buddies because they feel that the program would have nothing to offer them and they do not want to identify as having that type of disability. Although Melissa thinks that the Best Buddies program has a lot to offer all participants in terms of socializing and relationship building opportunities, some people may not want to be involved because they are aware of the stigma around intellectual disability.

When there is a lack of respect and equality in society for people with intellectual disabilities, this can begin to affect their self-esteem and confidence. Melissa told me that a lack of confidence can be a hindrance in making friends beyond facilitated programs that initiate friendships, such as Best Buddies. For example, if people have been disrespected in the past or if they have been bullied and they feel like they do not fit in

because of their disability, this may make them hesitant to initiate conversation and to make new friends. Melissa explained:

It's probably nothing for you and I to strike up a conversation with the person sitting next to us in class, but maybe if that person has been picked on for having a disability, then it's kind of picked away at their confidence. You know, maybe they're going to be afraid to turn around and say: 'Hey how was your weekend?'

Despite the detrimental impact of being treated with a lack of respect in society, many people with intellectual disabilities are resilient and maintain a strong sense of self-worth. Alison (L'Arche) notes that many of the core members at L'Arche "have a good sense of self-esteem. Like 'I'm important, I deserve to be here, I want to do this, this is mine'. So it's neat. I admire that in them". However, it is understandable that a lack of respect and equality in the form of discrimination and stigmatization can begin to erode one's self-esteem. Elaine (L'Arche) shared with me that she hates it when people walk by her and stare at her in her wheelchair. She found that this happened frequently, especially at the beginning of the school year when there are a lot of new university students around. She told me, "It's like, what the heck are you staring at?" This type of attention irritated Elaine, but she clearly attributed this behavior to their rudeness, rather than to something being inherently wrong with her. She told me that she can address this rude behavior by going up to them and saying: "Could you kindly not... you can walk by me, but not just keep turning your head and staring at me while you keep going". She does not mind if people stop and talk to her because they are her friends or they want to get to know her, but when strangers stare blatantly at her she feels differently. Elaine shared with me, "If you don't know them, it's like what the heck. It's like get out of my face". Elaine's attitude suggests resilience and confidence. However, being stigmatized, treated unfairly and disrespected because of your differences can be hurtful regardless of how resilient and strong you are. A lack of respect and equality prevents inclusion and has a detrimental impact on the lives of individuals.

5.4 LOOKING BEYOND OUR DIFFERENCES TO HONOUR OUR SHARED HUMANITY

An important aspect of the paired concepts of respect and equality, identified by my participants, was the need to look beyond individual differences to recognize and

honor the common denominator; our shared humanity. Alison (L'Arche) described her experience of inviting her mother over to have dinner at one of the L'Arche houses. During the dinner her mother was so distracted by the superficial behavioral differences apparent in the way that the core members ate. Alison found it frustrating that after finishing a nice dinner her mother made a negative comment about the way someone ate. She observed that some people have more difficulty moving beyond their discomfort with behavioral differences. Kate (L'Arche) believed that telling stories about the lives of people with disabilities helps others to see them as *people first*, rather than seeing only the difference of the disability. Similarly, Jane (L'Arche) explained that in L'Arche you begin to see people as truly equal *through relationship*. L'Arche strives to reduce power imbalances between assistants and core members by promoting the message that everyone lives with some type of disability and/or weakness, even though they may not be visible at first (Angrosino, 2003; Sumarah, 1989; Vanier, 1997). For example, people with intellectual disabilities may require more support in initiating friendships or gaining employment, but Alison (L'Arche) pointed out that people *without* intellectual disabilities also have insecurities, or certain behavioral and emotional issues that can create challenges when trying to make friends and gain employment. Alison explained to me the L'Arche model of equality and respect: "Jean Vanier talks a little bit about how we all have disabilities, there's broken pieces of us. We're not perfect and that's how we can connect with each other in the most meaningful way... if we admit to each other I'm not perfect, but let me help you. And that's where the relationship comes in". Equality at L'Arche is based on an acknowledgement that *everyone* has disabilities and weaknesses, and that we are all relational, interdependent beings who need each other.

Donna (NSACL) echoed this belief when she pointed out that we are really no different than people with intellectual disabilities. For her, achieving social inclusion would mean that people with intellectual disabilities would be accepted for who they are. Like anyone else living life in our communities, "They would be working, and they would be parents, or they would be married and they would be struggling like newly married couples... we all have abilities and disabilities and for some reason or another, we seem to think that we have to separate the people with disabilities from the nondisabled". Claire (L'Arche) would have agreed. She recounted seeing a billboard

promoting inclusion and she found herself wondering whether it was really necessary to have billboards telling us to be respectful of others. She longed for the day when we would not have to use the word ‘inclusion’ anymore, because social inclusion would be fully manifested, instead of being only a potential reality, and having an intellectual disability would not be “a big deal”. It would be just one difference among a sea of diversity, in a world where everyone was respected as a human being of equal worth.

Participants also highlighted other perspectives that could help society move beyond individual differences to recognize and honor the common denominator; our shared humanity. While participants pointed out that everyone has certain challenges that they deal with throughout their lives, they also noted that we are all vulnerable to *acquiring* particular disabilities, even if we are not born with them. Disabilities can be acquired at any point throughout the life course due to an accident or illness; no one is immune from this risk. There is also the possibility that a currently nondisabled person, which may include ourselves or someone we are close to, could give birth to a child with an intellectual disability in the future. These are additional reasons for treating people with intellectual disabilities with the respect and dignity they deserve as equal persons. Chris (Special Olympics) expressed, “If I had a kid that had an intellectual disability or anything like that, I’d want them to have the same opportunities that I did growing up, so it’s really the luck of the draw for them”. Peter and Lorraine (a special care home agency) also highlighted these reasons as another justification for social inclusion:

Peter: All but by the grace of god any of us could end up in a wheelchair tomorrow, just like that. And then I would hope that I wouldn’t be shunned and thrown to the side of the road. Cause that’s not the society that I want to live in.

Lorraine: Exactly. It’s important to everybody, because you never know what could be down the road for yourself or grandchildren, great grandchildren that may be born with disabilities. So it’s you know, I think it’s a value for everybody in society to really want people with disabilities to be included and treated with dignity. Cause you never know, there could be something in your family that you’re going to need to deal with.

Participants highlighted how everyone experiences challenges in their life and they struggle with personal issues and vulnerabilities even though their challenges may not be

labeled as ‘disabilities’. Furthermore, as my participants pointed out, no one is immune from suddenly acquiring a disability or having a family member born with a disability. Looking beyond our differences to recognize our similarities and our shared humanity enables us to perceive and relate to each other as equals.

5.5 VALUING DIFFERENCE WITHIN OUR SHARED HUMANITY

Another aspect of the paired concepts of respect and equality my participants identified, was the importance of *valuing difference* and diversity while simultaneously recognizing our shared humanity and similarities as discussed above. Peter (a special care home agency) pointed out that it was normal to recognize differences in human capacity – “you see the difference; it’s what you do with that. It’s how you process that thought”. *Every human being is unique* regardless of disability or ability. As Peter noted, it is how we respond to these differences that matters. Lorraine (a special care home agency) pointed out that there is so much discrimination occurring within our societies – not just with people with intellectual disabilities, but with visible minorities as well. Lorraine told me that “it just seems like we live in a society where sameness is what everybody’s goal is... we don’t strive to be different or unique; we strive to blend in”. Melissa admitted that many people tend to be afraid of the unknown, and this can cause them to be nervous or hesitant about embracing diversity. Sometimes people are more comfortable encountering physical and sensory disabilities, than they are with encountering a person with an intellectual disability. Ann (L’Arche) believed that her son experienced greater inclusion because he used a wheelchair. His classmates were familiar with this symbol of physical disability and they felt comfortable with it, even though her son also had intellectual disability as well. In comparison to some of his friends who were physically-able, but had intellectual disabilities that were less immediately obvious or predictable, Ann’s son was more frequently welcomed into social circles. People were more nervous and uncomfortable around the boys who had intellectual disabilities and no other obvious disabilities. Their classmates were more hesitant to interact with them. However, she anticipated that in thirty years people will have become increasingly more comfortable around people with intellectual disabilities. Melissa said that breaking down the barriers and facilitating social inclusion may need to begin with first identifying our differences,

trying to understand them, and then “just acknowledging that we’ve all got differences, but who cares”. In this way, difference would be normalized, rather than erased.

Managing the tension between valuing difference, and acknowledging our similarities and honouring our shared humanity emerged as essential for enacting the paired concepts of respect and equality. What does it mean to value difference? For example, does the use of the word ‘special’ indicate a valuation of difference? Although the word ‘special’ on its own tends to have a positive connotation and may be applied with good intentions to people with intellectual disabilities and the environments and activities they participate in, it sets up a dichotomy where the word ‘special’, as a reference to people with intellectual disabilities, is perceived as being the opposite of ‘normal’, a word that supposedly references people *without* disabilities. Participants did not always perceive the word ‘special’, as used in the terms ‘Special Olympics’ and ‘special care homes’, to be indicative of a valuation of difference by participants. Kate (L’Arche) described an inclusive society as one where there “would not be any ‘special’ because the world would run in such a way that different needs would be met... I think we will have reached social inclusion when the day comes where we don’t have to have anything special for somebody”. She described visiting Disneyland with one of their core members and how impressed she was at the inclusion she found there, both with the accessibility of the built environment as well as in the attitudes of the people that worked there. She told me that at Disneyland she observed that “it was not a hardship to accommodate difference. Instead of making accommodating difference a hardship, difference should be celebrated”. *All* human differences should be valued and celebrated, rather than making one type of difference ‘special’, which further isolates or segregates people. It is not about making everyone *the same*, or ‘normal’, but it is about making it acceptable for everyone in society to be different in a variety of ways.

My interview participants highlighted many different strengths and abilities they had noticed among the people with intellectual disabilities that they interacted with. Linda (NSDCS) expressed how welcoming they were and how uplifting it can be to spend time. Catherine (Stantec) spoke to me enthusiastically about their employee with an intellectual disability: “She is just like the most amazing person in the world, she’s just always happy and she has such a positive affect on the staff in this office...She can put a

smile on anybody's face". While Catherine mentioned the employee's efficiency at carrying out with her work-related cleaning tasks, the employee's less quantifiable traits also came through in the interview as being valuable contributions to the office environment. Jane (L'Arche) spoke of about how people with intellectual disabilities are often less inhibited than most people and are more prepared to encourage and bless others. She told me about a core member who greets new people she meets with compliments such as: "I like your hair, you look beautiful today". Jane told me that "you can tell that that's the waitress' or janitor's nicest interaction they've had all day. They just light up and like 'oh my god it's nice to meet you, what's your name?'" Melissa (Best Buddies) also spoke of how much society would benefit from the full inclusion of people with intellectual disabilities and from the contributions they can make to their communities. Kate (L'Arche) pointed out that people with intellectual disabilities may not fit into the economically-driven image of a "productive member of society", but from a gift-based perspective, such as the one L'Arche applies (Pottie & Sumarah, 2004; Vanier, 1997), people with intellectual disabilities have many gifts to share with us, as does every human being in this world.

Chris (Special Olympics) has been so impressed with the dedication of their athletes and he said that he has learned something at every single Special Olympic event he attends. He believed that their athletes can teach people a lot about the meaning of life. He told me:

I don't know how many races I've watched where one of the athletes has fallen and the other six guys racing against him (to get the medal and move up to nationals), in many cases are stopping and they're all going back and picking up that one person and making sure they're ready and then all racing from there... you'd never see that in the generic world, in a big competitive race.... so it's just kind of, it's the heart and soul that's really different. They have a lot to teach the general public on just the meaning of life.

Ann (L'Arche) commented that what she has learned from her son and the other core members was "unbelievable". She also referred to them as being so welcoming and kind. However, not all people with disabilities are 'welcoming and kind' as the participants have described. Kate (L'Arche), for example, spoke about the "harshness" and severity of

Ian's Brown's (2010) son's disability in *The Boy in the Moon*. Like other people without disabilities, people with intellectual disabilities can have a bad day. However, Kate pointed out that regardless, people with intellectual disabilities are "usually very honest about who they are. What you see is often what you get... and they develop a great trust in people". Alison (L'Arche) wanted to see a world where people with intellectual disabilities could be recognized for what they have to offer. Recognizing people's unique gifts and contributions empowers them, and facilitates inclusion into a society of equals. Edward (People First) commented that even in the cross-disability community he feels like people with other disabilities (e.g. sensory and physical disabilities) have sometimes devalued the contributions of people with intellectual disabilities, but he believed strongly, that people with intellectual disabilities have just as much to contribute to society. Acknowledging and encouraging the different types of contributions made by people with intellectual disabilities in our society, is a way of enacting respect and equality.

5.6 SUMMARY

According to participants, it is natural for humans to notice differences. However, differences can make us uncomfortable or make us feel threatened, causing us to draw closer to those who are more similar to us while trying to distance ourselves from people who seem different from us (Pickering, 2001). As discussed in Sections 5.4 and 5.5, participants indicated that achieving respect and equality for people with intellectual disabilities involves recognizing both our *similarities* and the common denominators we share as fellow human beings, as well as valuing the *differences* within our shared humanity. These differences may include different ways of communicating, different types of 'contributions' to society, and differences in abilities, which is sometimes referred to as 'ability diversity' (Burt, 2007). I also discussed participants' belief that when there is a deficit of respect and equality, people with intellectual disabilities experience stigma and discrimination, and this can detrimentally impact the way they perceive themselves. Based on my data analysis, the paired concepts of rights and equality were more central to participants' understanding of social inclusion, than whether a particular environment or activity was segregated or not. Participants indicated that achieving social inclusion for people with intellectual disabilities requires people

without disabilities to perceive them as equal human beings, and to treat them with the respect they deserve as equal human beings. Respect and equality are the first set of three paired concepts that form my explanatory theory and my definition of social inclusion. In the next chapter, I present the second paired concepts of opportunities and self-determination.

CHAPTER 6: THE EXPLANATORY THEORY (OPPORTUNITIES AND SELF-DETERMINATION)

6.1 INTRODUCTION

The concepts of ‘opportunities and self-determination’ are the second set of paired concepts that emerged as central to my explanatory theory and my participants’ understanding of social inclusion. In this chapter I will first explain why I have chosen the words ‘opportunities’ and ‘self-determination’ to refer to the concepts that emerged in my interviews with participants. In particular, I will provide reasons to justify my choice to use the word ‘self-determination’ instead of ‘independence’ and ‘autonomy’, which are closely related words. In Section 6.2, I will demonstrate how my participants drew on the concepts of opportunities and self-determination to make arguments against or in favour of the four segregated environments and activities discussed in Chapter Four. In Section 6.3, I will discuss the differences between independence, dependence, and interdependence that emerged in the interviews, as this discussion further clarifies how participants understood ‘self-determination’. Section 6.4 and 6.5 continue to describe how participants understood the concepts of opportunities and self-determination by identifying how these concepts could be enacted through supported decision making, removing barriers to opportunities, and allowing people the dignity of risk.

The concept of self-determination, as defined at its most basic level, “involves people controlling their own lives and determining what they want to do or not do” (Stroman, 2003, p. 208). Stroman (2003) describes self-determination as a “social movement” that began taking shape in the late 1980s following the move to deinstitutionalize people with intellectual disabilities. The concept of self-determination has gained new significance in recent years as it has been carefully incorporated into agency programming in new and deliberate ways (Bach, 1998; Stroman, 2003; Walker et al., 2011). I paired the concept of self-determination with the concept of opportunities, because providing people with intellectual disabilities the freedom to make their own decisions and take control of their lives, necessitates the pre-existence of opportunities for them to pursue, to engage in, and to choose between. There are other terms and concepts that are related to, or implicated by, the enactment of opportunities and self-determination. First, there is the concept of independence. The concept of independence

is prevalent in disability literature; particular through its association with the ‘independent living movement’, which began in the 1970s (University of California Berkeley, 2004; Brisenden, 1986). The independent living movement defines an independent person *not* as “someone who can do everything for themselves, but to indicate someone who has taken control of their life and is choosing how that life is led” (Brisenden, 1986, p. 27). Although this definition is aligned with the concept of self-determination, I have not incorporated the concept of independence into my definition of social inclusion, because readers may confuse it with the concept of *being ‘independent’* as defined by the Merriam-Webster’s (2015) dictionary: “not requiring or relying on others”. Many participants made it clear that they did *not* agree that this dictionary-based definition of independence was a vital component of social inclusion. To avoid conceptual confusion, I decided that the concept of self-determination best represented what my participants were describing. It is about being able to make choices; not about physical independence per se.

There is also the related concept of *autonomy*, which is defined by the Merriam-Webster’s Dictionary (2015) as meaning “self-governing” or “self-directing”. Cardol, De Jong, and Ward (2002) write that the “most influential model of autonomy in Western countries is the individualist-liberal view, which stresses freedom of *choice* and *action*... [and] tends to *equate autonomy with physical independence*. As a result, dependency measures are widely used as markers of quality of life” (p. 971, emphasis added). Many people with intellectual disabilities (particularly if they have additional physical disabilities) are not able to exercise physical independence and they have to rely on support to achieve daily tasks. Consequently, they would be scored low on a quality life measure that included an individualist-liberal definition of autonomy as one of the measures. Therefore, Cardol et al. (2002) address this issue with terminology by making several recommendations. Cardol et al. want to see a distinction between two different types of autonomy – executional autonomy and decisional autonomy. Whereas Carol et al. define *decisional autonomy* as being able to “make decisions without external restraint or coercion, e.g. deciding when and how to get dressed”, they define *executional autonomy* as the “ability and freedom *to act* on the basis of decisional autonomy, e.g. actually dressing oneself as one wishes” (2002, p. 972, emphasis added). According to

this definition, executional autonomy equates with physical independence. In contrast, Cardol et al. believe that decisional autonomy is more closely correlated with the goal of self-realization; “the ability not only to make choices freely and independently, but also to shape one’s life into a meaningful existence which expresses individuality” (Cardol et al., 2002, p. 972). Both types of autonomy are important, but I have decided to utilize the concept of ‘self-determination’ rather than ‘autonomy’, to avoid confusion with the concept of *physical independence*, which autonomy is sometimes equated with. Self-determination (which is closely related to *decisional autonomy*), is defined as the ability to shape one’s life by making decisions and choices, and it is the concept that most accurately captures what emerged throughout my interviews with participants.

6.2 APPLYING ‘OPPORTUNITIES AND SELF-DETERMINATION’ TO THE FOUR CONTENTIOUS TOPICS

6.2.1 ‘OPPORTUNITIES AND SELF-DETERMINATION IN LIVING ENVIRONMENTS

Participants used the concepts of opportunities and self-determination to highlight both the detrimental aspects of living in a special care home, as well as its benefits. Donna (NSACL) made a strong case *against* congregate special care homes that limit the freedom and self-determination of their residents. She observed that when people were allowed the *opportunity to make choices* in their lives, their ‘difficult behaviors’ diminished. The paired concepts of opportunity and self-determination were also used to argue *in favour* of special care homes. Linda (NSDCS) noted that some people want, and require, the care and supports that can be delivered in special care homes, even in their larger institutional form. She acknowledged that her client’s choices may be different than her choices. Linda told me, “I’m always cognizant that I should not enforce my own standards on them. What makes me happy might not make them happy”. By providing this option of care and support services for those who wanted and needed it, it could be argued that the concepts of opportunity and self-determination were potentially enacted through the provision of special care home services. The concepts of opportunity and self-determination were apparent when Ann (L’Arche) told me that her son had *gained* independence when he moved out of his family home into a special care home run by L’Arche. Several participants mentioned that protective parents are often a barrier to

achieving social inclusion for people with intellectual disabilities. It is natural for parents of people with intellectual disabilities to be protective, but it is also important for people with intellectual disabilities to be allowed to “claim their adulthood”, as Kate (L’Arche) described it, and be empowered to make their own decisions.

Ann (L’Arche) admitted that when her son first moved from his family home into a L’Arche community, it was a big adjustment and learning experience for her as a parent, as well as for her son. She learned to how to step back in order to let him live his own life, whereas he learned to rely less on his parents for support and guidance, and more on his own ability to stand up for himself and exercise self-determination. Special care homes vary significantly in their size and in how they operate on a daily basis. In a best case scenario, special care homes cultivate traits of autonomy and self-determination by providing more opportunities to participate in daily activities than people may have had in other living arrangements. As mentioned previously, Allen (RRSS) told me how at RRSS they have created resident councils composed of client representatives in an effort to provide them with the opportunity to have greater authority within the agency and hold the staff accountable to their clients. Lindsay (RRSS) expressed that it was exciting to observe these residents becoming self-advocates on the council: “People are learning that they’ve always had [their own power], they just didn’t know it... finding their voice and that’s, I think, far more powerful than us using our voice on behalf of somebody else”. These examples illustrate how the paired concepts of ‘opportunities and self-determination’ can be used to make a case against, or in favour of, special care homes in various situations.

There is always the risk that special care homes can unconsciously promote a culture of dependency in their attempt to care for people with intellectual disabilities and keep them safe. My interview participants acknowledged that providing opportunities for inclusion, participation, and self-determination, often required the care-giving staff to resist defaulting to what seemed to be the easiest and most efficient solution or approach. To support the self-determination of people with intellectual disabilities care-givers and assistants often need to expend more energy and effort in order to offer a broader range of opportunities. It might be tempting to jump into complete a task for someone with an intellectual disability, but if they do not request assistance, completing a task for them

may deprive them of their right to exercise autonomy and self-determination. For example, Allison described how one of the core members really enjoyed cooking and liked to help out in the kitchen. She admitted that it can be difficult for assistants, herself included, to truly allow the core member the space and opportunity to explore her independence in the kitchen. She explained that the typical default response was to give the core member the task of making the salad and setting the table when in fact, the core member was actually capable of taking on a more complex task and had the desire to do so. Although Alison was aware that sometimes they, as assistants, can get lazy or busy, and sometimes neglect to prioritize a core member's right to self-determination and their desire to participate, she recognized how vital it was to include them in these types of opportunities. She commented on the nice moments of connection that can develop between assistants and core members when they worked on tasks together. In another example, Ann (L'Arche) described a situation where she observed an assistant and a core member working together on building a garden frame. It was obvious to her as an observer that the task could be done more efficiently if the assistant did it by themselves, but she was impressed that the assistant patiently supported the core member's autonomy and participation in the task. These examples highlight *the potential* for increased opportunities and self-determination to occur in a special care home.

Initially, when her son first moved into a L'Arche special care home, Ann was not thoroughly satisfied with L'Arche's support of her son's desire to exercise self-determination. However, Ann acknowledged that the assistants cannot be expected to appropriately support self-determination in *every* situation. Living in a L'Arche community as an assistant is a continual process of learning and personal development, as it is for the core members as well. It requires frequent critical self-reflection and awareness to create a culture of respectful interdependency that supports personal independence, and wards against a culture of dependency, which undermines self-determination. Ann encouraged her son to speak up if he felt his right to self-determination was not being fully respected. A year following his move to a L'Arche house, Ann reported that her son was now comfortable with speaking up and exercising his decisional autonomy, and the assistants that work with him have learned how to better support his right to self-determination. Claire (L'Arche) explained to me that as care

providers and community members, L'Arche assistants have the responsibility to provide both the opportunities and the necessary supports to core members to enable their participation in decision-making and their independence within an interdependent framework and environment.

In the same way that RRSS has made progress toward supporting greater self-determination for their clients through the residents' council, Allison (L'Arche) has also observed a new emphasis on the core member's choice at L'Arche. When a decision needs to be made Allison's job now requires her to speak with the core member *first* (e.g. before contacting family members) and provide the information necessary so that the core member can make an informed decision that is aligned with their preferences. Allison had also seen a significant difference in the way that L'Arche community vacations are organized. Usually, during the two weeks of community vacation in the summer, all core members and assistants were assigned to different groups that they would travel with to their vacation destination. While community vacation should presumably be a fun opportunity to go on an exciting trip and enjoy a break from work and routine, it can backfire in some cases. For some core members (and assistants), community vacation ended up being more stressful than enjoyable. L'Arche Homefires recognized that many people did not actually like to go on big trips because it was too disruptive for them. In the summer of 2011, the community decided for the first time to try to tailor the vacations more to the desires of the core members and to ask each of them how they would like to spend their vacation. While some people might assume that going on a big trip to somewhere exciting like New York or camping on Prince Edward Island would be preferable to staying at home, not everyone shares this perspective. For example, a core member living in L'Arche Homefires, was thrilled that she had the opportunity to design her own vacation. I spoke with her a few months before community vacation and she was excited that she would be able to choose the people she wanted to travel with and decide what she wanted to do. Because this core member was more independent than some core members, she found that during vacation the assistants would pay more attention to the core members with higher needs. Normally, the core member explained to me, they traveled in big groups, but she was able to assert her preference to travel with a smaller group. She also disliked staying overnight away from home and she thus had decided that

her community vacation would be spent doing shorter day trips to different places in Nova Scotia. She told me enthusiastically that this year her community vacation was “going to be awesome”. It was clear in my interviews that special care homes were capable of both depriving their residents of choices, *and* of enacting the paired concepts of opportunities and self-determination.

6.2.2 ‘OPPORTUNITIES AND SELF-DETERMINATION’ IN EDUCATION

Both Melissa (Best Buddies) and Donna (NSACL) spoke of the potential of the inclusive education model, but expressed that there were many ways that schools could improve on the model by increasing their inclusivity. Melissa commented that there were so many fun extracurricular activities available through the school system (e.g. sports teams, dance, choir, band), but unfortunately students with disabilities were not always encouraged to participate in these opportunities. Donna commented that sometimes children with disabilities were excluded from school excursions if their parents were not able to take time off work to support them during the trip. They both wanted to see more inclusion in the school system and identified examples where the paired concepts of opportunities and self-determination were lacking. In contrast, Jane (L’Arche) used the concepts of opportunities and self-determination to make an argument *against* inclusive education. She believed that an education that was more individually tailored to the needs of the individuals would be more beneficial for people with intellectual disabilities. Jane argued that individually tailored education and supports may be better provided in a segregated environment. She believed it was unfortunate that the choice and the opportunity to learn in a specialized setting was not often offered to students with intellectual disabilities because of the dominance of the inclusive education model. Claire (L’Arche), Ann (L’Arche), Allison (L’Arche), Allen (RRSS) also wanted to see students with intellectual disabilities receive an education that was tailored to their capabilities, as well as their dreams and goals for the future. This tailored, person-centred approach that they advocated for, highlighted the concepts of opportunities and self-determination. For example, participants indicated that if a student dreamed of obtaining community employment in a certain area, specialized training could be incorporated into their education, which would enable them to accomplish this goal and increase their *future opportunities*. According to some participants, this could prove to be a more significant

contributor to social inclusion than engaging in mainstream academic curriculum within the spatially inclusive classroom. The concepts of opportunities and self-determination emerged again as central to their arguments.

6.2.3 ‘OPPORTUNITIES AND SELF-DETERMINATION’ IN WORK CONTEXTS

The paired concepts of opportunities and self-determination also emerged when participants discussed ASCs and community-based employment. In Chapter Four, Donna (NSACL) shared a story about a man with an intellectual disability who dreamed of having the opportunity to work in a community-based job, but the ASC never allowed him the chance to act on this desire. However, other participants, such as Peter (a special care home agency), told me of clients they knew who had obtained a community-based job position, but then chose to return to an ASC where they felt more comfortable, thus exercising their self-determination. Peter cautioned against using a standard measure of success that evaluates progress toward social inclusion by simply counting how many people have jobs in a community. He told me, “At the end of the day you have to go to that person and ask them, are you happy with this job? Is this what you want? That’s where the measurement should come from – is from the individuals. *And then I believe it is true inclusion*”. Peter believed that agencies should be self-reflective and ask themselves: “Am I forcing that person just to get a job because they have to have a job? Have they had all kinds of choice in this?”

Peter recalled a story of one of their clients who had secured a community-based job, but was not enjoying it. The client was not able to maintain the position at that time and he was looking at other options. Peter told me: “You can’t get any more normal than that”. Peter emphasized that just because that particular job did not work out for that individual, the conclusion should not be that he is was not capable of employment in the community. However, Peter pointed out that sometimes a client simply does not want to have a job, and that is also a legitimate choice. Regardless of whether they decide they want a job or not, people with intellectual disabilities need to know that that opportunity is there and that they have access to the supports they require to obtain employment if they decided that they wanted to. Peter noted that all of us struggle with various issues in life and have to maneuver and navigate different circumstances on a trial and error basis

in society. Many people (with and without disabilities) accept job opportunities that they do not enjoy, and then they need to reflect and make a decision that is best for them. For Peter, social inclusion begins with giving people opportunities so they can make appropriate decisions. People with intellectual disabilities, just like anyone, need to pursue options and test them out to see if they are a good fit. Sometimes they are not a good fit, and that's life. That is normal. Then you start looking at your other options.

Claire (L'Arche) echoed Peter's statements and emphasized the importance of opportunities and self-determination when she told me: "I think as long as we are not asking ourselves sheltered versus non-sheltered [i.e. ASC versus community employment], if we're asking ourselves what's the best for the individual than we are asking the right question". She believed that some individuals were truly going to be more comfortable and happy in a segregated ASC environment while others would be happier working in the community. Kate (L'Arche) noted that our society often "defines a person's value by their job or by what they contribute as a productive member of society, and we have a certain mind-set about what productivity is". She believed that people with intellectual disabilities are productive members of society, but not necessarily in a way that meets society's economically-driven definition of productivity. For some individuals it may be extremely difficult to find a job position that is a perfect match for them and allows them to utilize their strengths, especially if they have more profound disabilities. For example, Kate described one core member who is quadriplegic, does not speak with understandable language and would probably not be seen as a productive member of society, but "she has the most incredible gift of welcome". Kate told me that "you will never be welcomed as greatly as you will be by this woman". To try and convince someone, such as this individual, that community-based employment was the most ideal option for them, may not be in their best interest. This woman deserves the opportunity to access an environment where her contributions will be recognized and appreciated.

Claire (L'Arche) shared that for her it comes down to "honoring choice". She said, "Our people don't always have the choice because the resources aren't always there, but if the resources are there, we can offer the choice to the individual, [then] I think that's the best way to go". In an effort to 'honor choice', as part of L'Arche's person-

centred planning process, every year L'Arche staff ask core members a set of questions that include a question about whether they want to work only with people with disabilities, or if they would rather work with people with and without disabilities. Many of the core members at L'Arche Homefires work in L'Arche's ASC (Applewicks), but other core members work at jobs in the community and also volunteer at various places. Allison (L'Arche) noted that even when people are provided with choices in an unbiased and informed way, their ability to exercise self-determination can still be undermined. She referenced an individual who worked at both Applewicks and at a fast food restaurant. It was clear that his parents valued the employment at the fast food restaurant, but did not value his work at Applewicks as much. When the client said that he did not want to work at Applewicks, Allison was not sure if it really was his freely made choice, or if it was the influence of his parents' preference, or a combination. Regardless of whether the core member was influenced by his parents or not, informed and genuine choice should always be something to strive for.

During my interviews, participants highlighted many different employment or work options that people with intellectual disabilities could potentially choose from. These included working in the community; in a sheltered workshop; working part time in both the community and sheltered workshop; job sharing; starting a family business; volunteering; and not working at all. Participants noted that unfortunately sometimes the range of choices and opportunities is not as broad as it should be and because of a lack of resources, some choices are less appealing than others. Therefore, even if people are provided with choices, if certain choices are less appealing due to a lack of resources or societal barriers, social inclusion may not be fully manifest because the available *opportunities* are not as good as they could be in order for people with intellectual disabilities to truly exercise their *self-determination*. For example, as previously mentioned, for people who want to find gainful employment in the community, this aim might not be a financially viable option for them because if they earn more than \$150 a month while on income assistance the majority of their additional earnings is appropriated by the government to go toward paying for their living expenses (Nova Scotia Department of Community Services, n.d.). Many people with intellectual disabilities are not able to work enough hours at a sustainable wage that would allow

them to step away from income assistance and the health benefits that accompany it. Furthermore, as Allen (RRSS) pointed out, government policies around income assistance discourage employment because,

if you do find yourself gainfully employed, and are making a living wage ... and can get out of the system, if you [then] find yourself on hard times again [because] your disability creates difficulty for you again and you have the need to go back to get assistance, you essentially have to prove again how disabled you are so that you can get that money back. So it creates a dependence that many people have said over the years I'm not even going to try, it's too hard.

Edward (People First) informed me, "I've never met anyone who says they don't want to work, I have met many people who say I can't work because I'll lose my supports". In this way, income assistance policies *limit* the opportunities and self-determination of people with intellectual disabilities.

6.2.4 'OPPORTUNITIES AND SELF-DETERMINATION' IN SPORTS

Again, as with the other areas discussed, participants indicated Special Olympics should be just one choice among many valid choices. People needed to have options. Kate (L'Arche) did not go so far as to say all segregated activities (or anything with the word 'special' in it) were not beneficial, but for her it was about giving people choices and opportunities. Kate told me:

I think for me, if the only choice that's given to somebody is to bowl with Special Olympics then that certainly goes against everything about inclusivity. Like if the only option for people is to work in a sheltered workshop [i.e. ASC] then that's where I have a problem. If the only thing available, or the only thing that's offered, is something that isolates people then there's a problem for me. So for me if somebody is introduced to bowling with Special Olympics, in an ideal world, we would also be able to find an integrated bowling option for them and then let them choose. And we never do that. Like for the most part, as caregivers, Special Olympics is easy.

Special Olympics is usually the more convenient option for the caregivers. As Kate pointed out, it required more energy and effort to find and approach generic sporting teams and advocate for the person with the disability to have the option to join. However,

this extra effort and advocacy was necessary in order to be able to provide a wide array of choices. For Kate, offering an array of choices was essential to inclusion. She emphasized:

It's like if you say to me that somebody loves chocolate ice cream and you've only ever offered them vanilla and chocolate, then how do you know they won't like strawberry? How do you know that they actually would prefer frozen yogurt than ice cream? So part of our job as caregivers is to try and have the menu as broad as it can be. But sometimes that takes a lot of energy, *a lot* more energy, and I think that's why we'll choose the easier option, which is the Special Olympics or you know the coffee house that's just for people with disabilities. And there's nothing wrong with those things, as long as it's not the only option. But it generally is the only option. And it further isolates people in some ways.

In this quote, Kate was referencing the concepts of opportunities and self-determination. According to her, these components of social inclusion are often missing when people with intellectual disabilities participate in Special Olympics because they are rarely given a *choice* of whether to participate in Special Olympics or another sporting or recreational activity. Donna (NSACL) expressed that she would prefer for Special Olympics to be a program that anyone could participate in; in other words, she would like it better if it was not segregated. When Donna works with people with intellectual disabilities she tries to present them with information on a broad range of activities – not just Special Olympics – so that they can exercise self-determination and make an informed choice.

Participants also used the concepts of opportunities and self-determination to make arguments in favour of Special Olympics. Allen (RRSS) and Chris (Special Olympics) both commented that through engagement with Special Olympics, they have witnessed people with intellectual disabilities growing in confidence and recognizing that “they can have the same things that they see other people having”. Therefore, through Special Olympics the athletes' horizons have expanded and they have identified additional opportunities that they would like to pursue, such as acquiring employment in the community. Special Olympics has also indirectly created more job opportunities as volunteers and sponsors involved in Special Olympics see what the athletes are capable of and are propelled to create other opportunities for them.

In summary, in this section I returned to the debates outlined in Chapter Four to illustrate how the paired concepts of opportunities and self-determination emerged as key components of social inclusion to make arguments against, or in favour of, special care homes, segregated education, ASCs and Special Olympics. Sometimes participants pointed out how people with intellectual disabilities had *not* been provided with a range of suitable opportunities within, or in relation to, these segregated environments and activities. They indicated that spatially segregated environments and activities could hinder self-determination and the experience of social inclusion. In other examples, spatially segregated environments and activities were described by participants as supporting self-determination and contributing to increased opportunities for people with intellectual disabilities in both their immediate short-term and long-term future. Ultimately, the concepts of opportunities and self-determination appeared to be more important determinants of social inclusion than whether or not the setting or activity was considered segregated or not. The paired concepts of opportunities and self-determination are the second key components of my explanatory theory, which seeks to explain how participants were able to justify their divergent opinions described in Chapter Four. In the remainder of this chapter, I will provide examples from my interview data that expand on how participants understood the concepts of opportunities and self-determination.

6.3 INDEPENDENCE, DEPENDENCE AND INTERDEPENDENCE

In this section I discuss the differences between independence, dependence, and interdependence that emerged in the interviews, in order to expand and clarify my participants' understanding of 'self-determination'. One of the reasons L'Arche communities are perceived as a unique, or even *radical*, model of care (Angrosino, 2003), is because L'Arche philosophy does not emphasize independence for people with intellectual disabilities. Instead, they acknowledge that all human beings have weaknesses and vulnerabilities, and consequently they emphasize our *interdependency* rather than our independence (Kelly, 2007; Pottie & Sumarah, 2004). In her study of a L'Arche Community in Winnipeg, Kelly (2007) states that "the most apparent counter-cultural value of L'Arche communities is the rejection of the idea that 'independence' is the ultimate goal for people with disabilities" (p. 26). During my interviews with L'Arche members (core members and staff) as well as parents of core members, I would state

Kelly's (2007) quote about independence and then ask them to respond to it and indicate whether they agreed or disagreed. Kate (L'Arche) responded to the quote with the following:

I think independence isn't necessarily a value in L'Arche. *Interdependence* is more of a value. At the same time, *dependence is not a value*. So there's a fine line between a person being supported to be as independent as they can be, so that they can make their own choices. So for example, if a person can learn to wake up to an alarm clock, that reduces their dependence on the system. It somehow increases their independence, but it also allows them to make *the choice* about when they want to get up, so that's why for me, you teach the person the skill to benefit the person.

According to the majority of my participants, it was clear they believed that the concept of 'independence' (i.e. not relying on anyone or anything else aside oneself) should be *subservient* to the concept of 'self-determination'. So although participants did not want to encourage someone to become more independent just for the sake of becoming more independent, developing one's capacity for independence was perceived to be beneficial if it supported an individual in exercising their self-determination.

Ann said she hoped that although her son lived with both physical and cognitive challenges, he would still be encouraged to live as independently as possible while at L'Arche. Ann realized that her son would not be able to live in an apartment by himself and she would not want that for him, but she would still like to see him be able to function more independently in different areas of life. When I presented Kelly's (2007) aforementioned quote to Ann, she deduced that for her, the meaning of independence was about having *access to choices*, rather than about being able to do everything by oneself. Ann told me how her son used to attend a centre that focused heavily on developing independence. Her son did not like it at all. Since it was difficult for him to participate independently, he would end up sitting alone by himself; excluded. The staff would not engage with him or help him regularly, because they expected him to figure out what to do on his own and learn independence, even if this was not realistic for him or what he wanted. Consequently, her son was bored and lonely there. She was satisfied with L'Arche, because L'Arche enabled him to make choices in life and for the most part,

supported his independence. However, he was not left alone and *forced* to be independent. In other words, L'Arche encouraged self-determination and developed the independence of core members for the purpose of empowering them to make their own decisions. They do not focus on building independence simply for the sake of being independent like Ann's son experienced at the centre he attended.

Kate (L'Arche) explained how a few years ago someone from the Department of Community Services was appalled that there was no toileting training program in place for one of the core members who relied on incontinence products. The lady from the Department of Community Services insisted that L'Arche implement a toilet training program for the core member that would involve the core member being forced to sit on the toilet every two hours until she learned how to use it. Kate told me that the core member hated to use the toilet and she questioned what the point would be of toilet training her. The person from the Department of Community Services responded that they should do it because "it would increase her independence". They had attempted toilet training the core member in the past and the attempt had been a miserable process and eventual failure. Kate said,

Years ago somebody had said that she should learn to use the toilet and it caused this poor woman such stress, and grief and anger and there were more incidents cause she literally had to be held on to the toilet. To me that's just inhumane.

Like, you can't do that to a human being. She's clearly saying, 'I don't want to do this'. She's non-verbal, she will need 24-hour support all her life – the least of her issues is the fact that she doesn't go to the toilet independently.

When the Community Services staff member tried another approach by arguing that toilet training the core member would relieve the staff of doing her personal care, Kate responded that the staff should not be in this field of work if they do not like doing personal care. In L'Arche communities, personal care is not treated as a burden. They see it as a privilege to be trusted in assisting a person with a disability with these sensitive tasks. However, the Community Services employee simply could not be shifted from her perspective that L'Arche was limiting the core member's independence by not toilet training her. Kate believed that people should be supported in gaining the independence necessary to enable them to achieve their personal goals and to increase their capacity for

self-determination. Unfortunately people with disabilities can be pressured to work toward other people's goals, all in the name of 'gaining independence', which is assumed to be for the benefit of the person with the disability. Kate explained:

So it's like for a person with a disability, they are constantly having to meet goals that are set by people who believe in programs creating independence. I would hate that. Like, I don't want to live with constantly having to achieve somebody else's goals. And then when I get there, they change the finish line again... So right, I think in L'Arche we're much more about interdependence than independence.

Interdependence involves mutual reliance on each other, rather than everyone relying on their own strength and abilities alone (independence).

Claire (L'Arche) explained that by focusing on involving people in decision making processes and supporting them in exercising their self-determination, L'Arche avoids creating a culture of dependency, while simultaneously resisting the glorification of independence for its own sake:

So yah as far as choices, we're all about choices and making sure people are making the choices that they're able to make and if they can't, that they're involved in the process. But we don't think someone needs to be able to walk down the street alone to have a great quality of life.

She disagreed with what she called 'the independence agenda', which can become an all or nothing approach that risks losing the individual in the process. Within the independence agenda, independence becomes the goal in itself, rather than the achievement of the person's own individualized goals. Claire emphasized that it really comes back to focusing on the individual – their preferences, their choices, and capabilities – rather than adopting a harmful "all or nothing" approach to achieving independence. She said,

Every person who is in this house is independent to the degree that they're able to be. So we have someone who can, you know, she does all her own medical appointments, she takes her own medication. She can leave here and take her bus independently to Sackville. We have other people - it's just not safe for them to leave this house without one of us with them... So we focus on ways that they can

be independent and [what] choices are important to them and if there's a decision that they're not able to make [alone], they are part of the decision making process. So all of our members, any decisions that they can make on their own, they make them.

The philosophy of L'Arche indicates that no one is completely independent, including L'Arche assistants (Vanier, 1997). Both the assistants and the core members participate in the interdependency of L'Arche communities and they engage with the reciprocity of friendship and support shared between themselves and other members of the community.

Many of my research participants recognized that no human being is truly 'independent', regardless of whether they have a disability or not. Allison (L'Arche) cited the example that most people rely on farmers and grocery stores to obtain the food they need. While acknowledging the value of interdependence, Alison could still see how important it was for many of the core members to complete tasks and activities on their own if they were able to. It might not be important for all core members to do all tasks independently, but certainly she had noticed that for some of them completing some small acts independently was "a matter of pride and accomplishment". Exercising independence is still important within the larger context of interdependency; an interconnected web of which all humans are a part of (Armstrong et al., 2009; Etmanski, 2002). The concept of interdependency is an integral part of L'Arche philosophy (Cushing, 2002), but other research participants outside L'Arche also referenced the concept. For example, Peter (a special care home agency) found that the concept of 'independence' was overused in the disability field and he made it clear that he did not think anyone truly lived independently in this world:

Cause what really is to be independent? Does that mean that you're living by yourself without any supports, taking care of yourself...? Sure. But some people can't. I don't want to. I can't. I need to be interdependent on a lot of things to get me through my life. So, to me it's having choices to be able to make your web so that you can have whatever you need to move yourself forward. So it's an interdependence on a lot of things - friends, family, vocational, educational - it's all together. So I strive towards interdependence, not so much independence, because really at the end of the day you're not standing on an island by yourself.

Having opportunities, choices, and being able to exercise self-determination was perceived as more valuable than living independently. Even participants who were unconnected to L'Arche communities, expressed that while they believed that independence was important, they did not perceive it as being vital to social inclusion in the same way that the ability to exercise self-determination and make choices was.

6.4 SUPPORTED DECISION MAKING

In order to make the abstract and intangible concepts of opportunities and self-determination more applicable to specific situations, I will expand further on how participants believed these concepts could be enacted through supported decision making. Supported decision making is a method that can be used to assist someone who needs some help making a decision (Devi, 2013; Werner, 2012). The *Handbook for Parliamentarians on the United Nation's Convention on the Rights of Persons with Disabilities* (United Nations Enable, 2007) describes supported decision making as follows:

The individual is the decision maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual. Even when an individual with a disability requires total support, the support person(s) should enable the individual to exercise his/her capacity to the greatest extent as possible, according to the wishes of the individual. (p. 90)

Lindsay (RRSS) believed that having choices and opportunities was essential to social inclusion, but she also believed that it was important that the person with the intellectual disability was informed and educated about the pros and cons of all their options so that the individual was in a position to make the best choice for themselves. Claire (L'Arche) provided the example of how one of the male core members had asked for an assistant to paint his fingernails dark brown after he observed the assistant painting the nails of a female core member. He was thrilled with the results and felt like "a rock star". When his mother came to visit him later that day she expressed displeasure with his painted fingernails and said that the core member's father would be really upset about it. Claire spoke with the core member about the incident afterwards and reinforced that as an adult, it was completely his decision whether he wanted to keep the nail polish on or not. She told him:

It's our job to kind of let you know the consequences of your actions. If you choose to do this, this could happen. If you choose to do that, that could happen, but in the end the choice is yours. I said unless you're going to put yourself or someone else in danger or break a law, then I'm not going to step in. But other than that, your choices are yours.

Claire was able to support the core member in making an *informed* decision without compromising his autonomy. The next day she noticed that he had removed the nail polish. When she asked him about it, he replied that he removed the nail polish because he was going to see his father that day and he did not want to upset him. He had decided that the consequences of keeping the nail polish on and upsetting his father were not worth it to him. However, he added that immediately after his visit with his father he planned to put the nail polish back on. In this example, the core member was able to successfully exercise his decisional autonomy, guided by an understanding of the consequences of his available choices.

Allison (L'Arche) provided me with another example of supported decision making. At the time of my interview with her, there was a political election approaching and Alison had been working on explaining to the core members what the different political parties stood for, so that they could make an informed choice about who they wanted to vote for. She was finding it difficult and complicated to explain some of the concepts and differences between the party platforms. One of the core members indicated that they wanted to vote for a certain politician because one time the politician took a photo of them together. While this may not appear to be an example of informed decision-making to some people, Alison pointed out that there are many people *without* intellectual disabilities who did not understand politics and would not be considered 'educated voters' by some standards. Voting for a politician because he took a photo with her was the core member's legitimate choice. In the same way that it was also a legitimate choice of another core member to not vote because they were uninterested in politics and did not want to. According to participants, supported and informed decision making needs to be undertaken with a high level of reflexivity on the part of the supporter to ensure that they are not evaluating the person's decision or decision-making process according to their own standards, and subtly trying to influence them toward one choice

over another. Melissa (Best Buddies) noted that rather than “assuming we know what’s best for [people with intellectual disabilities] and dictating what their life is going to look like”, we should use creative approaches to supporting them with decision making, such as the use of pictures representing different options that can be pointed at for someone who is nonverbal.

According to Edward (People First), the majority of people in society, disability or no disability, rely on external support and guidance in making life decisions. He rejects the idea that the concept of supported decision-making only applies to people with intellectual disabilities. People make many other personal life decisions in consultation with their partners, families, and friends. This is an example of how we are all *interdependent* and we rely on each other throughout the life course. Edward acknowledged that some people may need more careful and detailed explanations of the available choices, as well as the pros and cons of potential decisions, but he pointed out that sometimes care providers go beyond providing reasonable support in decision-making to the point where it becomes patronizing and condescending. Edward believed that everyone should have access to opportunities and choices, as well as access to respectful consultation services to help them make an informed and educated decision.

Allison, a L’Arche assistant, commented that she had noticed a change at L’Arche within the past two years when they began using the Personal Outcome Measures® tools. Personal Outcome Measures® were developed by *The Council of Quality and Leadership* (CQL) in 1997. Rather than assessing the quality of services according to a general set of standards and criteria, the use of Personal Outcome Measures® identifies “whether the services and supports are having the desired results or outcomes *that matter to the person*” (CQL, 2015, emphasis added). Person-centered, or person-directed planning, is central to this approach. Person-centered planning involves focusing on the unique needs and desires of the person living with the disability, rather than on what professionals and care providers perceive to be the needs and goals of the individual (Dingwall, Kemp, Fowke, 2006; Stroman, 2003). Within a person-centered planning approach it is people living with intellectual disabilities who are defining what ‘quality of life’ or a ‘good life’ means to them as individuals. They are exercising their self-determination by setting their own goals and priorities that they believe will support them in creating the good life that

they envision. In a 2008 report, commissioned by Nova Scotia's Services for Persons with Disabilities (SPD) program to assess ASCs and day programs in the province, the authors indicate that while the majority of service providers in the province tailor their programs to the individual to some extent, it was the minority that were truly utilizing person-centered planning and tools such as Personal Outcome Measures® (NSDCSSPD, 2008). Both L'Arche Cape Breton and L'Arche Homefires were two service providers that were noted in the report as having a strong commitment to achieving person-centered outcomes; "the stated choices and goals of the individual participant" (NSDCSSPD, 2008, p. 11). However, L'Arche was certainly not the only service provider to put person-centered planning into practice. Peter and Lorraine (a special care home agency) also discussed the goal setting they do each year with their clients. They emphasized that "it's not our goals, it's their goals". In making this statement, they were indicating their support of self-determination for people with intellectual disabilities.

6.5 OPPORTUNITIES, CHOICES AND DIGNITY OF RISK

As I stated in the introduction to this section, providing people with intellectual disabilities the freedom to make their own decisions and take control of their lives necessitates the pre-existence of opportunities for them to pursue, to engage in, and to choose between. In order for people to exercise self-determination they first need to *know* about what opportunities and choices are out there, and they also need to have *access* to these opportunities and choices. Lindsay (RRSS) pointed out that if she did not know what opportunities and resources existed in her community, then someone could assume that she was content and uninterested. When people are living in special care homes and are heavily dependent on support from staff and caregivers, assuming that people with intellectual disabilities are not interested in certain opportunities is a convenient, but potentially harmful assumption for staff members to make. Lindsay explained: "I can't be interested in what I don't understand or what I don't know about, so first of all I need to know what's out there, and then the next step is I need to be able to be involved in what I want to be involved in". Donna (NSACL) emphasized the importance of providing both knowledge and access to a broad menu of choices. She told me, "People need to have choice. Really, really big and not just a choice of do you want an apple or an orange, but do you want an apple, orange, or do you want a bag of chips?" Once people are aware of

the opportunities and potential choices available to them, then the next step is remove barriers and to support them as necessary in exercising self-determination.

Some of the barriers to opportunities and self-determination that were identified by the participants included a lack of accessible and convenient transportation options, the inaccessibility of built environments, and a lack of financial resources. They emphasized that accessible and convenient transportation options were needed in order to allow people to participate in community events, fulfill activities of daily living, and maintain relationships. One participant pointed out that when multiple people are living in special care homes it can be difficult to accommodate everyone's schedules and travel requests when there are a limited number of staff and vehicles. One participant I interviewed expressed frustration that living with eight people and having access to only one van meant that house members were limited in the frequency and types of outings they could enjoy. Accessible transportation options like Access-A-Bus exist in Nova Scotia, but Heather (Prescott) recognized that people with disabilities often choose this option by default because they think it is easier and safer. This option was far from ideal however, because it lacked flexibility and Access-A-Bus must be booked a week in advance (Halifax Transit, n.d.). Heather would prefer to see people with intellectual disabilities learn to take public transport to the extent that it is possible for them, because this option offers them greater opportunity for self-determination by rendering them less dependent on the staff and vehicles of special care homes or the restrictive scheduling process of Access-A-Bus. Depending on the nature of a person's disability, public transit may not be an option, but it is probable that it may be a viable option for more people with intellectual disabilities than is assumed by their care providers. Catherine (Stantec) was aware that during her employee's first few days on the job, an employment support worker rode the bus with her so the employee could become comfortable with the transit schedule and routine. However, Catherine said that after the first few days her employee was able to successfully navigate the public transit system on her own.

If a person has a physical disability as well as an intellectual disability, they will likely encounter additional barriers. If they use a wheelchair for example, like Elaine does, they may find themselves prevented from accessing public and private buildings due to a lack of ramps or doors that are not easy to open. Elaine told me she was thrilled

that she can now do her own laundry at L'Arche because they bought a new front-loading laundry machine that she can comfortably access. She was disappointed that because of the low height of her wheelchair she could not access the knobs on the stove and was unable to use the stove top to cook independently. However, Elaine did appreciate being able to access the bus system in her area (Kings Transit Bus), which was wheelchair accessible. She was able to use the bus independently to do her shopping, and enjoyed the freedom it gave her. Edward (People First) said that before the Kings Transit Bus began servicing a broader area and creating new bus routes many areas in the Valley, such as Windsor and New Minas, were quite isolated without accessible transit options. In rural areas it is particularly difficult to access transportation in order to take advantage of potential employment opportunities as well as leisure opportunities. In rural areas public transit is infrequent, inconvenient, or nonexistent (Annapolis Valley Poverty Coalition, 2012; Devet, 2013; Thomson, 2013). Taxis are expensive and can quickly drain the monthly transportation allowance that is allocated for a person with an intellectual disability. Peter (a special care home agency) stated that people with intellectual disabilities living in rural communities "become prisoners of their locations and that's not fair". As discussed in Chapter Four, zoning by-laws can also exacerbate this issue if they do not allow special care homes to be opened in residential areas. This forces them into more isolated and rural areas.

A lack of financial resources and a lack of control over how financial resources could be used was another practical barrier to exercising self-determination that emerged in the interview data. Several participants complained about the inflexibility of disability funding. The amount of income assistance that people with intellectual disabilities receive and the rules that dictate what they are allowed to spend money on currently limit their opportunities for self-determination. Edward (People First) provided me with many examples of how limited funds, received through income assistance, can reduce one's quality of life. A lack of financial resources restricts people to only pursuing opportunities and engaging in activities that are free or inexpensive. Peter (a special care home agency) expressed a desire to cultivate more opportunities for his clients, but he acknowledged that this was challenging because of the scarce financial resources, as well as the lack of political and community will to facilitate the full inclusion of people with

intellectual disabilities. Edward (People First) insisted that facilitating social inclusion did not require huge sums of money. For Peter, the root of the funding and policy issues lay with government bureaucracy, a lack of stakeholder involvement in decision-making, and a lack of political will. He saw the potential for positive and significant changes to occur if the province collaborated more closely with the disability sector and demonstrated a greater openness to creative solutions that would facilitate social inclusion.

A lack of accessible and convenient transportation options, the inaccessibility of built environments, and a lack of financial resources are all significant barriers to supporting opportunities and self-determination for people with intellectual disabilities. Sometimes barriers to opportunities and self-determination are less obvious, such as attitudinal barriers. Participants expressed how attitudinal barriers can include parents' overprotectiveness of their children, as well as the attitudes of care providers when they uphold the culture of dependency in their organizations. Addressing parental barriers to self-determination requires a more sensitive and nuanced approach. Donna (NSACL) worked with families and parents to "to help them see that they have to let go and it's very, very hard, but once they do it's a good thing". In special care homes, unless there is deliberate and intentional effort expended to provide people with intellectual disabilities with the knowledge of, and access to, a wide range of opportunities and to support them in exercising their self-determination, special care homes can easily create a culture of dependency by default. For example, Allison (L'Arche) was aware of how when you are "taking care of people" it is easy to contribute to creating a culture of dependency, which undermines self-determination.

Edward (People First) believed that people with intellectual disabilities should be allowed the *dignity of risk*. He argued that a primary focus on ensuring the *safety* of people with intellectual disabilities could actually work to limit their opportunities and self-determination. Providing dignity of risk involves treating the person as an equal human being; as being capable of making their own decisions. Edward said that people with intellectual disabilities "need to be allowed to experience things like anyone else". Peter (a special care home agency) also expressed that social inclusion involves giving people the opportunity to aspire to achieve their dreams and allowing them the

opportunity to make mistakes. Failure is always a possibility when you give someone the dignity of risk, but according to Peter “failing is [not] a bad thing, because when you fail you learn... you learn from the negative and the positive; you have to have both”. When society refuses to see people with intellectual disabilities as capable of making their own decisions, this attitude becomes a barrier to opportunities and self-determination, and thereby prevents social inclusion. Kate (L’Arche) believed that many people with intellectual disabilities have never been allowed to claim their adulthood. She pointed out that when people with intellectual disabilities are consistently perceived to be children by their care providers and other adults, even when this perception is obscured by the intention to keep them safe, society does not feel obligated to honor their desire for self-determination. Kate believed in giving people the dignity of risk, but she acknowledged that sometimes it can be difficult when working with people with profound intellectual disabilities who require significant supports.

Supporting the self-advocacy and leadership skills of people with intellectual disabilities is another way to support their self-determination. Involving people with intellectual disabilities on advisory committees and involving them in policy and programing decision-making is empowering. Although there is the risk that advisory committees can become mere examples of ‘tokenism’ if they are not taken seriously (Hutton, Park, Park, & Rider, 2010), these types of committees provide opportunities for people with intellectual disabilities to have a say on important decisions that affect them. Claire (L’Arche) explained that L’Arche has core members on all of its community boards and the core members retained the right to vote on important community decisions. Other examples would be People First self-advocacy groups, Special Olympics’ *Athletes Leadership Program*, and RRSS’ resident council (discussed previously), as well as Best Buddies’ Advocate Program. Best Buddies is committed to providing leadership opportunities to participants with disabilities through their Buddy Advocate Program where buddies are encouraged to become involved with the chapters’ leadership teams. The buddy advocate (with an intellectual disability) is invited to all the chapter’s executive group meetings and is the voice for all the other buddies involved in the chapter. Melissa insisted, “We don’t want to be running these programs for people who have disabilities without their input... So by them becoming leaders, it’s increasing

confidence, it's giving them responsibility, and they're contributing to the chapter". When discussing the inclusion of people with intellectual disabilities in policy-related decisions, Edward (People First) warned that obscure political language and jargon can be a barrier to people being able to understand the policies that impact their lives, and thereby a barrier to being able to mobilize, advocate and have their voice heard in the political sphere. Edward wanted to see policies and government legislation (including government websites) written in "plain language" with a clear indication of how a policy may directly or indirectly impact the person with a disability. These actions would help to enact the paired concepts of opportunities and self-determination, and contribute to building a more socially inclusive province.

6.6 SUMMARY

In the beginning of this chapter, I defined the concepts of opportunities and self-determination and explained why I had chosen these concepts to symbolize what emerged in the interview data as a central component of social inclusion and the second key aspect of my explanatory theory. I distinguished self-determination from other related terms such as independence and autonomy, and I demonstrated the various ways in which the paired concepts of opportunities and self-determination were central to participants' understanding of social inclusion. In Section 6.4, I wrote about how participants described supported decision-making as a way to empower people with intellectual disabilities to exercise their self-determination. However, it is difficult to make decisions when there are no opportunities and choices available. Thus, as discussed in Section 6.5, participants also emphasized the importance of informing people with intellectual disabilities of *all* of their options, and addressing the barriers to opportunities. Kate (L'Arche) observed that allowing people to exercise the right to make their own choices is powerful. She noticed that when people are able to exercise self-determination there is great reduction in violent incidents because they do not need to get upset in order to avoid going somewhere or doing something they do not want to do. When people begin to claim their right to make choices, she explained, they seem to experience more peace. Opportunities and self-determination are concepts that emerged as essential to social inclusion and people's quality of life. In the next chapter, Chapter Seven, I present the third and final paired concepts of my explanatory theory – friendship and belonging.

CHAPTER 7: THE EXPLANATORY THEORY (FRIENDSHIP AND BELONGING)

7.1 INTRODUCTION

In addition to the paired concepts of respect and equality, opportunities and self-determination, the concepts of friendship and belonging also emerged as central to social inclusion. The concepts of friendship and belonging are the third and final set of paired concepts that compose my explanatory theory. In this chapter I will define the my use of the words ‘friendship’ and ‘belonging’ to establish a common understanding of these concepts before demonstrating how they emerged in the data. As I did in the previous two chapters, I will apply the set of paired concepts to the four contentious topics that were discussed in Chapter Four to show how participants utilized these concepts to make arguments against or in favour of segregated environments and activities. In Section 7.3, I discuss three benefits of friendship and belonging that my participants identified – protection against loneliness, increased safety, and acceptance. In Section 7.4, I present my participants’ perspectives on the value of friendships between people with similar disabilities and the value of friendships across ability. In Section 7.5, I describe the various strategies participants discussed, that could be used to support people with intellectual disabilities in finding and maintaining friendships. Finally, I conclude this chapter by summarizing the explanatory theory that has been described throughout Chapters Five, Six and Seven.

Belonging is a concept that has been described as: experiencing a sense of relatedness and connection; being part of a group of people or a community; being missed by other members if you are absent; shared experiences, feelings and beliefs with others; being accepted for who you are; having your unique contributions appreciated; and feeling at home in the world (Mahar, Cobigo, & Stuart, 2013; Reinders, 2008; Swinton, 2012; Vanier, 2008). Reinders (2008) believes that friendship and belonging represent the “ultimate good[s] of being human” (p. 131, 132). He emphasizes that the experience of friendship and belonging is not something that can be cultivated solely by the individual; the enactment of these concepts necessitates the involvement of others in extending a welcome and offering a *place to belong*. Reinders (2008) writes,

Belonging is of itself necessarily other-dependent: wherever you belong, you only

belong there because significant others in your life will confirm that you do... A full sense of belonging is created by a different relationship, one in which others affirm our sense of belonging, but not because of natural necessity. Not only have I not been able to choose my family; neither has my family been able to choose me. A full sense of belonging does not depend on choice but on being chosen. Therefore, it is more properly found in relationships *with friends* than within the family. (p. 131, emphasis added)

Reinders (2008) makes a strong case for the concept of belonging being “other-dependent” and related to the experience of “being chosen” *to be a friend*. This underscores what was discussed in Chapter Three; that genuine social connectedness and belonging is more meaningful to people with intellectual disabilities than simply being physically included in communities (Cummins & Lau, 2003), or families for that matter. Hall and Kearns (2001) suggest that although the agency of people with intellectual disabilities to facilitate their own social inclusion is certainly not negated, “the community’s willingness to accept intellectually disabled people may be more important than any individual’s capacity to seek out such acceptance” (p. 242). It does not necessarily follow from Reinders’ aforementioned quote that families *cannot* cultivate environments of belonging. Indeed, families, just like communities, can create a rich environment of belonging through *intentionally building friendships* with family members. I have paired the concept of belonging with the concept of friendship, because the experience of belonging is developed through friendships and relationships of reciprocity and mutuality (Cushing & Lewis, 2002; Reinders, 2008). It is through friendship and relationship that people become part of various groups in society, and it is often within the context of friendships, that one can be fully accepted for who they are (Reinders, 2008; Vanier, 2008; Vanier, 1997).

7.2 APPLYING ‘FRIENDSHIP AND BELONGING’ TO THE FOUR CONTENTIOUS TOPICS

7.2.1 ‘FRIENDSHIP AND BELONGING’ IN LIVING ENVIRONMENTS

Peter and Lorraine (a special care home agency) expressed concern that if people with intellectual disabilities had to live in more isolated, less residential areas due to zoning by-laws, they would lose out on the social interaction that is more accessible in

residential neighborhoods. Melissa (Best Buddies) also prioritized the paired concepts of friendship and belonging when she expressed that she would like to see more people being able to continue living with their families rather than being removed from their familiar homes to live in special care homes. She wanted to see familial relationships strengthened. Allison (L'Arche) pointed out that it can be difficult in a special care home for people with intellectual disabilities to visit their friends whenever they want to because in a special care home environment, such as L'Arche, there are limited transportation options and "everything has to be scheduled", including people's social lives. When he lived with his parents, core member Jeff (L'Arche) used to take part in many social activities, such as swimming and bowling, because his parents were able to drive him around. Since moving into the L'Arche community, he has had to adjust to being dependent on the schedules of the assistants and other core members, who also require the L'Arche vehicles on a daily basis. Consequently, according to his mother who pointed this out with some disappointment, although he now can enjoy social time with other core members at his L'Arche home, Jeff is less engaged in social activities *outside* the community.

Other participants emphasized the positive aspects of experiencing friendship and belonging in special care homes. Linda (NSACL) pointed out that many people with intellectual disabilities, who remain in their family homes, may lose their social networks when peers and family members move or pass away. As a result, they may not have many opportunities for social interaction. Furthermore, experiences of friendship and belonging were not always available for those that were able to secure independent living in an apartment or home of their own. Edward (People First) pointed out that "you can be included in your community, but still be isolated in your apartment". Jane (L'Arche) also expressed concern that achieving the socially valued goal of living independently in an apartment or house, may not be the ideal scenario for people with intellectual disabilities if they are at risk for becoming isolated and unconnected from social networks. In contrast, Claire (L'Arche) spoke highly of the social benefits of living with other people as they do at L'Arche. Claire emphasized that one of the benefits of L'Arche communities and other special care homes was that people "don't need to leave the home to have a social experience". Claire recalled a time when a core member had to stay at the

hospital for a week, and how much she was missed by the other core members while she was there. For Claire, this highlighted the valued social roles and friendships that each core member has within the L'Arche community. This example also exemplifies the concept of *belonging* and the experience being missed by one's community when one is not present. Special care homes were capable of cultivating a sense of belonging and opportunities for friendships to develop. Jane and Ann (L'Arche) described how everyone at L'Arche ends up feeling like family and friends, rather being known primarily by their differentiated roles as assistants, core members, and roommates. It was mentioned by participants that L'Arche, as a special care home agency, was particularly skilled at fostering a sense of connectedness and belonging in their special care homes, and nourishing friendships.

L'Arche is unique in contrast to other special care home agencies, in that it explicitly and intentionally encourages assistants to be emotionally vulnerable and open to developing friendships with core members. This was a significant adjustment for Kate (L'Arche) when she first became involved with L'Arche. As a social worker, she was trained to have "controlled emotional involvement". At L'Arche, they encouraged the opposite. She said as a social worker, controlled emotional involvement "was the mantra, and in L'Arche that would be taboo". According to L'Arche philosophy, in order to build genuine and reciprocal relationships, it is necessary to embrace emotional vulnerability (Vanier, 2008). Since people with intellectual disabilities are at a higher risk than the rest of the population for experiencing physical and sexual abuse (Mikton, Maguire, & Shakespeare, 2014), L'Arche's promotion of reciprocal relationships between assistants and core-members may initially appear to some people as being unprofessional and risky. However, Kate believed that the risk of abuse was actually reduced within a L'Arche context because as assistants develop meaningful friendships with core members, she believed they would be "more likely to become an advocate for them". In the past, Kate has not hesitated to fire assistants who were disrespectful to core members – she had no tolerance for disrespectfulness. She believed that it was more likely for abuse to be hidden in large institutions than at L'Arche, because at L'Arche the concepts of respect and equality combined with the concepts of friendship and belonging, were so strongly embedded in L'Arche culture.

The value of relationships between *paid staff members* and people with intellectual disabilities has been previously dismissed and discredited by advocates and academics in the literature, because of the transactional nature of the relationship between the paid staff member and the client (Hastings, 2010; Shakespeare, 2014). However, Kate (L'Arche) described the relationships that form between assistants and people with intellectual disabilities as genuine friendships that extend beyond the employment contract. These friendship dyads chose to spend time together “not because they have to or they're being paid to, but because they like being together”. She told me how sometimes the assistants will choose to stay on beyond their contract, and when this occurs it is often due to a close friendship that the assistant has developed with a core member; “it's because they've developed a friendship with a core member, that's real, that's not just surface”. Kate pointed out that one of the benefits of L'Arche Homefires was that because the agency operated five different houses, there were more opportunities to socialize with different people and more than one house to visit. As Kate told me, “friendships aren't limited to the people you live with”. The community regularly came together for large community events, and core members and assistants from different houses frequently invited each other over for dinner. The assistant positions at L'Arche have a high turn-over rate because many of the assistants are young students and/or are from other countries and many of them only stay for a year's duration. Despite these barriers to long-lasting friendships, participants provided evidence of how many of these friendships continued. For example, Claire (L'Arche) told me about a group of approximately 15 people who now live in Halifax, but were previously assistants at the L'Arche Cape Breton community at some point during the past 20 years. The former staff members would meet up regularly with visiting core members from L'Arche Cape Breton, to share a meal and to spend time together. Technology had also been an important tool in supporting the capacity of these friendships to continue. Kate (L'Arche) shared how one of the assistants, after returning to Germany, continued to skype with a core member with whom he had developed a close friendship with. Through these skype conversations the core member had also had the opportunity to meet the assistant's entire family. Despite these friendships having their origins in a paid arrangement and despite barriers of distance, many of these friendships between assistants and people with

intellectual disabilities continue, even when the dyad can no longer depend on proximity to sustain the relationship.

Linda (NSACL) was also aware that close friendships sometimes developed between paid staff members and clients. These friendships were capable of opening up doors to additional social opportunities. She told me that staff members often invited clients back to their home or out to an event after they finish their work shift. Linda said:

There's a lot of social inclusion that goes on, like there's a lot of one-on-one time and just natural relationships, outside of the paid relationship. You know they might go to work for eight hours, but if after that eight hour shift, they're going to their mom's birthday party they might say, 'Hey Brian do you want to come with me to my mom's?'. And Brian will go 'Yah sure', and away they go. So, they are paid staff, but they are also including them, so that Joe Blow gets to go to mom's birthday party, meets the whole family and he does that over a ten-year period. They become part of his extended family... so other things grow out of that and it's pretty cool.

Despite originating in an employment contract, friendships between staff and clients can become a point of access to many other opportunities where people with intellectual disabilities can extend their social networks. During my data analysis it became clear that the paired concepts of friendship and belonging were central to my participants' discussion of special care homes, whether they were making arguments against or in favour of them.

7.2.2 'FRIENDSHIP AND BELONGING' IN EDUCATION

Concepts of friendship and belonging emerged again when participants discussed the pros and cons of segregated versus inclusive education. When Chris (Special Olympics) reflected on his observations during his time in high school, he said he felt the greatest benefit of inclusive education for people with intellectual disabilities, was not the academic component, but rather the social component. Ann (L'Arche) agreed that from her perspective as a parent, the primary benefits of the inclusive education model for her son was the social interaction with peers, rather than acquiring academic knowledge. Although Ann expressed conflicted feelings about the overall benefits of the inclusive education model, she believed that people with intellectual disabilities should be in an

inclusive classroom for at least part of the day when it was appropriate. When I asked Jeff (L'Arche) what he liked most about his time in high school, he confirmed that what he liked most about school was "being around people". Chris (Special Olympics), described himself as a "big supporter of inclusive education", but he also believed that many schools were not doing enough to truly include people with intellectual disabilities, even after they are placed in the mixed classroom. For him, it was the social interaction that was more valuable than the academics. Chris indicated that putting a youth with an intellectual disability in an advanced grade 12 calculus class may not benefit anyone, but ensuring that people with disabilities were included in group work, sitting with friends in the cafeteria, involved on student councils and extra-curricular work – that is what Chris believed was vital. Chris believed that inclusive education could be positive when it promoted social interaction and friendship. Social interaction was clearly a greater priority than academic learning for several participants.

Linda (NSDCS) was not as convinced of the benefits and potential of inclusive education. She noted that it could be embarrassing to be in classes with other people who can do things better than you could, and this scenario could lead to students with intellectual disabilities being ridiculed. Linda also told me that many of her clients had expressed that they would have rather been in school with other people with intellectual disabilities, rather than in an integrated environment because it had been difficult for them to watch their peers go on to University or college while they could not. Her clients had told her that they would rather have had the opportunity to develop friendships with people like them; people whose lives would follow similar trajectories. For those who enjoyed social opportunities in the school system, graduating from high school could be a difficult and isolating transition. Claire (L'Arche) pointed out that when young adults with intellectual disabilities graduate, their friends all leave. Ann (L'Arche) and Kate (L'Arche) also commented on how people with intellectual disabilities often experience a significant reduction in social interaction after completion of grade school. Participants indicated that ultimately it is not about whether segregated or inclusive education is preferable, but rather it was about ensuring that the experience of friendship and belonging is realized for people with intellectual disabilities since this is a priority for many of them. Elaine, a middle-aged L'Arche core member I interviewed, expressed the

desire to upgrade some of her high school courses, but after she realized that upgrading meant that she was going to have spend her free time doing homework, the value she placed on friendship and belonging led her to decide *not* to pursue the upgrading at that time. She told me that her priority was “being with other people [rather] than stuck in here doing homework all the time”. Elaine already had a strong social network and enjoyed her daily work at an ASC. For Elaine, her friendships and opportunities for social interaction was a more important aspect of inclusion than upgrading her high school courses. The importance of friendship and belonging were concepts that were prominent throughout my interview discussions about segregated education versus inclusive education.

7.2.3 ‘FRIENDSHIP AND BELONGING’ IN WORK CONTEXTS

Donna (NSACL) was aware that many people with intellectual disabilities had developed close friendships within their spatially segregated ASC environment. However, she expressed concern that perhaps because no one had explained to these individuals that they could make *new* friends in community jobs *and* maintain their older friendships, people were afraid to seek community-based employment. Certainly there was evidence in my interviews that people could create friendships and increase their social networks in community employment settings. In Chapter Four, Edward (People First), Linda (NSDCS), and Catherine (Stantec) provided me with several examples of the friendships and social connectedness that had developed between people with intellectual disabilities and their co-workers in community-based jobs. Underscoring these conversations was the implication that the importance of friendship and belonging in the workplace should not be underestimated. Edward made it clear that paid employment without being included in a social network or without being invited to work-related events and parties, was not genuine social inclusion. For example, Edward told me that even if you are employed in the community,

[but] meanwhile your buddies are going out for beer at the end of the day and going out for a meal or doing whatever right, but you go home – *that’s not social inclusion...* it’s more than having a job, it’s being a part of a social network, a friend network... It’s very isolating to be part of a job and then having to eat

alone and you have no friends at work and everyone else is buddy-buddy and doing other stuff outside of work.

Whether in reference to a living space, an education setting, or place of employment, it was clear from my participants that inclusion was about more than involvement in an environment or activity; it was about experiencing belonging through friendship.

Heather (Prescott) said that within the supported employment program at Prescott, the employment coaches visited the clients on the job site not only to provide support and training, but to help them feel less isolated. She had observed that some of their clients were more integrated into their work settings than others were. Heather told me that some of their clients who had progressed to the supported employment program only worked part-time in the community and continued to participate in the ASC environment so that they could continue their friendships with the other clients there. However, some people with intellectual disabilities, as previously mentioned, chose to return to working full-time in an ASC because they were more comfortable working there with their friends than in a community-based employment setting. Ann (L'Arche), a mother of someone with an intellectual disability, believed that having a job in the community is unrealistic for many people, and for her: "as long as a person with a disability feels that they're part of something, I think it's wonderful". For her, a spatially segregated ASC can cultivate a meaningful sense of 'belonging' for people with intellectual disabilities. Jeff told me that what he liked most about his work at Prescott was "hanging out" with other people and that his least favourite part was having "too much work". Jeff's mother Ann confirmed that for Jeff, regardless of what he was working on at Prescott, it was the social aspect of the segregated ASC setting that he most enjoyed.

7.2.4 'FRIENDSHIP AND BELONGING' IN SPORTS

Some participants, such as Donna (NSACL) and Ann (L'Arche) pointed out that people did not need to participate in Special Olympics to experience friendships and positive social interaction in recreation and sporting activities. For example, in Chapter Four, Ann spoke highly of her son's social interactions during his involvement in mainstream bowling and swimming settings. However, regardless of the opportunities outside of Special Olympics, participants had many positive things to say about the potential for friendship and belonging within the segregated environment of Special

Olympics. Linda (NSDCS) observed that for people with intellectual disabilities, the focus of the Special Olympics training sessions and events was not always about the sporting activity itself, but instead it was about the social opportunities. Linda told me:

I talked to ten clients this week and they're like, 'we had a barbeque after the bowling tournament!'...Cause then everybody was together socializing, so that's the highlight. They don't care that they got three strikes or whatever right; that their score was 73. It's like, 'I get to hang out with Beverly. I never get to see her because she lives in another group home in Dartmouth and I never get, I can't get there by myself'.

Many people with intellectual disabilities have been involved with Special Olympics for many years; it has been a constant throughout their life. This long-term involvement creates conditions which are conducive to fostering sustainable friendships and a sense of stability. For example, Claire (L'Arche) shared that although one of the core members at L'Arche has lived in different group homes in different locations, "His Special Olympics' family is always the same and they're always there. So that's wonderful. There's stability and a security and friendships". For Chris, Special Olympics encouraged "real social connection". Not only do athletes have the opportunity to socialize with their peers who also have disabilities, but Chris highlighted the many moments of positive social interaction and the many friendships that had developed between the athletes and the coaches, the volunteers, or even the family members of other athletes that show up to Special Olympic practices.

In this section, I demonstrated how participants used the paired concepts of friendship and belonging to make arguments against, or in favour of, special care homes, segregated education, ASCs and Special Olympics. Participants provided examples of how segregated environments were barriers to friendships and a sense of belonging. However, participants also described the four segregated settings as fertile environments for cultivating friendships and a sense of belonging. Many participants indicated that mainstream community-based living environments, educational contexts, work settings, and sporting activities, were not necessarily inclusive if they did not involve opportunities for friendship and belonging. Friendships and belonging were more important determinants of social inclusion than whether or not the setting or activity was

considered segregated or not. The paired concepts of friendship and belonging emerged throughout my interviews with participants, as a central component of social inclusion and key to my explanatory theory.

7.3 THE BENEFITS OF FRIENDSHIP AND BELONGING

Participants highlighted three key benefits to having close friends and establishing a sense of belonging. These benefits included: protection against the detrimental experience of loneliness; increased safety; and acceptance. A deficit of genuine friendships can contribute to a pervasive sense of loneliness. Research has indicated that loneliness and a lack of social connection is epidemic in today's society and has a negative impact on both the health of individuals and communities, regardless of whether someone has a disability or not (Cacioppo & Patrick, 2008; Cacioppo, Hughes, Waite, Hawkley, & Thisted, 2006; Griffin, 2010; Beaumont, 2013; Hawkley, Thisted, Masi & Cacioppo, 2010; Holt-Lunstad & Layton, 2010; Holwerda et al., 2012; Putnam, 2000; Vanier, 2008; Victor & Bowling, 2012). Research has also demonstrated that people with intellectual disabilities are at greater risk of experiencing loneliness because they tend to have small social networks, few close interpersonal relationships, and minimal social capital (Lippold & Burns, 2009; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006; Mithen, Aitken, Ziersch, & Kavanagh, 2014; Stacey & Edwards, 2013). Claire (L'Arche) told me that a lack of friendships "is definitely a source of pain for some of our members". Several participants highlighted the acute loneliness of people with intellectual disabilities, their experiences of being bullied, and their trepidation with initiating new friendships. Many people with intellectual disabilities also crave the companionship found in a romantic relationship (Rushbrooke, Murray, & Townsend, 2014). Melissa (Best Buddies) told me about a friend of hers who has Down's syndrome. Her friend presents as high functioning and holds a community-based job, "but all she wants is a boyfriend". Her friend has observed many of her family members and people that she has grown up with having romantic relationships and starting families, and she wants this for herself. Melissa is aware of people with intellectual disabilities who have boyfriends and girlfriends, and she even knows of a couple who have married, but Melissa admits there can be additional challenges when pursuing romantic companionship when one lives with intellectual disability.

Another benefit of increasing the social networks of people with intellectual disabilities is increased safety. Linda (NSDCS) said that many of her clients are very isolated and she often tells their families that,

The more people that know your son or daughter or loved one, the safer they are... Cause if they've met somebody on the bus every day for ten years and then that person sees them out of context, say at the Atlantic Winter Fair and somebody's being abusive to them, they're going to say, 'Hey I know where that guy lives', and then they're going to knock on the door and say 'I saw that respite staff person not being nice to your son'.

Kate (L'Arche) believed that abuse occurs and "bad things happen, when we hide sectors of our society away", and when people are not known by their neighbors. Neighbors call Kate directly whenever they notice something in a L'Arche house or an interaction with a L'Arche member that does not seem quite right. Kate told me that for her "community integration is so important because that's when you begin to care; that's when neighbors begin to care". Neighbors then become part of the social network that ensures the safety of people with intellectual disabilities who belong to their communities.

Participants identified *acceptance* as another benefit of friendship and belonging. Friendship is not about perfection. Disagreements, annoyances, and frustrations within a dyad do not negate the value of a friendship. Donna (NSACL) pointed out that regardless of whether someone has an intellectual disability or not, "nobody is perfect and we like them for who they are... and there's probably a side or there's something that they do that just irritates the hell out of you, but you just live with it, because you like them". When Kate (L'Arche) talked about her friendship with a core member she told me, "He's my friend and I treat him exactly as I would treat any friend. You know when he drives me crazy I tell him 'you're driving me crazy'...and it's quite touching, like when he talks about... who would he call for help if he needed help. It would be myself and [name]". Participants indicated that a good friendship did not mean that friends would never annoy each other or disagree. Having a good friend means you appreciate and accept each other, imperfections and all, and you know that you can depend on that person. Elaine, a core member at L'Arche, told me that having lots of friends coming to visit was what gave her the greatest sense of fulfillment and purpose in life.

7.4 FRIENDSHIP BETWEEN PEOPLE WITH SIMILAR DISABILITIES VERSUS FRIENDSHIPS ACROSS ABILITY

There was significant disagreement among participants regarding whether people should be encouraged to develop friendships with people *without* intellectual disabilities or if they should focus on the friendships with other people who also had intellectual disabilities. Peter (a special care home agency) said that he had noticed the tendency for people with intellectual disabilities to gravitate toward others with intellectual disabilities. Peter indicated that he did not believe this was either wrong or right, but believed that it indicated a natural human tendency to want to interact with people who were similar to one's self and who understood where one was coming from. Friendships *between* people with intellectual disabilities can be easier to establish through disability-specific programming and events. Staff admitted that many of their clients' friendships required significant facilitation and encouragement in order to be maintained, although several friendships were described as being independently sustainable. Good friendships are valuable wherever they may be found. There is nothing inherently wrong with developing friendships with people who live with similar disabilities, but participants emphasized that it was important to have many different opportunities to develop friendships. Rather than be restricted to only looking for friendships in disability-specific segregated settings, participants believed that people with intellectual disabilities should have access to a wide range of social settings and opportunities where they have the chance to establish a greater number of friendships among diverse groups of people.

Lorraine (a special care home agency) commented that most of the agency's clients do not have *nondisabled* friends, unless the friends are staff persons and care providers. Their social networks tend to be limited to those they interact with within their special care home environment. In addition to the environmental barriers that can restrict their social networks, such as a lack of transportation or inaccessible homes, people with intellectual disabilities face additional barriers in making friends because people *without* intellectual disabilities are sometimes unaccustomed to interacting with someone who has a disability and may be hesitant to initiate conversation. Lindsay (RRSS) described observing university students when they come to meet one of the RRSS clients that they have been partnered with through the Best Buddies program. She described the students

as initially being nervous and unsure of what they were getting themselves involved with, because perhaps they had never really interacted with someone who had an intellectual disability. Quickly, however, the friendships naturally evolved and, as Allen (RRSS) told me, “The disability disappears. You’re just friends. That’s it. That’s the inclusion piece”. Catherine (Stantec) described how her employee with an intellectual disability gradually became more comfortable and social with other employees as time went on. Catherine spoke very highly of the employee and valued not only her work ethic, but also the positivity she brought to the environment and her social engagement with other staff members. Just like any new friendship or relationship, there is the initial period of time where friends only know each other at a superficial level. Melissa (Best Buddies) pointed out that gradually a friendship deepens as you share more of yourself; you become more vulnerable with each other, and establish a greater comfort level with the other person through increased trust. Disability or not, most people experience this type of progression when getting to know someone. Any existing initial awkwardness or discomfort is not a reason to avoid developing friendships with people without intellectual disabilities. Furthermore, disability or not, “nobody is perfect”, as Donna (NSACL) said. She pointed out that we like our friends for who they are, regardless of whether they irritate us or annoy us at times. People with intellectual disabilities are just as capable of developing and maintaining friendships with people *with or without* disabilities, and should not be held to a higher standard of friendship than anyone else is.

In relationships between people with and without intellectual disabilities there is often an initial power imbalance, whether latent or explicit, which is due to the person with the disability presenting as being more vulnerable and dependent (Cushing & Lewis, 2002). A power imbalance in a friendship (i.e. when one person feels as though they have greater power/authority and the other person feels vulnerable) can potentially impede the development of a genuine, reciprocal relationship. L’Arche, acknowledges this risk and encourages reciprocity and mutuality in friendship; where the contributions of both people are acknowledged and valued, and both people in a friendship dyad are willing to give and are open to receiving from the other (Vanier, 2008). Kate (L’Arche) recounted a time when she provided accompaniment and emotional support for a core member who was going to the hospital for a necessary surgery. Driving back from the hospital, after

spending the day comforting and calming the anxious core member, Kate received a call from her family informing her that their dog of 16 years was missing. Kate was overcome by an emotional reaction and had to pull over by the side of the road. In this moment their roles were reversed. The core member became Kate's support person as she responded to Kate's grief and concern by comforting her. Kate pointed out that their friendship demonstrated *interdependency*. In that moment Kate did not feel she had to hide her emotions, but instead she felt comfortable being vulnerable with her friend. Kate cautioned that engaging in a reciprocal friendship of mutuality does not mean:

you bleed all over every single person with a disability and you share your deepest most intimate secrets and how hard your life has been. That's not appropriate either, but there is a mutuality that as your relationship develops you don't have to have this controlled emotional involvement cause that's a barrier.

Kate referred to mutuality and interdependency in a friendship as a "healthy intimacy", where each person is respectful and honours the other as an equal. By creating an environment for assistants and core members to enjoy each other's company as friends and as *equals*, L'Arche facilitates the creation of friendships between people *with and without* disabilities and perceives both types of friendships as important.

When asked about friendships that developed across ability, between people *with and without* intellectual disabilities, my participants identified the following types of people with whom friendships developed: volunteers, paid staff, and other people in the community that they frequently had contact with, such as store owners and bus drivers. I will examine these three different types of friendships in turn. Best Buddies was mentioned as a friendship catalyst not only by Melissa, a Best Buddies employee, but also by other service providers who were aware of the value of the volunteer program. Melissa stated that many of the Best Buddy friendships last beyond the length of the program, which runs over a school semester. She observed that many of the students are surprised to develop a good friendship through the program, when at the outset of their involvement they perceived themselves to be 'doing volunteer work' to support the 'buddy' with the intellectual disability. For the buddies with intellectual disabilities, the Best Buddies program is a great opportunity for them to have access to typical social opportunities that are available to their peers (Donna, NSACL). While participants

indicated that there is nothing inherently wrong about *only* having friends *with* intellectual disabilities, many participants believed that people with intellectual disabilities should have access to a much wider range of social opportunities to extend their social circle if they chose to. Best Buddies is one example of a broad-scale effort to create new social opportunities.

In addition to the Best Buddy volunteers, people with intellectual disabilities found friendships with volunteers in other contexts. When I asked about who her friends were, Elaine (L'Arche) identified a few of her closest friends as being someone who tutored her in school and another person who used to volunteer at the ASC that Elaine works at. Neither volunteer is still acting in their volunteer role, but the friendships have continued. When Elaine and her friends get together they usually go for a walk, they go out for lunch, or they go to the friend's house for dinner. Recently her old tutor drove several hours to celebrate Elaine's birthday with her. Even informal volunteer arrangements can offer new social opportunities. For example, Ann (L'Arche) was a mother of one of the core members who lived at L'Arche, but she regularly engaged with the *other* core members living in the L'Arche house. She would take them on trips and would take them out to celebrate their birthdays. Recently one core member wanted to be involved with a particular committee, so Ann decided to join the core member and supported her in doing some fundraising for the committee. She described the core member as being part of her life now and she loves going to visit the L'Arche house. Ann described all the core members as being very welcoming and fun to spend time with. This is another example of how friendships can be created through volunteer arrangements and opportunities.

Jane (L'Arche) told me how she met one of her good friends when she began volunteering one day with a L'Arche community in Antigonish. Since the individual she was matched up with tended to spend a lot of time at his home, Jane points out that she would not have met this core member if she had not volunteered weekly at L'Arche. She admitted they did not have a lot in common and he was not able to communicate using the English language, but managed to cultivate a good friendship. It was 2005 when Jane first began volunteering with L'Arche Antigonish and at the time of the interview she was a full-time assistant at another L'Arche community. She never would have

anticipated that she would stay involved with L'Arche as long as she had. It was that initial friendship, facilitated through a volunteer arrangement, which was pivotal for her and led her to where she is now. Jane told me that it is "really valued by the [core] members when they get out one-on-one with someone who has a different life... who lives somewhere else and knows different people, and is going to talk about different things than the people they see every day". The point that was clear in my participants' examples of friendships was that it was not about *avoiding* friendships with people who have similar disabilities, but it was about *extending* people's social networks by providing new social opportunities. As is evident in the examples provided by Melissa (Best Buddies), Elaine (L'Arche), Ann (L'Arche), and Jane (L'Arche), volunteers can play an important role in extending social networks and offering social opportunities.

The second type of friendship that developed *across* ability was those with paid care providers and assistants. Chris (Special Olympics) described how his leadership and involvement in the disability community began with a paid arrangement in high school where he was paid to provide support to another high school student with an intellectual disability. This relationship developed into a deep, long-lasting friendship. Through Chris's involvement with the individual a friendship developed not only between himself and the individual, but also with Chris's friends. The paid arrangement was a catalyst for the extension of the individual's social network. Ann (L'Arche) also spoke of several respite workers who used to provide paid care for her son. She said that these workers will still make time to hang out with her son Jeff even though they are no longer working with him and getting paid for it. For example, one of the respite workers called recently to find out if she could borrow Ann's wheelchair-accessible van to take Jeff out to Shubenacadie Park with herself, her partner, and her baby. Consequently, Jeff was able to spend time with two other individuals he otherwise would not have had the chance to if he had not met the respite worker. Ann said that when Jeff was going through a rough time, the other respite worker would be there to meet with him and talk with him about what he was going through, because they have developed a friendship built on trust that extends beyond on the previous paid arrangement.

The third type of friendship that occurred *across* ability were those that developed naturally through repeated encounters and proximity in the community. Linda (NSDCS)

described attending a funeral of one of her clients who passed away shortly before the interview. During the service there was an opportunity for attendees to stand up and share a memory about the deceased. Linda told me about how a man who worked at the convenience store across the street from where the deceased had lived, stood up and shared:

‘You know she came into my store every day for like twenty years, and me and my wife are going to miss her so much’. And like just how much she meant to him, was like amazing. And then somebody stood up and said, ‘She was in Sunday school with me and I haven’t kept in touch as much as I’d like to, but when I’ve seen her over the years, she’s always brightened my day’. Those connections are so important... I guess the bottom line is the more we can support people to be in the community, the better, in my mind.

While the interactions with the man working at the convenience store may not be considered to be a ‘friendship’ by some standards, these interactions in the community appear to still be meaningful and capable of contributing to enlarging an individual’s social network.

Claire (L’Arche) described how a core member enjoyed her positive social interactions with her daily bus drivers. She prayed for her bus drivers every night and Claire pointed out: “They are her friends - they joke with her, they laugh with her. She sees them twice a day, Monday to Friday. It’s really important to her”. The value of these interactions in the community should not be underestimated. Elaine (L’Arche), another core member, is very independent and has no qualms about initiating friendships with new people. One of her good friendships was created through encounters with a woman who works at the library. When she found out that the woman’s parents were moving close to her, Elaine decided to begin visiting them as well. As a result of this initial friendship with the librarian, Elaine had developed a good friendship with the woman’s mother, and the two of them would sometimes eat supper together and chat outside while interacting with people who pass by. Allison (L’Arche) and Melissa (Best Buddies) acknowledged that the majority of core members have difficulty securing *long-term* friendships, but that is something that can be difficult for many people to do, regardless of whether they have a disability or not. Over time people have a tendency to drift apart –

“it’s an unfortunate part of life”, Melissa told me. People drift apart because they are no longer part of the same social activity anymore, they live far away from each other, or their priorities change. Allison was able to identify several core members who have long-term friends in their community who they see on a regular and consistent basis. She cited the example of a one core member who goes out once a week for dinner with a long-term friend who is dedicated to making sure they see each other consistently. For Elaine, her fear is she will lose some of her elderly friends when they pass away. She told me, “I hate it when some people die... Like right now I have a friend that’s like 80, that lives down by the duck pond so she’s getting older and older, I hope she holds on longer, but she’s like energetic right”. There are some inevitable factors of life that will ultimately bring a close to even the most long lasting friendships, and this applies to all of us regardless of ability or disability.

Not everyone is welcoming to people with intellectual disabilities. Some people may hold stereotypes that prejudice them against people with intellectual disabilities. This can prevent relationships from naturally occurring in the community. However, Daniel (L’Arche) has observed that some people, due to personal experiences, are more understanding, patient, and empathetic. Daniel spoke highly of an individual who connected with his son, Caleb (who has an intellectual disability) when he was in high school. Daniel feels that this young man was more predisposed to treating Caleb with respect and putting effort into including him within his circle of friends, because of the man’s own difficult circumstances and family situation. Daniel said that the man knew what it was like to face challenges in life; “He knows what it’s like to be at the bottom of the ladder, and he’s not going to put down somebody else who for physical or intellectual reasons is at the bottom of the ladder - he just won’t do it”. During high school, largely because of the support of this particular friend, Caleb was treated “like one of the gang”. This man still made an effort to see Caleb regularly even though years had passed since they were in high school together.

In summary, participants reported developing friendships with the following types of people: other people with intellectual disabilities, volunteers, paid staff, as well as community members and friendships that developed spontaneously through proximity and repeated contact. Regardless of how or where these friendships started, and

regardless of whether the friend also had a disability or not, the importance of friendships to people with intellectual disabilities underscores the centrality of the concepts of friendship and belonging to social inclusion.

7.5 CULTIVATING OPPORTUNITIES FOR FRIENDSHIP DEVELOPMENT AND THE SOCIAL SKILLS TO MAINTAIN FRIENDSHIPS

Participants highlighted a number of barriers that could prevent people with intellectual disabilities from finding and maintaining friendships. These included: a lack of access to environments and contexts where friendships could spontaneously develop; the unreliability of other people; challenges in overcoming language barriers; and insufficient financial resources. Participants believed that care-providing staff could play an important role in overcoming some of these barriers and supporting people with intellectual disabilities in finding and maintaining friendships. They also noted that sometimes people with intellectual disabilities do not automatically acquire social skills as they grow up, and they need to have social skills explicitly and intentionally explained and taught to them. Acquiring social skills can enable people with intellectual disabilities to navigate the social world and establish friendships.

A lack of opportunity is often one of the biggest types of barriers facing people with intellectual disabilities who want to find new friends. In the previous section (7.4), participants referenced the following *contexts* where they had been able to make friends: their special care home (e.g. friendships with other residents, paid staff, or volunteers); the school system; camps for people with disabilities; disability-related associations; ASCs; community employment settings; and Special Olympics. However, people were often not able to access environments where they could make friends and even if they could access these environments, opportunities for friendship were not always plentiful or sustainable in these settings. For example, environments such as education or employment setting, can provide opportunities to make friends, but ASCs often have long wait lists, community employment can be difficult to secure, and many friendships that are made in grade school do not always persist beyond graduation. Ann (L'Arche) expressed disappointment that her son lost many of his high school friends when he graduated. She described a couple friends in particular that her son Jeff would hang out with outside of school. At the time, she was certain that they were going to be long-term,

sustainable friends. However, after high school ended, or in one case, after junior high ended, the friendships ended as well.

Jane (L'Arche) expressed that due to various barriers, it can be difficult for people with intellectual disabilities (particularly more profound disabilities) to *independently* develop friendships. Daniel (L'Arche) believed that because expressive language is often a challenge for someone with an intellectual disability, friendships were “not going to happen spontaneously by people who just happen to be in the same place and start talking with each other”. Because we commonly rely on verbal communication when making first contact with a potential friend, having a language deficit can be a barrier. Daniel believed that in order for a friendship to develop with between people with and without intellectual disabilities, the person without the intellectual disability needed to be able to be willing to commit to developing the friendship in unconventional ways (e.g. by not depending on verbal language). For those who may have limited capacity to initiate and seek out friendships in the community, an artificial catalyst and facilitator of friendship, like the Best Buddies program, can be effective in extending one's social network. Claire described the Best Buddies as a program that “sets up the opportunities” between people with and without intellectual disabilities. Best Buddies merely presents the opportunity for friendship and then it is up to the individuals to decide if they will continue it. Alison (L'Arche) observed that “some Best Buddies are more loyal than others”. Whereas some core members see their buddy regularly every two weeks, which is the time commitment outlined by Best Buddies, unfortunately other people can go six weeks without seeing their student buddy.

Participants also identified insufficient financial resources and inaccessibility as barriers to friendship. Insufficient financial resources can be a barrier because most leisure and recreational opportunities in the city have a fee attached to them. As an example, Linda (NSDCS) told me that every month there is a dance hosted at Cole Harbour Place for people with intellectual disabilities that is an important social opportunity for many of her clients. She calculated the costs of attending the event - \$40 for a cab both ways if they live in Halifax and \$5 for the admittance fee. She said that people with intellectual disabilities on income assistance receive a small personal allowance of \$115 each month from the government, which needs to cover all personal

spending costs that may include buying deodorant, shampoo, clothing, and paying to go see a movie. If someone on this budget were to attend the dance at Cole Harbour Place, they would only have \$70 remaining to cover any other costs for the month. According to Linda, for her clients “money is a big factor for social opportunities”. Physical accessibility was another big factor. Claire (L’Arche) shared how one of the advantages of their L’Arche house was that it was completely accessible to people in wheelchairs with various physical limitations. These features made it possible for L’Arche core members to invite other friends with physical disabilities over to the house to spend time together. The L’Arche house demonstrates what has been labeled ‘VisitAbility’, because it offers an accessible and “welcoming environment for visitors of all ages and mobility” (VisitAble Housing Canada, n.d., para. 1). However, if their friends are not able to access affordable transportation, a barrier discussed previously, this would be another challenge that would need to be overcome.

Staff members at special care homes can be instrumental to initiating and supporting friendships between people with and without disabilities, and overcoming some of the barriers their friendships face. Although she sees the staff’s involvement in initiating and facilitating friendships as being less than ideal in a perfect world, Claire (L’Arche) believed that for safety reasons and because of the lack of independence that some of the core members experience, staff members and assistants are often in a position where they need to help facilitate friendships. She referred to friendships that begin through Best Buddies or through the intervention of staff members as being “natural”, but with “synthetic roots”. Both Claire (L’Arche) and Jane (L’Arche) described examples where they were able to support a core member’s friendship. After recounting how she had recently dropped a L’Arche core member off at another group home to spend time with a friend, Jane stated that the staff at the friend’s group home “really value [the core member’s] friendship with their resident, and we really value it too so we try to facilitate their friendship. We try to get them together when we can”. During one of these days when the core member’s friend was visiting L’Arche, Claire described the following scene she happened upon: “They were all sitting around the table. [Another core member] wasn’t feeling well that day so he was home and they’re all playing a game of Monopoly and it was just so normal. Sort of average, and so wonderful in just the

simplicity. Like yah, she had a friend over”. There was significant evidence among my interviews that staff and assistants strove to support friendships of people with intellectual disabilities as much as possible.

In fact, some staff members were so willing to support the friendships of those they worked with that they sometimes felt as though they invested more interest and effort into the relationship than the individual themselves. Alison (L’Arche) observed, “It’s funny because they don’t really ask...I never get any of them say ‘I want to call my friend’, or ‘I want to invite so and so over’”. Consequently Alison was often in a position where she was the one taking initiative and continuously suggesting that a core member invite someone over or arrange a get-together, because the core member “doesn’t often think of it”. Another female core member had a boyfriend who lived forty minutes away and they did not see each other often. Alison had attempted to talk about the relationship with her and Allison had suggested that they get together at some point, but she felt awkward doing this because it was the core member’s relationship, not hers. Kate (L’Arche) noted that some core members were more independent and motivated to make friends than others. She believed that the most successful friendships were those that are initiated by a core member, whereas it is

harder for the people who don’t have that self-motivation. Because what happens is it becomes dependent then on the assistants to maintain the friendship. So the assistants have to support the person to make a phone call or have to support the person to make the invitation for supper. Occasionally the friend keeps the relationship going, but what I find happens is if the assistants don’t put the effort into supporting a core member’s friendship outside of L’Arche, it doesn’t happen, which is so sad. So some people have friends, absolutely, but they’re often the people who can make it happen for themselves, that are a bit more independent. Other people that are more dependent, many of their friends would be people somehow connected with L’Arche.

Learning how to initiate and maintain a friendship is a component of learning social skills. While people pick up on appropriate social skills naturally as they grow up, many people with intellectual disabilities need to be explicitly taught social skills.

Donna (NSACL) pointed out that although people with intellectual disabilities are

quite capable of making and maintaining friends, they often lack the necessary skills to do this. For example she said, “They don’t know that if someone calls them, that they [are expected to] call back”. Donna emphasized: “I’ve stressed this all of my working life in the disability field – that the thing that individuals lack most and need to work on most, is building relationships”. She encouraged the young people she worked with to get involved with whatever clubs, teams, or student councils they could so that they could become part of a group and start building friendships and learning social skills. Donna recommended that people with intellectual disabilities start learning how to develop friendships as early as possible. Whereas some people with intellectual disabilities are not sure how to initiate friendships and may present as more withdrawn, other people with intellectual disabilities are very outgoing, but have difficulty comprehending appropriate social boundaries. Melissa (Best Buddies) reported that sometimes a person with an intellectual disability can misinterpret a person’s friendliness and assume that because the person initiated a nice conversation, they are now their best friend and they can follow them everywhere. Melissa acknowledged that appropriate boundaries and respect for personal space is something that everyone has to learn at some stage, although this typically happens at a younger age. She believed that it would be beneficial for people with intellectual disabilities at a young age, to have both opportunities to develop friendships as well as concrete guidance and training regarding appropriate social boundaries and behavior. Linda (NSDCS) also commented on how some of her clients were overly affectionate when they met someone new. Linda would have to remind them that it is more appropriate to shake hands with someone they just met, rather than to hug everyone that entered their life. In another example, Donna (NSACL) referenced a young man she had worked with and supported through facilitating a peer-based “circle of friends” for him at school. When she recruited students for the peer circle, “he thought all of the girls in the circle were his girlfriends, so we had to work on that”. Donna clarified that the girls were his “friends” to spend time with, but not go on dates with. Participants emphasized that people with intellectual disabilities need to be given the opportunity to learn how to be a friend and have access to helpful guidance in this area.

7.6 SUMMARY

After defining the concepts of friendship and belonging, I applied them to the four contentious topics (i.e. the four examples of segregated environments and activities) that were discussed in Chapter Four to demonstrate how participants used the concepts of friendship and belonging to justify conflicting perspectives on these topics. In Section 7.3, I discussed the benefits of friendship and belonging, such as increased wellbeing, safety and acceptance, as well as the detrimental impacts of not experiencing friendship and belonging, such as the experience of loneliness. In Section 7.4, I presented the types of environments in which people create and sustain friendships, as well as the types of people who were referenced as being friends of people with intellectual disabilities, which included people *with* intellectual disabilities and those *without*. In Section 7.5, I emphasized the importance of cultivating opportunities for the development of friendships, such as through a peer program like Best Buddies or through staff intervention. My participants also pointed out the need for many people with intellectual disabilities to learn social skills so that they can more effectively initiate and maintain friendships. The concepts of friendship and belonging emerged as essential to participants' understanding of social inclusion and they are the final set of concepts to contribute to my explanatory theory.

7.7 EXPLANATORY THEORY CONCLUSION

In Chapters Five, Six, and Seven, I presented my explanatory theory that attempts to explain the research problem I described in Chapter Four. The emergent research problem, expressed as a question, was as follows: If all of my participants upheld the concept of social *inclusion* as an ideal, how were they then able to justify their support both in favour of, and against, *spatially segregated* environments and activities for people with intellectual disabilities? My explanatory theory responds to this question and addresses the research problem by demonstrating how my participants were able to justify their various divergent opinions by prioritizing one, two, or three of the three paired concepts of social inclusion. The majority of participants did not ultimately appear to assess an environment or an activity as being socially inclusive simply based on whether it was or was not spatially segregated from other people without disabilities. According to participants, the degree to which an environment or activity was genuinely

inclusive, seemed to be determined by whether or not these three paired concepts were present or not. The three paired concepts that were essential to participants' understanding of social inclusion include: respect and equality; opportunities and self-determination; and friendship and belonging. Special care homes, segregated education, Adult Service Centres, and Special Olympics are all examples of spatially segregated environments and activities that on first impression would appear to conflict with the idea of social inclusion. However, through prioritizing different key aspects of social inclusion, participants demonstrated how it is possible for these segregated environments to be capable of cultivating inclusion within their borders, and of promoting inclusion beyond their borders.

Unfortunately the lack of consensus around the concept of social inclusion (what it is and how it should be facilitated) is hindering society's ability to achieve social inclusion for people with intellectual disabilities (Cobigo et al., 2012; Kendrick & Sullivan, 2009; Martin & Cobigo, 2011; Sherwin, 2010). In Chapter Eight, I present my operational theory and action plan. My operational theory suggests that *all* three paired concepts identified in my explanatory theory are necessary for social inclusion. They all need to be given equal weight when making policy and programming decisions. Holistically addressing and enacting all three paired concepts of social inclusion does not necessarily mean that spatially segregated environments must be avoided at all costs, but rather, by simultaneously focusing on all three paired concepts of social inclusion, we can work toward creating a future reality in Nova Scotia; a reality that *includes* each and every individual with their unique preferences and desires. We need to approach social inclusion *without* value-laden societal ideals, such as the belief that success equates to *everyone* having full-time community employment (Kittay, 2002), or that the good life is only achieved when one is able to live *independently* in their own home (Clegg, 2009; Oldman, 2003), or that people with intellectual disabilities should *only* having friendships with people without disabilities (Cummins & Lau, 2003). Instead, we need to put aside narrow and short-sighted visions of the future, and holistically enact the potentiality of social inclusion using a person-centered approach.

CHAPTER 8: THE OPERATIONAL THEORY AND ACTION PLAN

8.1 THE OPERATIONAL THEORY

In this chapter, I describe stages two and three of grounded action methodology: the operational theory and the action plan. According to grounded action methodology operational theory is developed from the explanatory theory after “revisiting the action problem in light of what has been discovered while generating the explanatory theory” (Simmons & Gregory, 2003, p. 9). The action problem I observed in society was the lack of progress in achieving social inclusion for people with intellectual disabilities (Barken 2013; Devet, 2014; Encol & Orrell, 2013; Wicks 2010). Upon commencing my qualitative data collection I uncovered a more latent issue that lay at the root of the action problem – the lack of consensus and clarity around the concept of social inclusion was hindering progress toward an inclusive society (Cobigo et al., 2012; Kendrick & Sullivan, 2009; Martin & Cobigo, 2011; Sherwin, 2010). After developing a grounded theory to explain this research problem, I returned to the original action problem (or ‘social issue’) and guided by my explanatory theory I made a “theoretical prediction”; also referred to in grounded action as the “operational theory” (Simmons & Gregory, 2003). My theoretical prediction and operational theory indicate that social inclusion and consensus among stakeholders is achievable if *all* three paired concepts identified in my explanatory theory (respect and equality; opportunity and self-determination; and friendship and belonging) are addressed simultaneously and holistically during policy and programming decisions. Disagreements arise and progress stagnates when the debate becomes preoccupied as to whether or not spatially segregated environments and activities, such as Special Olympics and Adult Service Centres, are ‘good’ or ‘bad’. Focusing on *all* three paired concepts shifts social inclusion efforts beyond these gridlocked disagreements and facilitates a more holistic and productive dialogue. As discussed in Chapters Five, Six and Seven, according to my participants, the presence of respect and equality, opportunities and self-determination, and friendship and belonging, were more important determinants of social inclusion than whether or not the environment or activity was spatially segregated. I have selected a few direct quotes from my participants to emphasize again, how vital these three paired concepts were to their understanding of social inclusion.

Respect & Equality

Everybody in that room got an award. For this person it might have been he was 'the greatest dancer' because he was a good dancer. For somebody else it was 'the greatest helper'... For somebody it might have been because she has a beautiful smile. There's always something to celebrate and [L'Arche] always brings that to the front.

- Daniel (L'Arche), telling me about a L'Arche community social event.

It does open [the eyes of volunteers and sponsors] more to 'I never thought they'd be able to do that. If they can do this, well then why can't they push our mail from the mailroom? Why can't they do this? Why can't...' so it does open up a lot more doors.

- Chris, discussing how Special Olympics has changed the attitudes of volunteers and sponsors.

Opportunities & Self-determination

Like to me, inclusion is the basics: Do I have a choice in my life? Do I have a choice where I live? Do I have a choice of what I eat? Do I have a choice of where I go? Do I have human rights? Can I make friends? Am I allowed to make friends? Do I have a choice in that? I mean we can complicate this as much as we really want... But if you really forget about the fluff, inclusion should mean choice.

- Peter (a special care home agency).

I think for me, if the only choice that's given to somebody is to bowl with Special Olympics then that certainly goes against everything about inclusivity. Like if the only option for people is to work in a sheltered workshop [i.e. Adult Service Centre] then that's where I have a problem. If the only thing available, or the only thing that's offered, is something that isolates people then there's a problem for me. So for me if somebody is introduced to bowling with Special Olympics, in an ideal world, we would also be able to find an integrated bowling option for them

and then let them choose. And we never do that. Like for the most part, as caregivers, Special Olympics is easy.

– Kate (L'Arche).

Friendship & Belonging

If you're eating alone at the lunch room or there's no one around, your friends [are not] there, that's not social inclusion... [if you are employed in the community but] meanwhile your buddies are going out for beer at the end of the day and going out for a meal or doing whatever right, but you go home – that's not social inclusion... it's more than having a job; it's being a part of a social network, a friend network... It's very isolating to be part of a job and then having to eat alone and you have no friends at work and everyone else is buddy-buddy and doing other stuff outside of work.

– Edward (People First).

The disability disappears. You're just friends. That's it. That's the inclusion piece.

– Allen (RRSS), describing what happened as friendships naturally evolved through the Best Buddies program.

I did not have the opportunity to *empirically test* the operational theory in this master's project, but I am in an excellent position to provide rich scenarios to demonstrate how the operational theory as a theoretical prediction and definition of social inclusion, contributes to what social inclusion should look like. When considering the hypothetical case of someone who has been working in an Adult Service Centre for many years, in order to apply the three paired concepts, the following questions should be asked: Is the individual truly being treated with respect, as an equal human being in the context of the Adult Service Centre? Have they been presented with other potential employment (and leisure) options, and allowed the chance to explore these options further either by gaining more information about them or giving them a trial run? Have they been truly supported in making their own decisions regarding work opportunities and how they want to spend their time? Or have they been pressured to decide in

accordance with other people's preferences? Do they have valued friendships at the Adult Service Centre and are these social networks supported by staff members? Has it been explained to them that they can maintain old friendships while also making new ones if they choose to spend their time in other environments – whether that be in community-based employment or something else? Are there people and supports in place that can assist them in maintaining old friendships that were created at the Adult Service Centre, and also in cultivating new friendships in other environments?

Perhaps the hypothetical individual has been presented with a range of valid employment opportunities and staff members are genuinely prepared to support them in making the transition to community-based employment, but the individual clearly indicates their preference for staying at the Adult Service Centre and continuing their involvement with the social network they belong to there. Assuming that the person is being treated with respect in that context, this could be an example of social inclusion. For another individual in that situation, they may choose to instead accept an offer of community-based employment and they may thrive in that environment if they are treated as an equal employee and have the opportunity to engage in quality social interaction with other employees. This too, could be social inclusion. Finally, there could also be someone in this situation who, after being presented with a wide range of options, prefers not to work at an Adult Service Centre *or* in a community-based employment context. They would rather spend the day at their home with occasional visits from friends and volunteering part-time. If this choice can be honored and supported, if they are treated with genuine respect in this context and have plenty of opportunity for valued social interaction when they want it, then this scenario could also be an example of social inclusion.

When one or two sets of paired concepts are prioritized over the others, disagreements between stakeholders can result and efforts toward social inclusion risk being inappropriate or incomplete. Therefore, my operational theory indicates that it is crucial that *all* three paired concepts are enacted simultaneously and awarded equal value. All three paired concepts are integrally linked with each other. For example, if people with intellectual disabilities are treated with *respect*, as an equal member of society, they will have more *opportunities* in life and will be more appropriately

supported in exercising their right to *self-determination*. If respect and equality are not present, even if a range of opportunities are available, the opportunities may not be appropriate or appealing, or the person with the intellectual disability may be coerced or pressured into a decision that is preferred by staff and family members. Genuine *friendships* develop when two people have the *opportunity* to meet and choose to voluntarily interact and invest in building a reciprocal relationship of mutuality. Peter (a special care home agency) explained that people with intellectual disabilities need the freedom to exercise their *self-determination* when designing their own social circles and deciding what communities and networks they want to *belong* to. Genuine friendships of reciprocity must be accompanied by *equality* and *respect*; otherwise the resulting power imbalance could interfere with these friendships. These examples illustrate the different ways that each set of paired concepts support the enactment of the others.

Furthermore, addressing and focusing on all three paired concepts also protects the concept of ‘social inclusion’ from being co-opted by socially normative ideals and standards that are upheld by those who hold more power in society (Allman, 2013; Johnson, Walmsley, & Wolfe, 2010; Labonte, 2004; Shakir, 2005). As discussed in Chapter Three, these socially normative and valued ideals include ideals such as living independently in one’s own apartment or house, working full-time in a mainstream employment context, and socializing with non-disabled people (Cummins & Lau, 2003; Hall, 2010; Kittay, 2002; Oldman, 2003;). While someone with an intellectual disability should have the opportunity to live independently, to work full-time, and socialize with non-disabled people, the degree to which they are experiencing social inclusion should not be measured by these standards as this could lead to potentially inaccurate conclusions. Cobigo (2012) speaks to the “injustice of imposing dominant values on vulnerable groups”. The prevailing social inclusion discourse promotes values such as productivity, independence, and attachment to the labour market (Rose, Daiches, & Potier, 2012). Cobigo (2012) advises that “social inclusion targets must respect the individual’s expectations, choices, and needs... Although rehabilitation services and policies embrace this principle, they tend to use dominant values and norms as benchmarks. There is no fit-for-all social inclusion” (Cobigo, 2012, p. 2). I agree with Cobigo, Ouellette-Kuntz, Lysaght, and Martin (2012) that social inclusion is the “result

of complex interactions between personal and environmental factors” (p. 82). It is a relative and dynamic concept that should be addressed at the micro individual level, as well as the macro level. Cobigo et al. (2012) write,

Social inclusion is not an absolute or dichotomous (included/excluded) phenomenon. The level of inclusion may vary across roles, environments and over time. For example, one may be included amongst a peer group in a social setting, but less so amidst a work group in a new job setting. (p. 82)

My operational theory seeks to build consensus around a definition of social inclusion that is not limited by inflexible quantitative and concrete measures of inclusion, but instead sustains a flexible applicability to unique individuals with intellectual disabilities in Nova Scotia over time.

8.1.1 THE IMPORTANCE OF A HOLISTIC, LONG-TERM VISION

There is another condition associated with the successful application of the operational theory. In addition to the addressing *all* three paired concepts of social inclusion simultaneously, *a holistic, long-term vision* is crucial for the application of my definition of social inclusion. Sometimes when evaluating two different options in the pursuit of social inclusion, one option may appear to be unappealing. While it may simply be an inadequate option, it may also be that the option requires that more resources are invested into it so that it can *become* a viable option. To illustrate this, I will return to my case example described in Chapter One – the recent recommendations regarding inclusive education in Nova Scotia (Minister’s Panel on Education, 2014a). The Minister’s Panel review of Nova Scotia’s education system (2014a) documented significant criticism of the current model of inclusive education that was being implemented in mixed classrooms around the province. These criticisms prompted the Panel to recommend that the Department of Education “assist schools and school boards to create a range of learning environments for students with special needs, *including congregated classes* taught by highly qualified specialist teachers, where appropriate” (2014a, p. 42, emphasis added). As previously discussed, this recommendation for spatial segregation angered and concerned inclusion advocates. However, a contrasting response to the report’s recommendations was expressed by a mother of someone with a disability in an online forum (November 18, 2014). I think it is pertinent to repeat her statement

here, because she highlights the need for a *holistic* and nuanced vision of social inclusion, which is relevant to this discussion:

Inclusion and disability have many layers. I would love to see more thought go into this process. *What is the purpose of inclusion and is this method achieving that purpose? ...* In my opinion *true inclusion* – every child having meaningful interactions which result in personal and communal growth – requires *a radical change* in curriculum, class structure and supporting staff. Real inclusion is expensive. In our personal experience our child begged to be placed somewhere where he could learn with children who were 'like him' – his words. We moved here because N.S. offers the Tuition Support Program, which funds specialist schools – *which on the outside seems like segregation, but which has given him the tools to become a contributing member of our community – inclusion.*

(Anonymous, personal communication, emphasis added)

The child's preference to be placed in a classroom with people who had similar disabilities was respected and honored by his parents, thus supporting his right to self-determination. If the child found respect and equality, opportunities and support of self-determination, as well as friendship and belonging *within* his new specialist school, then he likely experienced social inclusion in that spatially segregated context. However, his mother also spoke to the *potential* of mainstream classrooms to become more genuinely inclusive. If the necessary resources were invested into the 'option' of the mixed-ability mainstream classroom, and the radical changes she referred to were implemented, her son may have chosen to stay in the mainstream classroom. If all three paired concepts had been genuinely manifest in the mainstream classroom, her son could have experienced social inclusion in this context as well.

8.1.2 ENHANCING OPPORTUNITIES AND CAPITALIZING ON IMPROVEMENT POTENTIAL

The danger of pursuing social inclusion with a narrow perspective and lack of holistic vision is that an opportunity could be dismissed as inappropriate simply because its *current state* may be less than ideal. While some of my participants appeared to utilize the paired concepts through a narrow and short-sighted lens, other participants applied a holistic perspective and believed in the *improvement potential* of certain options.

Through my analysis of the data I observed that even when people are provided with choices, if certain choices are less appealing due to a lack of resources or other impediments, this is indicative that social inclusion may not be manifest because the *opportunities* are not as good as they could be, in order for people with intellectual disabilities to truly exercise their *self-determination*. For example, just because the current inclusive classroom model is criticized as faulty, this does not mean that we should return to a completely segregated education model for people with intellectual disabilities. Instead, it may be an opportunity to enact the “radical change” in the mainstream school system that the mother quoted above, believed was necessary. This would capitalize on the improvement potential inherent in the mixed-ability classroom and would enhance the range of opportunities available to an individual. Similarly, just because people with intellectual disabilities enjoy Special Olympics, does not mean we should stop investing resources into improving the accessibility of other recreational and sporting options. It is important to respect the preferences and self-determination of people with intellectual disabilities, even if that means honouring their decision to be involved in a spatially segregated environment. However, we must still continue to invest resources toward removing access barriers and improving the range and quality of opportunities that are available to them.

It is also important to note that some people are fully *not aware* of the opportunities that exist, and part of enacting the paired concepts of opportunities and self-determination (as well as respect), is to ensure that they understand what is available to them. On the topic of friendship, Amado et al. (2013) point out that “if an individual has primarily been schooled with, lives with, and works with other people with disabilities, they may not be able to express any preference other than what is already known to them” (p. 365). For example, it is unfortunately too easy for a caregiver to ask a person who has never been exposed to mainstream sporting opportunities, if they would like to leave Special Olympics to try something else and consequently receive a negative answer – simply because the person may not understand their options. Therefore, it is essential to apply social inclusion holistically – in a way that respects the personal decisions of individuals, addresses the improvement potential of various opportunities, and involves fully informing individuals of a wide range of options.

8.1.3 SUMMARY

As discussed in Chapter Three, a poor understanding and application of social inclusion may not be able to achieve more than mere physical presence in the community, for people with intellectual disabilities (Bigby, 2008; Bigby & Clement, 2009). Not only can social inclusion efforts be inadequate and ineffective, but social inclusion efforts can also cause harm if they are misguided in their application (Cummins & Lau, 2003; Kendrick & Sullivan, 2009). My hope is that my research can prevent misguided efforts and instead, contribute to creating a clear vision of inclusion. Through application of my operational theory – by focusing on all three paired concepts of inclusion *and* applying them holistically – social inclusion efforts will be better safeguarded and protected from misuse. My definition of social inclusion, based on the presence of the three paired concepts, is flexible and broad enough to encompass and protect a variety of individual desires and personal preferences among people with intellectual disabilities in Nova Scotia. Most importantly, the definition is grounded directly in qualitative data collected from an array of participants in Nova Scotia.

8.2 THE ACTION PLAN (RECOMMENDATIONS)

The third stage of grounded action methodology is to create an action plan (Simmons, 2006). An action plan is essentially “the roadmap for measuring and putting the operational theory into motion” (Olson, 2008, p. 4). If this were a completed grounded action study, it would involve the implementation of the action plan (stage four). This is a partially completed grounded action study and I am not in a position to implement this action plan, but I will outline in this section, a number of suggestions for how the operational theory and the associated definition of social inclusion, can be applied. The suggestions are based on the data collected from participants and the strategies and actions they had observed to be effective and necessary, or those they believed should be implemented in the future. The suggestions and recommendations are organized according to each of the three paired concepts, and according to the four topic areas discussed throughout this thesis (i.e. living environments, education, work contexts, sports). These suggestions and recommendations demonstrate various ways that all three of the concepts can be holistically applied in different types of situations.

8.2.1 ENACTING RESPECT AND EQUALITY

Changing society's attitudes toward people with intellectual disabilities is a key factor in achieving respect and equality. It requires a diversity of strategies at both micro and macro levels of society. Many authors (e.g. Cushing, 2002; Prince 2009; Reinders, 2000), as well as many of my participants, believe that attitudinal barriers are one of the most difficult societal barriers to overcome in the pursuit of an inclusive society – people cannot be coerced to *care* about other people (Ignatieff, 1984). However, certain actions can create a fertile ground for these attitude shifts to occur. The broader community needs to be engaged through intentional actions and outreach efforts that go beyond ensuring community presence for people with intellectual disabilities – actions that have the potential to shift society's attitudes in significant ways. My participants attested to the difficulty in doing this in larger cities, but it is still possible. L'Arche, for example, hosted a successful art show and sale to raise funds, but also to introduce the members to the broader community.

Enacting the paired concepts of 'respect and equality' in living environments.

- To respect the dignity and the rights of people with intellectual disabilities, they must be provided with the privacy they desire within their homes, whether it is a special care home or not.
- Residents in special care homes should be empowered through training, and encouraged to speak up and protect themselves against abuse. Abuse is an assault on someone's dignity as an equal human being and participants indicated that empowering residents to speak up can be another powerful preventative measure in addition to increasing staff training.
- All special care home organizations should include their clients in decision-making processes and in the management of the home to the greatest extent possible, such as through the creation of resident councils.
- When a group outing is organized for residents of special care homes, staff members should be aware that just because the outing is considered to be a 'fun' opportunity, it is possible that not everyone is interested in that particular outing. They should be given the opportunity to 'opt out' and select another outing or event to participate in.

Enacting the paired concepts of 'respect and equality' in education.

- In the school setting, through programs like Best Buddies and Circle of Friends, non-disabled peers can demonstrate to their classmates how healthy respectful friendships can develop with people with disabilities. These programs have the potential to shift attitudes.
- In the school system, respect and equality can be honoured by increasing funding for in-classroom supports, such as for Education Program Assistants (EPAs), and creatively supporting people who do not want to spend their day in mainstream classrooms. Treating people with respect as equals means honouring their decisions and investing in the provision of tailored supports and services that are appropriate for what they want and need in life.
- High quality training for school teachers and caregivers has the potential to improve their ability to treat students and clients with disabilities with greater respect, and how to respond effectively to aggressive behavior without using violence and avoiding force. Their ability to model respectful interactions will influence other society members who witness it.

Enacting the paired concepts of 'respect and equality' in work contexts.

- Increased effort should be directed toward increasing awareness of the employability of people with intellectual disabilities among mainstream community employers in order to facilitate their receptiveness to hiring people with intellectual disabilities and to enact *Canada's Employment Equity Act* (Employment Equity Act, 1995, Section 2). Removing barriers to enable more people (who want) to work in mainstream employment settings will also help to shift society's attitudes as they see people with disabilities in valued social roles.
- The roles of job coaches and employment counselors should be sufficiently supported and these positions should be multiplied. Job coaches or employment counselors are often cited by participants as essential mediators between the person with the intellectual and their co-workers and/or employer. In addition to resolving misunderstandings and disputes in a respectful way, they can also provide education and training for both the employee and the employer to enable a better working relationship.

Enacting the paired concepts of 'respect and equality' in sports.

- Encouraging volunteer involvement in mainstream Special Olympics program and supporting their new mixed-ability program, Unified Sports, as well as their Athlete Leadership Program, will help to shift society's attitudes as they realize what people with intellectual disabilities are capable of. Special Olympics can also build the confidence and self-respect of people with intellectual disabilities.
- Any indication of disrespectful attitudes among volunteers and/or staff members of Special Olympics (or in another sporting context) toward people with intellectual disabilities should be addressed immediately. Volunteers and staff members should refrain from calling adult Special Olympics athletes 'kids'.

8.2.2 ENACTING OPPORTUNITIES AND SELF-DETERMINATION

All contexts and situations should be examined to ensure that people with intellectual disabilities have a wide range of high-quality choices and opportunities available to them. If any of the options are less appealing and are of a lower quality than others, they should be examined to identify whether or not there are any barriers that need to be removed, or whether more resources need to be invested to increase the value of the opportunity. Care providers and academics have acknowledged that people with *profound* and *multiple* intellectual disabilities that include serious communication limitations, have greater difficulty exercising their self-determination (Bigby, Clement, Mansell, & Beadle-Brown, 2009). However, as discussed elsewhere in this thesis, this does not negate the importance of upholding and honoring the concepts of opportunities and self-determination with these individuals. Regardless of a person's capacity, the aim of social inclusion should always be to maximize, rather than to diminish, people's opportunities for self-determination to the greatest extent possible within the situation or set of circumstances (Cardol et al., 2002). It is important not to underestimate the capabilities of those with even the most profound disabilities. For those who do not use or understand any form of understandable language (including symbols and images), it is still possible for those who work closely with them on a regular basis, to discern the subtle indicators of when these individuals experience emotions such as joy, anger, sadness, and curiosity (Porter, Ouvry, Morgan, & Downs, 2001; Thurman, Jones, and Tarleton, 2005). These emotional indicators can be used to understand the individual's current *preferences*, and

to guide the care provider in determining what types of opportunities the individual may want to engage in, in the future. Care providers should be appropriately trained on how to communicate a range of choices to people with communication challenges, and on how to provide supported decision-making.

In addition to care providers, other members of society, such as those belonging to community groups (e.g. church or faith communities), are situated in such a way that they could play a major role in promoting inclusion through creatively identifying opportunities for involvement. One participant explained how churches have various positions and roles that people with intellectual disabilities could easily step into (i.e. being a part of the service, or greeting people). Churches also host events frequently, such as bake sales and yard sales, which could include people with intellectual disabilities in intentional ways by providing them with certain duties and roles. People with intellectual disabilities should also have the opportunity to be involved in advocacy and leadership roles where they can exercise self-determination for themselves, and also in a way that could benefit other people with disabilities, such as through the People First organization. Furthermore, to enact the paired concepts of opportunities and self-determination, as indicated by a participant, policy documents should be written in plain language without jargon. This enables people with intellectual disabilities to better understand the policies that affect their lives, and therefore can empower them to mobilize, advocate and have their voice heard in the political sphere.

Structural, programming and policy barriers should be addressed and removed when necessary, in order to provide a wider array of opportunities. For example, participants identified how a lack of accessible transportation, as well as a lack of available finances could be significant barriers; preventing people with intellectual disabilities from taking part in opportunities such as social events and activities. Improving transportation options (particularly in rural areas) and increasing income assistance and addressing the inflexible rules regarding how it is to be spent, is one way to address this barrier to opportunities and self-determination.

Enacting the paired concepts of 'opportunities and self-determination' in living environments.

- Homes and communities should be physically accessible in all respects so those with additional physical disabilities have the option to access and travel to all locations that the general public has access to.
- Smaller special care homes, such as small option homes (SOHs), should be funded and permitted to proliferate. Zoning by-laws that prevent types of group homes from opening in family neighbourhoods should be examined and addressed if these by-laws are being discriminatory to people with disabilities.
- Efforts should strive toward making sure that Article 19 of the *United Nations' Convention on the Rights of Persons with Disabilities* is fully enacted in Nova Scotia by ensuring that: "Persons with disabilities have *the opportunity to choose* their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement..." (United Nations Human Rights, 2006, emphasis added). One participant told me: "people should just be allowed to live in homes or apartments or wherever they want to if they want to camp... I mean wherever as long as they have the supports to do it".
- Resident councils should exist within all special care home agencies where people with intellectual disabilities can provide input on agency decisions that will affect them.

Enacting the paired concepts of 'opportunities and self-determination' in education.

- Youth in the education system should be able to make supported decisions regarding how, where, and what they want to learn. Tailored support services should be available to allow them and their families to create the type of education that they need and desire. Whether the youth with a disability decides to participate in an integrated classroom for 100% of his school-day, or only for part of it, it is essential that his inclusive education experience is person-centred and tailored to meet his current and future needs and goals.

Enacting the paired concepts of 'opportunities and self-determination' in work contexts.

- Barriers to community-based employment should be removed so these opportunities are available for people with intellectual disabilities. This can be accomplished through investing more resources into job coaching and training opportunities, removing the financial disincentives to increasing one's working hours, and ensuring that people have the flexibility to design a work week that works for them.
- People currently working in Adult Service Centres should be supported in finding community-based employment if they desire to do so (and they should know this option is available to them).

Enacting the paired concepts of 'opportunities and self-determination' in sports.

- People currently involved in Special Olympics, or those considering future involvement in Special Olympics, should have access to (and know that they have access to) a range of other sporting and recreational opportunities, including mainstream, mixed-ability opportunities.

8.2.3 FRIENDSHIP AND BELONGING

Although I presented the criticisms of achieving mere 'physical presence in communities' in Chapter Three, this can be an effective *first step* toward achieving genuine social inclusion (Bates & Davis, 2004; Bigby & Wiesel, 2011). Opportunities where people with intellectual disabilities can engage with the public meaningfully (e.g. environments that have the potential to produce quality social interaction and friendships) should be identified and presented to people with intellectual disabilities if they are not able to seek out these opportunities on their own. However, care should be taken to ensure that friendships between people with similar disabilities are given the same value as mixed-ability friendships.

While many people pick up on appropriate social skills naturally as they grow up, many people with intellectual disabilities need to be explicitly taught social skills. One participant told me: "I've stressed this all of my working life in the disability field, that the thing that individuals lack most and need to work on most is building relationships". Social skills training would support people with intellectual disabilities in initiating, developing, and maintaining friendships.

Enacting the paired concepts of 'friendship and belonging' in living environments.

- When looking for admittance to a special care home, people with intellectual disabilities should be able to be placed at a location that is as close as possible to their family members and friends so they can successfully maintain these relationships. The current crisis-driven housing system unfortunately sometimes prevents this from occurring.
- In a special care home, friendships between staff members and residents should not be discouraged if they are respectful, reciprocal friendships. Participants spoke of the great value of these types of friendships.
- Recording someone's life story (such as in a binder or notebook) is a powerful way to build belonging (Johnson, Walmsley, & Wolfe, 2010), and something that some participants in special care homes had put into action.

Enacting the paired concepts of 'friendship and belonging' in education.

- Programs that connect youth with intellectual disabilities and their peers in grade school or university, such as Best Buddies and Circle of Friends, should be invested in and encouraged to multiply in all schools and universities across the province.
- Within the school system students with intellectual disabilities should be supported with their involvement in extracurricular activities beyond the classroom where they can meet new friends. Support workers, staff and students can assist the individual in finding a position in the extracurricular activity or program that they are comfortable with.
- According to participants, sometimes support workers and caregivers who accompany students with disabilities throughout their school day, can unintentionally get in the way of friendships naturally developing between classmates. Extra training on how and when to step back, and how to effectively support friendships, could help address this barrier.
- When youth with intellectual disabilities graduate from high schools, they are at risk of becoming socially isolated. They should be immediately connected with transitional program options or intentionally provided with opportunities to enjoy quality social interaction (according to their preferences).

Enacting the paired concepts of 'friendship and belonging' in work contexts.

- When providing people with employment opportunities beyond an Adult Service Centre, it should be explained to them that there is the potential to create new friends in new environments, while also maintaining old friendships. Those who are involved in their lives should prioritize supporting and encouraging the friendships of people with intellectual disabilities.
- When a person with an intellectual disability is hired or placed in a new job, the employment context should be examined to identify opportunities for them to engage in quality social interaction and cultivate a sense of belonging in their workplace.

Enacting the paired concepts of 'friendship and belonging' in sports.

- Whether the individual is involved in Special Olympics or another form of sporting or recreational activity, the individual's ability to form social connections in the various contexts should be assessed and supported if needed or desired.

8.2.4 SUMMARY

This action plan and list of recommendations illustrates different ways that the operational theory can be applied and the three paired concepts of social inclusion, enacted. This is far from being a complete list, but it builds upon many of the specific issues and concerns that were identified by participants throughout the thesis, and includes many of their direct suggestions for how to facilitate social inclusion. All recommendations should be addressed through the application of a holistic long-term vision guided by the individual's personal preferences, through enhancing the range of opportunities, and by capitalizing on the improvement potential inherent in possible paths to inclusion.

CHAPTER 9: CONCLUSION

9.1 SUMMARY OF RESEARCH FINDINGS

This grounded action study is a response to the demonstrated lack of progress toward social inclusion for people with intellectual disabilities in Nova Scotia (Barken 2013; Devet, 2014; Encol & Orrell, 2013; Nova Scotia Hansard Reporting Services, 2014b; Wicks 2010). Upon commencing my study I identified the following research problem: although all of my participants upheld the goal of social inclusion for people with intellectual disabilities, they expressed different opinions about the various spatially segregated environments and activities that this population engages with (i.e. segregated education, special care homes, Adult Service Centres, and Special Olympics). These different opinions reflect the prevalent lack of consensus evident in the academic literature, as well as in service programming and policies, as to how ‘social inclusion’ should be defined for people with intellectual disabilities (e.g. Clement & Bigby, 2009; Kendrick & Sullivan, 2009; Sherwin, 2010). This lack of consensus around the definition of social inclusion, and how it should be implemented or facilitated in society, impedes progress toward a more inclusive province (Cobigo et al., 2012; Kendrick & Sullivan, 2009; Martin & Cobigo, 2011). The findings from this research indicate that participants were able to justify their various opinions for, or against, spatially segregated environments and activities by providing examples that illustrated one or more of the following three pairs of concepts: respect and equality, opportunities and self-determination, or friendship and belonging. Building upon this study’s explanation of the research problem, I sought to offer a holistic and applicable definition of social inclusion for people with intellectual disabilities through my operational theory. My operational theory predicts that by holistically and simultaneously enacting all three of the paired concepts in programming and policy decisions in Nova Scotia, we can bypass gridlocked debates about spatial segregation, and more effectively work toward to the development of an inclusive province.

Within Canada, Nova Scotia has the highest reported rates of disability (Statistics Canada, 2012) and according to researchers and advocates, social inclusion for people with intellectual disabilities has not significantly progressed and has even regressed in some cases (Barken 2013; Encol & Orrell, 2013; Wicks 2010). Progress has stalled even

though the concept of social inclusion is embedded in policy documents and there have been public calls to implement and facilitate social inclusion (Dechman, 2003; NS Advisory Committee, 2013; Nova Scotia Department of Health and Wellness, n.d.; Nova Scotia Government, 2014). One recent effort to improve the social inclusion of people with intellectual disabilities is captured in the landmark report: *Choice, equality and good lives in inclusive communities: A roadmap for transforming the Nova Scotia Services to Persons with Disabilities Program* (2013) (discussed at greater length in Chapter Three). Although I believe this ‘roadmap’ document to be a significant contribution to the development of a socially inclusive province, the report’s five-year plan and recommendations lack the explicit guidance of a comprehensive definition of social inclusion. I believe the application of the recommendations contained in this report would benefit from the definition of social inclusion that has been produced through my research and expressed through my operational theory. My definition of social inclusion could also be utilized to guide the implementation of the Minister’s Casey’s (2015) recent report – *3 Rs: Renew, Refocus and Rebuild, Nova Scotia’s Action Plan for Education*⁶ – as it relates to students with intellectual disabilities.

In addition to contributing to resolving current policy and practice dilemmas, this research study addresses theoretical deficits and gaps in the academic literature. In Chapter Three, I analyzed the existing literature on spatially segregated environments/activities and their alternatives and discovered diverse opinions that echoed those expressed by my participants (e.g. Migliore Grossi, Mank, & Rogan, 2008). However, I did not find any literature that simultaneously assessed and compared perspectives related to *multiple* spatially segregated environments or activities. By analyzing my participants’ different opinions on the topic of four segregated environments and activities (i.e. segregated education, special care homes, Adult Service Centres, and Special Olympics), I was well positioned to identify common themes that intersected with all four topics. This enabled me to apply a broader, holistic perspective and develop a grounded theory that explained how my participants were able to express conflicting perspectives while they continued to uphold social inclusion as a goal for people with intellectual disabilities. Furthermore, while there has been numerous

⁶ See Chapter One, Section 1.2 for a more detailed discussion of Minister Casey’s report.

quantitative studies undertaken to measure the extent to which people with intellectual disabilities are included in their communities (e.g. Amado et al., 2013; Bigby, 2012; Cummins & Lau, 2003), the quantitative nature of these studies have been criticized for reducing inclusion to the irrelevant numeric indicators (e.g. Bigby & Clement, 2009; Cummins & Lau, 2003).

As discussed in Chapter Three, a poor understanding and application of social inclusion may not be able to achieve more than mere physical presence in the community, for people with intellectual disabilities (Bigby, 2008; Bigby & Clement, 2009). Amado et al. (2013) attempt to summarize the status of current research in relation to social inclusion and people with intellectual disabilities, and they identify key areas of emerging and unanswered questions that need to be addressed by future research. The first of these is as follows: “How do we move from community activities to a person having a sense of community and belonging?” (Amado et al., 2013, p. 366). My research responds to this unanswered question. Through *qualitative* interviews, this study sought to contribute to the small, but growing body of literature that strives to examine the nature of social inclusion in more subjective terms (e.g. Abbott & McConkey, 2006; Johnson, Walmsley, & Wolfe, 2010). In recent years, there has been a growing recognition that social inclusion as a concept is potentially useful, but lacks clarity and definition – both beyond the disability field and within it (Kendrick & Sullivan, 2009; Martin & Cobigo, 2011; Rose, Daiches, & Potier, 2012). As discussed previously, many definitions of social inclusion are heavily influenced by outdated theories or socially normative values and practices and utilize inflexible, concrete and specific measurements of inclusion (Johnson, Walmsley, & Wolfe, 2010). Not only can social inclusion efforts be inadequate and ineffective, but social inclusion efforts can also cause harm if they are misguided in their application (Cummins & Lau, 2003). Kendrick and Sullivan (2009) point out that not every version of social inclusion is beneficial, even if its implementers have good intentions. My hope is that my research can prevent misguided efforts and instead, contribute to creating a clear vision of inclusion – for people with intellectual disabilities in Nova Scotia.

In summary, the definition of social inclusion presented in this thesis, based on three pairs of abstract and flexible concepts, seeks to bypass the gridlocked debates about

spatially segregated environments and environments. Framed by a quality of life perspective (Brown, Cobigo, & Taylor, 2015), grounded in qualitative data, and designed to be flexible and broad enough to apply to different situations, this definition can safeguard a vision of social inclusion that will contribute to individual, as well as community, well-being in Nova Scotia.

9.2 RECOMMENDATIONS FOR FUTURE RESEARCH

My recommendations for future research include empirically testing the operational theory explained in this chapter, through the action plan recommendations or in whatever way honours the three paired concepts within the context where the research is undertaken. The final *fourth* and *fifth* stages of grounded action (Simmons, 2006) involve implementing the action plan (thus empirically testing the explanatory and operational theories), and engaging in transformative learning through reflection on the outcomes. Unfortunately I am not positioned to implement the action plan myself (and reflect on the outcomes), and consequently steps four and five of this grounded action study are incomplete. This study still remains however, a completed *grounded theory* study (Charmaz, 2014). I have chosen to refer to it as a *grounded action* study because I wanted to extend my explanatory grounded theory in order to at least develop an operational theory and action plan (grounded action stages two and three) with the hope that in the future the action plan could be implemented, and the operational theory empirically tested. I believe the operational theory and definition of social inclusion developed through this research has the *potential* to be applicable in locations beyond Nova Scotia, and possibly with other populations (other than people with intellectual disabilities). However, as a constructivist grounded theorist I will not immediately claim generality for my research results. Generalizing my grounded explanatory and operational theory to other contexts must occur gradually and cautiously; accompanied by additional data collection in all new contexts. After the operational theory is first tested and verified within the context of Nova Scotia, the explanatory and operational theory can then be tested in other substantive areas where it is apparent that the research or action problem defined in this study is present. Furthermore, when verifying the theories in new settings, to stay true to constructivist grounded theory and grounded

action, the theories must “remain open to modification, application, and transformation” (Simmons & Gregory, 2003, p. 11).

Another recommendation would be for the development of measurement strategies. Many authors have spoken of the need for a clear definition of social inclusion when developing valid indicators that can be effectively tracked and measured in order to assess and evaluate progress toward social inclusion (Cobigo et al., 2012; Mahar, Cobigo, & Stuart, 2013). Amado et al. (2013) point out that,

there is no systematic or agreed-upon method for measuring social inclusion, nor for determining progress in impacting such inclusion... An operational definition and measurement of social inclusion is needed, including measures of the amount, quality, diversity, and variations, as well as the influence on quality of life. The measurement strategies would reflect the conceptual framework agreed upon or developed. (p. 370)

While this research responded to the call for an operational definition, measurement strategies still need to be developed in order to determine how to best measure and assess the presence of the three paired concepts in various contexts.

9.3 CONCLUSION

At the end of each interview I would ask my participants what I called, my ‘utopia question’. I would ask: “Do you believe a truly inclusive society is possible and if so, what would it look like?” I received a range of answers to this question. Some participants were idealistic, while others refuted the possibility of a truly socially inclusive society ever being able to exist on earth. The humanitarian, author, founder of L’Arche communities, and the man who first inspired the topic of this thesis, posed a similar question. Vanier (2008) asked:

Is this a utopian vision, an impossible ideal?...Can we reasonably have a dream, like Martin Luther King, of a world where people, whatever their race, religion, culture, abilities, or disabilities, whatever their education or economic situation, whatever their age or gender, can find a place and reveal their gifts? Can we hope for a society whose metaphor is not a pyramid but a body, and where each of us is a vital part in the harmony and function of the whole? (p. 123)

Vanier believed it *was* possible. Whether or not we arrive at the destination in our lifetime, the vision of a truly inclusive society is a worthy aim. My effort to establish a definition of social inclusion for people with intellectual disabilities is a contribution toward this goal. We need to know where we are headed – the direction of utopia – in order to walk toward it.

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APPENDIX A: List of interview participants

The following names are all pseudonyms in order to protect the privacy of the participants. The organizations that the participants are affiliated with are indicated in the list below, with the exception of 'Lorraine' and 'Peter' who declined to have their organizational affiliation made public. The interviews are listed in order of when they were conducted.

1. Lorraine; an employee at a special care home agency (March 8th, 2011)
2. Peter; an employee at a special care home agency (March 8th, 2011)
3. Edward; a representative of People First Nova Scotia (March 21st, 2011)
4. Allen; an employee at Regional Residential Services Society (RRSS) (March 24th, 2011)
5. Lindsay; an employee at Regional Residential Services Society (RRSS) (March 24th, 2011)
6. Elaine; a core member living in a L'Arche community (April 26th, 2011)
7. Daniel; a parent of a core member living in a L'Arche community (April 26th, 2011)
8. Allison; an assistant at a L'Arche community (April 26th, 2011)
9. Kate; a staff member at a L'Arche community (April 27th, 2011)
10. Donna; a representative of the Nova Scotia Community Living Association (NSCLA) (May 3rd, 2011)
11. Claire; a staff member at a L'Arche community (May 11th, 2011)
12. Linda; an employee of Nova Scotia Department of Community Services (NSDCS) (May 12th, 2011)
13. Jeff; a core member at a L'Arche community (May 24th, 2011)
14. Jane; an assistant at a L'Arche community (May 24th, 2011)
15. Chris; a volunteer representative of Special Olympics (May 27th, 2011)
16. Ann; a parent of a core member living in a L'Arche community (June 1st, 2011)
17. Heather; an employee of the Prescott Group, Adult Service Centre (ASC) (June 21st, 2011)
18. Catherine; an employee of Stantec and a supervisor of an employee with an intellectual disability (July 26th, 2011)
19. Melissa; an employee of Best Buddies Canada (July 27th, 2011)