The Governance of Developmental Disability Supports for Older Adults in Ontario and Québec

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ABSTRACT

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This project aims to analyze the effects of Canadian provincial governance structures on support work provision for older adults with developmental disabilities. Drawing from multilevel governance literature, it compares Ontario's more centralized and policy-driven governance structure with Québec's more disentangled and multi-jurisdictional structure, which gives more autonomy to developmental support agencies in planning support provision. To facilitate this comparison the project uses semi-structured interviews with personal support workers for older adults with developmental disabilities in both provinces. By using an 'institutional ethnography' interview methodology, the work experiences of primary support workers are situated within operant policies and rules, specifically with respect to supporting their clients in 'social inclusion', a widely recognized core domain for quality of life outcomes for adults with developmental disabilities. Owing to dramatic improvements in life expectancy resulting from healthcare advancements and deinstitutionalization, Canadians with developmental disability are increasingly living into older age. Consequently, support work practice is challenged by the intersection of social constructions of aged and disabled identities, which can act against the social inclusion of this ‘new’ population. By comparing these two divergent provincial governance structures from the important perspectives of frontline workers, this project contributes to a discussion of best practices in Canadian policy and administration.

DEDICATION

I am grateful to my committee for greatly improving this thesis through their thoughtful input. I dedicate this project to the older adults with developmental disabilities that I have met and befriended in my life. I thank my family and friends for their unfettered support. Finally, and most importantly, I humbly thank my partner, Charleigh, whose inspiration and companionship is vital to everything I do.

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CHAPTER 1 INTRODUCTION

1.1 Introduction and Statement of Objectives

In the nearly twenty years since the release of the seminal *In Unison* report, Canadian disability policy has promoted a community-based social services model, which is predicated on a person-centred approach that targets the social inclusion of people with disabilities. For people with developmental disabilities (DD), this has involved substantial changes to the developmental services sector, including, most notably, the transition from isolated residential institutions into community residences, such as group homes, which are designed to promote greater integration and participation. For many in this unique cohort of institutional survivors, this residential transition has coincided with a lifecourse transition towards older adulthood, which itself is associated with changing needs and preferences to be addressed by social services

To support these transitions for older adults with DD on an individual level, authority is dispersed among several organizational bodies located at multiple levels within Canadian provincial governance structures in the area of developmental services. Interestingly, the designs of these structures may vary significantly between provinces, with authority more or less devolved from the ministry at the centre out to developmental agencies at the frontlines of service provision. Moreover, the provision of specific services can involve coordination between these multiple levels, which corresponds to provincial variations in structural design. For example, and as this thesis will demonstrate, the creation, implementation and monitoring of yearly support plans for older adults with DD are similarly regulated by provincial-level policies in both Québec and Ontario. However, the different degrees of decentralization within these two provincial governance structures significantly affect the options available to the support workers in charge of implementing these plans, by shaping the local capacity for targeting specific support objectives. As such, in yearly planning, and other specific developmental services tasks, it is possible to assess provincial governance structures by their influence on the precise practices of support workers.

In Canadian developmental services, personal support workers provide critical assistance to older adults with DD in overcoming barriers that have historically acted against their social inclusion. To facilitate this role, they must act in accordance to the rules laid out by provincial policies that seek to regulate the quality of service provision in promoting social inclusion. As such, personal support workers act as important mediators between the designs of public policy, and the social service outcomes experienced by the individuals they support. This project asks:

> *Does more decentralization in Canadian provincial developmental services governance increase the potential of support workers to promote social inclusion for older adults with DD?*

To address this question I compare two provincial developmental service systems – Québec and Ontario – that significantly diverge in the manner in which they regulate service provision to promote the social inclusion of older adults with DD. This divergence is puzzling because these two neighbouring provinces similarly employ a community-based service model that emphasizes person-centred care and prioritizes social inclusion outcomes in regulated yearly support plans for people with DD[1]. Ontario's system employs a centralized legislative framework that seeks to ensure the involvement of individuals with DD and their support

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[1] In Ontario, these priorities are identified by the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities* (2008). In Québec's *Act to secure handicapped persons in the exercise of their rights with a view to achieving social, school and workplace integration* (2004) different terminology is preferred. For example, the act favours the term 'integration' over 'inclusion'. Similarly, the act does not use the term 'person-centred care'; however, it lists "facilitating the autonomy of handicapped persons and their participation in individual or collective decisions that concern them and in managing the services offered to them" as a main policy direction (Chapter E-20.1, sec. 1.2(f)). In both cases, the minor differences in terminology do not impede comparison.

network in person-centred planning to actively promote ongoing development in the domain of social inclusion (Joffe 2010). By comparison, Québec's three-tiered health and social services system gives more autonomy to developmental services agencies, which specialize support planning in relation to the characteristics of the clientele within their geographic jurisdiction (Tremblay 2015). In both cases, there is an emphasis on catering service provision to the specific needs of the clientele. However, a problematic feature is also shared between the broad constructs of person-centred care embedded in ministry and organizational rules in Ontario, and the localized and agency-specific provision of care based on clients' interests in Québec. Both structures purport to empower the recipient of support in planning and decision-making, yet both problematize the potential for person-centred outcomes by embedding control over these processes within administrative rules that are levels removed from the support relationship (Parley 2001, Dowling et al. 2007).

An important distinction exists between Ontario's more centralized system, with greater control seated in the hands of the Ministry of Community and Social Services (MCSS), and Québec's more disentangled system, which promotes greater independent oversight by developmental services agencies, which are regulated by local centres specializing in DD services (Centres de Réadaption en Déficience Intellectuelle et en Troubles Envahissants du Développement (CRDITED)). I argue that, within the arena of social support policy for adults with DD, these two different systems conform to the two separate and distinct 'types' of multilevel governance identified by Hooghe and Marks (2003). The basis of this difference is the design of jurisdictional authority. In Ontario, the governance structure that regulates support planning for individuals with DD conforms to what Hooghe and Marks call 'Type 1' jurisdictions, because it employs a more traditional federal structure with non-intersecting membership, and a large concentration of authority at the centre or ministry level. Conversely, Québec's multi-level, intersecting and task-specific jurisdictions conform to what they label a 'Type 2' governance structure[2].

Both governance types are associated with strengths and weaknesses. Within the Canadian disability services literature, 'Type 2' systems like Québec's are thought to be advantageous in choosing program design measures and designing delivery systems, but disadvantageous – relative to traditional Type 1 multilevel governance – in terms of government funding, policy direction, monitoring and accountability (Bach 2002, Tremblay 2015). To test these theoretical expectations relating to the two distinct governance structures, I conduct semi-structured interviews with personal support workers using an institutional ethnography methodology that operates to situate work experiences within the 'relations of ruling' that frame them (Smith 2006). By exploring the link between operant policy structures and lived work experience, this study connects the design of the policy framework to its influence on support work practice. As such, the first objective of this project is:

Objective 1: *To assess the influence of governance structures on 'framing' the work practices of personal support workers for older adults with DD.*

PUBLIC POLICY → SERVICE PROVISION
DD Services Governance → *Primary Support Workers*

Why Older Adults?

Aging studies and disability studies have traditionally overlapped to theorize the implications of functional decline in later age – 'aging into disability'. However, over the past

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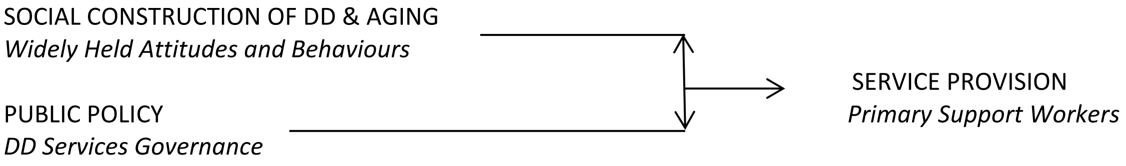
[2] It is important to emphasize that these stark distinctions are only proposed to exist within the specific arena of developmental services for adults with DD. While there are noted differences between the broader health and social services systems in Québec and Ontario (see for example Denis and van Gestel 2015), these are largely beyond the scope of this analysis.

twenty years there has been an increased focus within the academic literature on how these popular constructions of aging and disability act to 'make invisible' the small percentage of the population who are 'aging with a disability' (Washko et al. 2012, Putnam 2011, Bigby 2010). If the expectations from existing theories hold, then we are faced with the paradoxical reality that the increase of public policies targeting issues of disability and aging may have the effect of further marginalizing those 'invisible' adults who are aging *with* a disability by positioning them outside of the discursive boundaries that construct the identities of *disabled* and *aged* individuals. These rigid boundaries leave little room for intersectionality between DD and aging – both in theory and practice – and instead propel a myopic narrative of disability as a fact of functional decline in old age (Withers 2012, 99; Bigby 2004, 244).

In both aging and disability studies, emerging streams of literature have proposed that 'aged' and 'disabled' identities are socially constructed (Rapley 2004; Walker and Walker 1998; Barnes and Mercer 2004). By identifying and examining how provincial public policy, and the specialized internal policies of developmental service agencies, act either to promote or defy these dominant and exclusionary constructions, this study will contribute to a discussion of best practices in addressing the social barriers that act to marginalize the target population: older adults with DD. To enter this discussion, I will draw from the perspectives of personal support workers, whose job demands that they act as 'frontline' advocates for older adults with DD. In much the same way that accommodations like wheelchair ramps assist individuals with mobility impairments in overcoming physical and environmental barriers, personal support workers act to assist their clients in overcoming social barriers – such as stigma and discrimination – that have a 'disabling' effect that is external and unrelated to functional limitations (Barnes and Mercer 2004, 132).

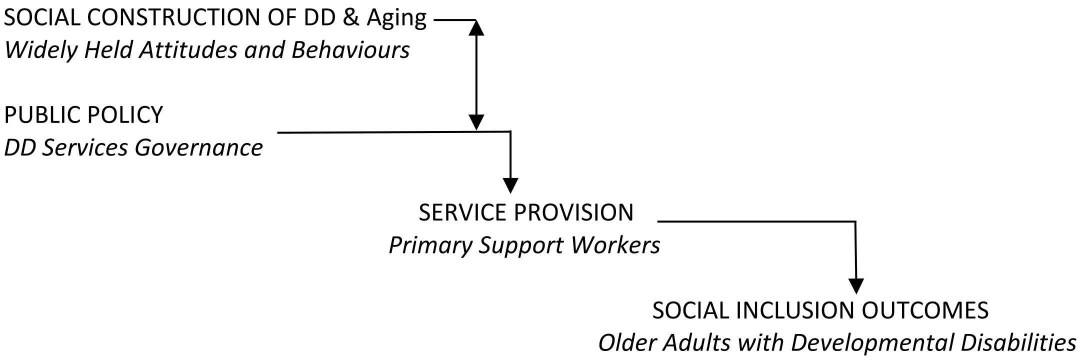
Moreover, support workers are educated and trained in adherence to requirements that are written into provincial, ministry and agency policies. For example, the roles and responsibilities of support workers in the Ontario developmental services system are meticulously laid out by the Quality Assurance Measures regulation (O/Reg. 299/10) which was introduced following a long consultation process with developmental agencies and an international management firm (Hay Group 2009). As such, their competencies are significantly influenced by prevailing sector-specific priorities (Carney 2013). A study conducted among support workers in the Toronto area found that 61% of support workers surveyed felt they were not adequately trained to support older clients who are aging with DD owing to a lack of emphasis on issues of aging, such as 'dementia care' (Sparks 2000, 214). Moreover, this and other studies highlight the existence of separate 'silos' within service provision, rigidly limited to either aging or disability support (Putnam 2014, Bigby 2010, Washko et al. 2012). This leads to the second objective of the present study:

Objective 2: *To assess the mutual relationship between social constructions of 'aging' and 'disability', and public policy in Ontario and Québec by tracing their influence on support work practice.*



Lastly, I explore the link between service provision by PSWs, and the effect it has on the quality of life (QOL) of older adults with DD. Drawing from the extensive use of QOL measures in the literature on service provision for adults with DD (Keith 2001, Schalock et al. 2002, Antaki et al. 2006 Wang et al. 2012), I aim to explore PSWs' understandings of the concepts that have been traditionally used to measure social inclusion as a QOL domain. Rather than seeking an objective QOL measure, I will encourage respondents to provide subjective interpretations of how social inclusion is promoted through work. Given that both the Ontario and Québec systems purport to cater support services to the specific needs of individuals, support workers' responses will provide insight into how they define social inclusion for their clients. This insight will embolden a discussion of what informs these definitions of social inclusion, be it education and training, individually held attitudes, or adherence to operant policy. Moreover, it will illuminate the potential presence and implications of social constructions of disabled and aged identities in the lived experiences of older adults with DD. Lastly, it will contribute to a discussion of how social inclusion might be differently defined for adults who are both in old age and have a DD. Therefore, to complete my conceptual model the final objective is:

Objective 3: *To assess the effects of developmental services governance structures on the promotion of social inclusion outcomes for older adults with DD from the perspectives of the support workers in charge of planning and implementing these objectives.*



1.2 Background and Concept Definition

Who are Older Adults with Developmental Disabilities?

The definition of developmental disability – often also referred to as intellectual disability or developmental delay – used by this study is taken from Ontario's *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act ("Social Inclusion Act") 2008*, which is one of the principle policy documents that will be examined:

> *3. (1) A person has a developmental disability for the purposes of this Act if the person has the prescribed significant limitations in cognitive functioning and adaptive functioning and those limitations,*

> *(a) originated before the person reached 18 years of age;*
> *(b) are likely to be life-long in nature; and*
> *(c) affect areas of major life activity, such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity.*
> (2008, c.14, s.3 (1))

An expansive list of diverse diagnoses fall under this umbrella, resulting from various etiological factors such as general and specific environmental factors (leading to fetal alcohol syndrome, ADHD, or intellectual impairment owing to prenatal malnutrition), general and specific genetic factors (including chromosomal disorders such as Down syndrome and single gene disorders such as Fragile X syndrome), and mental health impairment factors (such as autism and pervasive developmental disorders) (Percy and Brown 2003). However, despite the diversity of diagnoses of DD, in 2012 people with DD only made up 0.6% of the Canadian population over 15 years of age (Arim 2015, 10). Nonetheless, as a result of de-institutionalization, improvements in funding and support, and advances in medical treatment and early diagnosis, the average life expectancy of adults with DD has risen sharply over the past three decades, resulting in a dramatic increase in the percentage of this population living into later old age[3] (Shooshtari et al. 2012; Janicki et al. 1999).

Yet, despite their increasing demographic presence, the centuries-old construction of persons with DD as ‘eternal children’, coupled with their increased visibility, has raised the question of ‘when do people with DD become old?’ (Breitenbach 2001 232). This question has been problematized owing to the diversity of health outcomes associated with DD. For example, individuals with Down syndrome have been shown to exhibit premature physical signs of aging and a higher risk to Alzheimer’s disease at much earlier age (Evenhuis et al. 2001). Moreover, an

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[3] While it is well established in the literature that life expectancy among people with DD is increasing in Canada and globally, it is difficult to quantify the exact extent of this increase, owing both to the small percentage of the population comprised by this group, and the difficulty contacting these individuals using standard survey instruments (Ouellette-Kuntz et al. 2015).

Ontario study has found that frailty occurs in adults with DD aged 50-54 at a higher rate than adults 80-84 without DD (Ouellette-Kuntz et al. 2016, 5). This has led some in the literature to cautiously construct a lower bound of 'older adulthood' at 40 (Thompson 2002, Shooshtari et al. 2012) or 45 (Shapiro et al. 2003) years of age. While this type of caution has the benefit of increasing the research sample size of an already small demographic, it does not reflect the heterogeneity of the target population when allowing for the multiple disabilities and diverse etiology under the DD umbrella (Hilgenkamp et al. 2011). As such, this study employs the most common lower bound contained within the literature for older adults with DD by sampling individuals aged 50 years and older (Walker and Walker 1998, Bigby 2004, Mahon and Mactavish 2000, Percy and Brown 2003).

Which Canadian policies encourage social inclusion among older adults with DD?

Canada's commitment to promoting the social inclusion of persons with disabilities through a community-based model was first legislatively enshrined in the *In Unison* report of 1998[4]. In Unison aimed to establish full citizenship rights for persons with disabilities, and following its endorsement by all federal and provincial/territorial ministers in charge of social services (except for Québec's), it has resulted in significant change to the Canadian DD support structure, signalling a transition away from the previously dominant 'custodial care' model (Prince 2009, Levesque 2012). Another significant policy with reach at the national level in Canada is the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which Canada ratified in 2010. Aside from formalizing a definition of disability that incorporates

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[4] *In Unison* is a 'vision paper' that was drafted by Federal and Provincial/Territorial ministers in charge of social services following a request by the First Ministers in 1996 to prioritize significant changes in disability policy in upcoming social policy renewals (ESDC 1998, 6). The document outlines a comprehensive vision of 'full citizenship' for Canadians with disabilities that makes explicit mentions of the switch from a program-centred to a person-centred approach to services, and the promotion of full participation for people with disabilities in social functions such as employment and education, in contrast to the previous passive recipient model.

stigma and discrimination as elements of the disabling condition, the UNCRPD provides an extensive governance structure that lays out parameters for implementation of social inclusion measures in ratifying States (Power et al. 2013). Yet, despite the broad intentions of these two national level commitments, their emphasis on rights provision has not yet translated to national level policy governing disability services, and significant autonomy in support service provision remains in the hands of the provinces (Prince 2009).

To this end, Ontario's disability services governance structure is typical of Canadian multilevel governance in health and social services. It embodies 'classical' or 'disentangled federalism' because the MCSS has independent authority over social services, where it is deemed to have 'constitutional competence' (Bach 2002, 157). This authority has been bolstered since 2008 by the Social Inclusion Act, which provides significant regulatory reach into the realm of direct support provision, even by private and not-for-profit agencies, through minimum reporting standards and quality assurance measures regulated by the MCSS (Joffe 2010, 24). Moreover, the Social Inclusion Act aims to provide individuals with DD and their families with increased agency in choosing their supports – excluding residential services – through direct funding delivery, thus furthering the shift from custodial care toward person-centred care (Power et al. 2013, 165). As such, the intermediary role of disability services agencies has been reduced by top-down legislation that aims provide more choice to service recipients.

Within the Québec social services structure, there has long been an orientation towards 'atomistic' control by local health and social services authorities, making provincial disability services governance difficult to classify in terms of conventional multilevel regimes (Bach 2002, 155). This has been further complicated by the distribution of social services among three tiers of specialization among local jurisdictional authorities since the governance system was restructured in 2003. As a result of this restructuring, local Health and Social Services Centres (CSSS) have significant control over how support services for persons with DD are dispersed among the tiers, and there is no standardized procedure for allocating these services among individual cases (Tremblay 2015, 2). This reduces the reach of provincial level policies such as the 2004 *Act to Secure Handicapped Persons in the Exercise of their Rights with a view to Achieving Social, School and Workplace Integration* ("Disability Integration Act"), thus allowing both CSSS and CRDITED room for specialized interpretation with limited oversight (Prince 2009, 233). National level documents like *In Unison* have envisioned an important role for developmental service organizations in promoting social inclusion (Bach 2002, 157), thus it is possible that Québec's more specialized system may be advantageous to service provision in this pursuit.

Why Social Inclusion?

Both Ontario's Social Inclusion Act and Québec's Disability Integration Act have identified support services to promote social inclusion outcomes as key priorities of disability services. This is in keeping with a global shift towards the community-based support model, strengthened by disability services guidelines set out by a seminal report from the World Health Organization, which establishes this emphasis on social inclusion as a key guiding principle in the provision of services and supports (WHO 2010). However, in these policy instruments, and in everyday parlance, the idea of social inclusion is somewhat ambiguous, in that it is difficult to designate a clear threshold of where inclusion and exclusion begin and end.

Within the broad identity category of 'disabled persons' there are numerous 'hierarchies' of advantage owing to the intersection of disability with other marginalized identities (Prince

2009, 189). Moreover, barriers to inclusion can take very different forms for different types of disabilities. A frequent critique of policies promoting inclusion is that they are ‘creaming’, by prioritizing inclusion outcomes for individuals with fewer and less pervasive disabilities, who are thus easier to accommodate (Chouinard and Crooks 2008, 187). This is evidenced in the greater exclusion of people with DD in relation to other categories of disability in social functions such as employment (Prince 2014). Older adults with DD in particular have been excluded and made invisible, despite gains in life expectancy and deinstitutionalization, by persistent discriminatory attitudes and biased service structures which impose a situation of ‘double jeopardy’ (Walker and Walker 1998) on the intersection of aging and DD (Bigby 2004, 49; Raymond and Grenier 2015). In this way older adults with DD represent a significant challenge to the social inclusion focus of the community-based developmental services model.

It is precisely because of the location that older adults with DD occupy – excluded, invisible, and at the far margins – within the disability politics landscape that this project focuses on how social services are governed to promote their inclusion. However, it must be emphasized that this project does not assess social inclusion outcomes from the perspective of service users, or their families. Rather, this project is structured to derive data based on how support workers act as intermediaries between two levels. First, there is a macro level, where interrelated forces of operant policies and the structures they engender, combined with the broader attitudes that enable social constructions of marginalized identities, act to frame and shape support work as a practice. Second, there is a micro level where support workers help to create and work towards specific objectives with specific individuals, based on their relational understanding of their needs, and within a precise context. The level of analysis for this thesis falls at an intermediate level, between these macro and micro levels.

To facilitate this analysis, I engage with a conceptual model that is commonly used to measure social inclusion outcomes for people with DD, and which has been influential in defining and operationalizing the core principles of social inclusion in notable policy instruments: the Schalock model (Schalock et al. 2002; 2008). However, I must again emphasize that the objective is not to measure social inclusion based on individual outcomes. That type of analysis would, most importantly, require deep engagement with service users and their families (Cobigo et al. 2014, 95), which is well beyond the scope of this project. Instead, this project situates the work experiences of support workers between these two levels, and speaks to the unique pressures exerted on their practice as a means of assessing the influence of governance structures on service delivery in a precise service area (developmental services), and for a specific population (older adults with DD). To this end, the Schalock model is employed to provide general categories for comparison of support worker's definitions of social inclusion (Schalock 2004; Wang et al. 2010) and for applications these definitions as operationalized through specific practices (Schalock et al. 2002). This usage of the Schalock model is consistent with its application in another study that examines disability policy goals in relation to microsystem, mesosystem and macrosystem (Shogren et al. 2015), and represents a promising new direction for the study of outcome-driven policies targeting people with DD.

1.3 Research Design

This section provides a description of the general research design of the thesis, that is accompanied by a more detailed explanation of the interview methodology and the pertinent details of the semi-structured interview in the proceeding section. In accordance with this project's objectives, which connect support work practice to the broader spheres of influence that shape the social inclusion outcomes it is designed to produce, this project requires a research design that enables the linkages depicted by the full conceptual model as outlined in Objective 3. To attempt to elucidate these conceptual linkages, I conducted qualitative interviews with support workers in both provinces using the institutional ethnology methodology. This methodology aims specifically to assess the impact of overarching ‘relations of ruling’ – such as policies, organizational priorities, and socially embedded roles – on the individual and collective work experiences that they frame (Smith 2006).

More specifically, this design was chosen to test the theoretical expectations concerning the two types of governance structures proposed by the Hooghe and Marks MLG conceptual framework from the perspectives of support workers in relation to specific outcomes. For example, the expected advantages of Québec’s more decentralized system in designing recreational programs that are more flexible to the demand profiles of regional populations is tested by questioning support workers about responsiveness in the design and availability of recreational programs. In addition to providing concrete linkages between the various parts of the MLG structures in both provinces, this methodology also explores the both the connections and fissures between policy and practice from the perspectives of workers at the frontline.

It is important, however, to emphasize that this thesis gives emphasis to identifying connections rather than fissures. The MLG conceptual framework was chosen because of its potential for explaining how issue authority is dispersed through *different* jurisdictional designs to promote specific outcomes. This contrasts with the more actor-centred ‘street-level bureaucrats’ (Lipsky 1980) approach, which places greater emphasis on the individual agency of support workers in promoting outcomes that may diverge from the intentions of policy. The comparative nature of this project places greater emphasis on the contrasting designs of governance structures, and thus requires a conceptual framework that can account for these differences. Moreover, even where the 'street-level bureaucrats' approach has successfully compared street-level influences to influences from multiple higher levels within polycentric structures (see for example May and Winter 2009), it has only been applied to one specific jurisdictional design. Therefore while it might be possible, and indeed analytically fruitful (see section 6.4), to combine the MLG approach with the street-level bureaucrats approach, it is beyond the scope of this project.

The interviews that constitute the data in this thesis were preceded by informal discussions with support workers in both provinces, and with the direct supervisors of the respondents. These discussions were not recorded or transcribed, and served the purpose of building familiarity with some of the key terms and concepts that were likely to emerge, in order to maximize the efficiency of the interviews. This facilitated comparison between interviews by allowing me to avoid asking respondents – specifically the first respondents interviewed in each sample – to define the concepts, and explain the acronyms and vernacular that they casually employ when discussing their work. Moreover, this was helpful in the creation of a general interview guide in advance of the interviews. This preparation was necessary to conduct semi-structured interviews, which are more conducive to coding, comparison and testing theoretical expectations than standard ethnographic interviews (Leech et al. 2013, 210). Nonetheless, despite the inclusion of specified questions in all of the interviews, these questions were open-ended in nature to allow respondents freedom to draw from their personal work experience. To facilitate this informal interaction, respondents were given significant autonomy in identifying topics for discussion that they deemed important to the research.

I conducted semi-structured interviews with a purposive sample of the primary support workers of older adults with DD in the Toronto and Montréal areas. For the purpose of this project, the term ‘primary support workers’ refers to developmental agency staff in charge of identifying and documenting yearly planning objectives for an older adult with DD. In the Ontario sample, the primary support workers interviewed had the job title of ‘primary direct support professional’, and in Québec they were called ‘special care counsellors’ or ‘specialized educators’. In each province the sample consisted of five primary support workers working at a not-for-profit developmental agency providing residential and respite support to adults with a DD who are over the age of 50. I used semi-structured interviews to add explanatory depth to the themes revealed, while also allowing these themes to be grounded within the lived experiences of respondents. A list of questions was prepared in advance to provide a general guideline for the interviews; however, this list served primarily to provide examples of questions corresponding to themes that could emerge in the interview.

1.4 The Semi-Structured Interview

Each semi-structured interview took approximately one hour to complete. Only three questions were asked of all ten interview respondents, at the beginning, middle and end of the interview respectively:

i) *Generally speaking, what is your job?*

   Probe: *What job tasks are involved in your work?*

ii) *How would you define social inclusion for older adults with developmental disabilities?*

iii) *What is the biggest obstacle to promoting social inclusion for older adults with developmental disabilities?*

Interviews followed the ‘institutional ethnography’ interview methodology, which this project aimed at providing insight into governance structures through the ‘relations of ruling’ that underpin the location of power as manifested in social inclusion planning for older adults with DD (Smith 2005). Here the word ‘institutions’ does not refer to specific political institutions, but rather to “translocal social relations that carry and accomplish organization and control” (DeVault and McCoy 2002, 752). In this case, the way that respondents discuss their work tasks contain information about what is commonly shared across multiple sites, and what coordinates the commonality of those experiences (Ibid. 757). As such, the policy and governance structures are made legible through their influence, in practice, on the *work* of respondents. By engaging with support workers whose everyday work experience involves a person-centred application of the guiding principles of public policy promoting social inclusion, the institutional ethnography approach allowed the interviews to focus on authentic practice within the rules and guidelines derived from the overarching institutional framework (Townsend 1998, 17). In this thesis, this overarching institutional framework is operationalized as the relevant governance structures in Ontario and Québec and the precise policies, both at the provincial ministry and developmental agency levels, which have direct influence on support work practice for older adults with DD.

In the first part of the interview, I asked respondents to describe their job, both with a general description and a more in depth explanation of the specific tasks that comprise their work. In institutional ethnography, ‘work’ is an important representation of the influence of relations of ruling, and a respondent’s ‘work knowledge’ is informed both by the experiences and feelings that they derive from their own work, and by the coordination of their work with that of others (Smith 2005, 151). I placed this question at the beginning of the interview for two reasons. First, it establishes the respondent as an expert witness by indicating that their specific knowledge and the communication of their personal experience is the data in this study. A key feature of institutional ethnography is that it allows interview respondents to be empowered by the awareness that they are contributing data to an analysis that will serve their interests insofar as it identifies practical obstacles in their work experience (Campbell and Gregor 2004, 69). This ‘sharing of power’ is fundamental to the institutional ethnography methodology, which aims to bring excluded voices to the fore as valuable data points in the mapping of institutional relations, thus emboldening a more comprehensive account of best practices and potential avenues for change (DeVault and McCoy 2002, 771).

Second, by probing respondents on the specific tasks that constitute their work practice, these tasks are immediately identified as important to the research project, and can be referred to seamlessly throughout the interview. By emphasizing the value of the respondent’s work tasks, I hoped to take early action in the interview to avoid ‘institutional capture’, which occurs when respondents’ use of language that is influenced by institutional discourse intervenes to prevent more descriptive responses by “subsuming the actual under the institutional” (Smith 2005, 158). While a degree of institutional capture was expected, and indeed is helpful in assessing the ways that policies at the agency and ministry level shape practice, the interview was designed to give respondents an opportunity to give voice to their personal experiences, externalized from this professionalized discourse.

The second question posed to all of the interview respondents asked how they define social inclusion for older adults with DD. Unlike the other two compulsory questions which occurred at the beginning and end of the interviews respectively, this question was inserted in the interview at what I deemed the most appropriate time in each conversation. This was most often in the middle of the interview, and most commonly occurred immediately following the first time that the interview respondent mentioned social inclusion of their own volition. This question was selected because both Ontario's 'Social Inclusion Act'[5] and Québec's 'Disability Integration Act'[6] frame social inclusion as a vital component of personal well-being. Moreover, the current definitions in both acts are informed by the federally ratified United Nations Convention on the Rights or Persons with Disabilities (UNCRPD), which bases its definition on the 'Schalock Model' of the quality of life conceptual framework, which has been identified as the best fit for individuals with DD (Schalock et al. 2005, Wang et al. 2010). Given the widespread use of the Schalock Model both in defining social inclusion, and in providing support work applications of the social inclusion concept, it serves as a globally accepted standard by which the definitions and operationalization of social inclusion outcomes provided by support workers in this study can be categorized and compared.

The interviews also contain open-ended follow up questions relating to the 'social inclusion' domain to provide greater depth to the themes revealed. These questions attempt to identify the primary foci of service provision based on frontline practice, training, quality assurance measures (mandated individual support planning), and the priorities established in relevant policies. In institutional ethnography these guiding rules act as 'regulatory frames' which, for the purposes of my study, shape the support workers' roles by encouraging them to fit their practice of within the 'institutional categories' which define their professional responsibilities (Smith 2005, 199). Moreover, given that each person interviewed is the primary support worker for at least one older adult with DD, meaning they are in charge of identifying and documenting yearly support objectives, these questions attempt to identify respondents'

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[5] Recall that this is the short form this thesis uses to identify the *'Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities'* (2008)

[6] Recall that this is the short form this thesis uses to identify the *'Act to secure handicapped persons in the exercise of their rights with a view to achieving social, school and workplace integration'* (2004)

perceptions of the quality of service provision in promoting social inclusion based on practical applications with the individuals they support.

The final question that was posed to all of the respondents asks them to identify the biggest obstacles to the promotion of social inclusion for older adults with DD. This question was posed at the end of the interview with the intent that respondents would have the opportunity to reflect on prior responses to provide a thoughtful answer. Moreover, asking this question earlier might disrupt the ‘mapping’ of institutional relations that is achieved through respondents’ specific recollections of tasks and experiences. Specifically, I was attempting to avoid steering respondents towards an explicit discussion of policies and governance structures earlier in the interview, despite the fact that these are the primary focus of this thesis. In institutional ethnography these institutions – specifically texts, such as policies – act like a ‘central nervous system’ to structure and organize the attitudes and behaviours of individuals who work within them (Devault and McCoy 2002, 765). Before directing respondents’ attention to operant policies at both the government and agency level, I wanted to first allow them to express the influence of these ‘institutions’ through a description of their practice. As such, every direct reference to their work practice made by a respondent becomes legible within the overarching, yet unspecified, institutional framework. This strategy again seeks to avoid ‘institutional capture’, where a respondent’s account of their work knowledge based on their description of experience is obstructed by the ‘barrier’ of institutional vernacular, which acts to normalize and control individual action (Smith 2005, 155). By avoiding direct conversation about operant policy in the early stages of the interview, the respondent is encouraged to evade this capture.

The interview was also designed to test the theoretical expectations pertaining to the two types of multilevel governance (MLG) identified by Hooghe and Marks (2003), and indicate whether Ontario’s and Québec’s structures appropriately diverge in accordance with the expectations set forth both by the MLG literature (see Chapter 3) and by the Canadian disability politics literature (Bach 2002; Prince 2009; Levesque 2012; Tremblay 2015; Kelly 2016). However, this testing was designed to occur within the parameters of the respondent’s personal experience, and therefore no mentions were made of the study’s theoretical expectations during the interview. The outcomes that respondents describe in the areas of social inclusion for their clients are made legible through their account of even the most menial activities of daily work practice. Indeed, this is a furtive area for analytical inquiry relating to social service systems (DeVault and McCoy 2002, 760). For example, by asking respondents to outline the process of creating daily progress notes for the clients in their caseloads it may be possible, given sufficient detail and scrupulous comparison, to draw inferences about the ways that provincial level policies differently do or do not affect this seemingly minor task within the broader context of support work practice. This broader context is important, and it is for this reason that – outside of the specific questions identified above – the interviews were designed to allow respondents to guide the conversation as experts on the pertinent aspects of their work experience.

1.5 Participants and Recruitment

The first step in the recruitment process was to secure the participation of the developmental agencies, so that they could provide ethics approval for the research project. Once this was completed, recruitment letters were distributed by management to support workers who functioned as the primary support for an individual over 50 years of age with a developmental disability. The letter emphasized that participation was voluntary, and provided contact information so that potential participants could schedule interviews directly with the researcher. This was done so that management and direct supervisors would not know which five staff comprised the sample in each location as an extra confidentiality measure and to ensure that responses were unencumbered by fear of negative consequences in the workplace.

Prior to each interview, respondents were informed that they could discontinue their participation at any point during the interview and up to a date set one month prior to the completion of the final report. The research methodology ensures the confidentiality of respondents by withholding their identities and the identities of the individuals they support. Given the small percentage of the population comprised by older adults with developmental disabilities, even general demographic information such as exact age, sex and ethnic or cultural identity can be used to determine an individual's identity. To provide an additional measure of confidence in protecting the confidentiality of respondents, this thesis will not reveal the name of the cooperating agencies from which the sample was derived in this project. All of documents used in this project (the recruitment letter, consent forms, ethics approvals and interview guide) are provided as appendices to this thesis report.

1.6 Data Analysis

Once completed, the audio-recorded interviews were transcribed as quickly as possible to ensure that meaning was authentically captured. In order to preserve respondent confidentiality, I completed the transcription by myself. During transcription, any text referring to the developmental agencies, fellow support staff, or supported individuals by name were replaced by more general identifiers. Additional effort was taken to protect the identity of respondents by obscuring information from the transcriptions that could identify them, including references to their family, or their personal history.

Following transcription, the interviews were coded using NVivo 11 software. Open coding was used to identify key themes, and related themes were organized under ‘parent’ codes. While researchers in institutional ethnography have tended not to use coding software, it has been identified for its potential in providing a sort of thematic index within which to group sections of text (DeVault and McCoy 2002, 769). To this end, it was useful in organizing and quickly accessing key sections for comparison across the sample of respondents during data analysis. As a final measure to protect confidentiality, any references to support staff, supported persons or their relations that were contained within direct quotations included in the findings sections of this study were checked for identifying information. In particular, pronouns that could identify the gender of these groups were replaced with ‘them/they’ before being included in the report.

1.7 Conclusion

This thesis is organized to systematically analyze each element of the conceptual model that it sets forth. Chapter 2 contains a literature review that presents relevant Canadian and international publications dealing with social service provision to older adults with DD, prominent theories related to barriers to social inclusion from aging and disability studies, and the conceptual refinement of social inclusion within the academic literature as it pertains to developmental services. This is followed in Chapter 3 by a thorough treatment of current literature on the MLG conceptual framework. In this chapter, a clear organizing framework is provided to both identify the major frontiers of difference between Type I and Type II structures, and demonstrate the adherence of Ontario and Québec, respectively, to these designs. This adds greater specificity to the theoretical expectations related to the MLG designs in both provinces. Chapter 4 then tests these expectations by presenting findings from the semi-structured interviews in relation to each distinct level of governance within the two provinces. This serves both to demonstrate the predictive value of the MLG framework, and identify the shortcomings of this approach, specifically with respect to its failure to account for structural capacity factors such as the financial resources available within each system. These factors are then addressed in the concluding section of the chapter.

Next, Chapter 5 continues to work through the conceptual model by presenting findings related to the social constructions of aging and DD that are evidenced by the appearance of isolated service silos in aging and disability services under the emerging community-based care model. These constructions are found to have significant influence on the capability of support workers to produce social inclusion outcomes, in keeping with theories from aging and disability studies explored in Chapter 2. This is evidenced by a comparison of how the support workers in the interview sample define and operationalize social inclusion, with an emphasis on yearly planning for older adults with DD. By limiting support workers' potential for delivering social inclusion outcomes, these social constructions intervene to limit the divergence that was expected from the contrasting MLG designs of Québec and Ontario's developmental services systems. In this way, the findings presented in this thesis conform to popular critiques of the MLG conceptual framework's lack of conceptual clarity when applied to actual structures at the system level. However, the findings also provide evidence that MLG can be very useful in identifying the interrelationship between multiple levels of governance when it comes to the devolution of authority from the level of policy to practice. To this end, identifying both sector-specific and more general social constructions of aging and disability helps to distinguish the precise points at which structural designs are disrupted in the promotion of social inclusion outcomes for older adults with DD.

This thesis is concluded in Chapter 6 by a brief presentation of findings related to the persistence of discriminatory social attitudes in the broader public as a social barrier to developmental services promoting inclusion. While discriminatory attitudes in the wider public were not a specific focus of this analysis at the outset, they emerged in the data as a significant intervening factor influencing the relationship between the governance of developmental services and the social inclusion outcomes promoted by support workers. Having presented findings linking the full conceptual model, the thesis concludes by presenting policy implications for developmental services in concert with a summary of key findings. The final section addresses future avenues for similar research while assessing the potential of the analytical model and outlining the key limitations of the study. While the MLG framework is revealed to be limited in its ability to account for a full range of factors influencing system outcomes in specific issue areas, this thesis optimistically points to the potential for the evolution of the framework through conceptual refinement, and more practical application.

CHAPTER 2. LITERATURE REVIEW

2.1 Introduction

This thesis engages with several streams of literature in order to connect the numerous parts of the conceptual model it sets out. To this end, the literature review contained within this chapter covers the streams that are pertinent to the study of support work practices to promote social inclusion outcomes for older adults with DD. As such, the academic literature related to the MLG conceptual framework, broader theories of governance and their connection to Canadian multilevel politics are presented separately in Chapter 3.

The present chapter is structured to review six important streams from which this thesis draws. The first two sections deal with current literature on social services to older adults with DD both in Canada and internationally. These two streams of literature focus on the needs of the target population, and address how current developmental services models aim to meet them. The next two sections introduce relevant theories from the 'aging studies' and 'disability studies' streams of literature, followed by a section reviewing current trends in Canadian disability policy. Together these three streams of literature contribute to an understanding of the theoretical explanations of exclusion at the intersection of 'aged' and 'disabled' identity categories, prior to identifying studies addressing how these have been either included in, or neglected by, Canadian public policy governing developmental services. The final stream of literature concerns the most influential existing model of measuring social inclusion outcomes tied to support work practices for people with DD: the Schalock model. By engaging with a stream of literature that defines support work applications that are derived from the measurement of social inclusion outcomes for people with DD, it becomes possible to link support work practice to the broader influences that frame it.

2.2 Studies of Older Adults with Developmental Disabilities in Canada

Perhaps owing to the very small percentage of the population comprised by older adults with developmental disabilities in Canada, there is a scarcity of theory within the academic literature specifically pertaining to the influence of public policy on their social inclusion. Historically, the primary focus of academic literature on older adults with DD has been health outcomes (see for example Cleaver et al. 2010, Balogh et al. 2005, Shooshtari et al. 2012). Interestingly, despite this emphasis within the academic literature, and noted improvements in health outcomes for adults with DD, there remain substantial barriers to healthcare access. Ouellette-Kuntz (2005) underscores the complexity of measuring health outcomes for individuals with DD, and finds that despite significant disparities in key indicators of health and healthcare access – life expectancy, morbidity, uptake of health promotion/disease prevention activities, and access to health services – these disparities are problematized by the variation and complexity of health implications for different DD diagnoses. As such, she finds that it is difficult to attribute higher morbidity and lower life expectancies relative to the general population among adults with DD to lower access to health services, despite emphasizing that barriers to access could be avoided (Ouellette-Kuntz 2005, 118).

Within the Canadian literature on the social support landscape, several studies have emerged employing small sample qualitative methodologies to draw out themes related to social inclusion. Salvatori et al. (2003) use semi-structured interviews to explore QOL factors for adults with DD from three perspectives: the adults themselves, their family members and their service providers. They find that, owing to problems in coordination and planning across governmental departments and ministries, older adults with DD are not sufficiently supported in obtaining satisfying social relationships, promoting social functionality (e.g. education and employment) and establishing financial security (Salvatori et al. 2003, 15-16). Moreover, their study points to important distinctions between medical and social outcomes, finding that negative attitudes toward DD represent more significant barriers to achieving positive social outcomes, and that these complex outcomes are most likely to be identified through qualitative methodologies.

This strategy of including support professionals in the respondent pool has been elsewhere employed by researchers aiming to obtain more detailed explanation of the experiences of older adults with DD (Pedlar et al. 2000; Sparks et al. 2000; Mahon and Mactavish 2000). One reason for the popularity of this methodological strategy – rather than selecting only individuals with DD themselves as respondents – has been ethical concerns around the issue of informed consent among adults with DD. Indeed, sampling respondents with DD creates a difficult challenge to the researcher who must both respect their rights to be treated as equal members of society, while also protecting this population from taking actions that may compromise their welfare without fully understanding the implications (Fisher 2003, 27). Recruitment of respondents with DD has become more difficult in Canada owing to recent policy protections put in place to protect vulnerable populations, and the lack of clear and established best practices for recruiting and acquiring consent from individuals with DD (Cleaver et al. 2009). Given their intimate involvement in the daily lives of their clients, and their critical role in the policy-regulated service provision landscape, support workers can therefore be an important resource to researchers looking to explain the interaction between social policy and lived experience among people with DD.

Mahon and Mactavish (2000) note distinct differences in the types of themes revealed by older adults with DD when compared to those offered by their support network (service providers, family and support workers) in discussing social integration. The authors claim that this discrepancy may result from the overemphasis by advocates of older adults with DD on the barriers to social integration, rather than on the opportunities to overcome these obstacles that are valued by the individual (Mahon and Mactavish 2000, 52). Pedlar et al. (2000) conduct a survey of developmental service providers in Canada, and note very different service orientations among not-for-profit and for-profit agencies, particularly in the area of social inclusion which they find is afforded lower priority by for-profit agencies. Similarly, Hickey (2012) finds that neoliberal restructuring of the not-for-profit direct support sector in Ontario has resulted in lower wages and decreased working conditions for support workers, and correlates these worsening conditions with declining service quality and life outcomes for recipients. He also finds that wage gains among unions translate into reduced support provision for adults with disabilities, owing to the complex interplay of industrial dynamics between agencies, support workers and their clients.

Sparks et al. (2000) limit their interview sample to support workers for older adults both with and without DD, and find that training level and professional comfort among support staff are limited to one or the other overarching fields of ‘disability’ or ‘aging’ care. They note that workers in both fields report feeling uncomfortable with service provision outside of the professional boundaries reinforced by training and educational curricula (Sparks 2000, 218). A likely contributing factor to this separation between disability and aging care in Canadian public policy is the oft-noted prioritization of medical care over social care (Hickey 2012, CCSD 2005, Prince 2009). A recent Ontario study found that personal support workers performing comparable tasks were better-compensated in hospital and long-term care settings than in home care settings, evidencing a long-standing policy bias towards medical care (Lilly 2008). Thus, despite recent policy shifts toward promoting community-based service delivery to encourage social inclusion, there has not been a resulting shift in practice, or in the investment of resources to affect this change (Prince 2009, 208). The resulting emphasis on aging care through a more medicalized focus could serve to perpetuate the marginalization of older Canadians with DD, for whom social barriers are more repressive than medical barriers.

2.3 Important International Studies

The phenomenon of separation between disability and aging care has been consistently reported in relevant international literature on aging with a DD (see Walz and Wilson 1986; Simon-Rusinowitz and Hofland 1993; Walker and Walker 1998). Putnam (2014) describes the 'silo systems' of aging and disability as dominant in both policy and practice prior to recent reforms in the US system promoting coordination and integration through the 'bridging' of existing networks in long-term services and supports. This separation between silo systems is more thoroughly articulated in an earlier work (Putnam 2011), where she selects qualified professionals from three distinct service networks – i) physical disabilities ii) developmental disabilities and iii) aging – as interview respondents. Through these interviews she identifies several potential obstacles to rebalancing efforts for home and community-based services in the US, including the lack of professional and organizational capacity to support users outside of the primary service population (Putnam 2011, 335). Building on this research, Washko et al. (2012) highlight the lack of long-term services and supports for individuals at the 'nexus' of aging and disability, resulting in unmet needs for Americans, both aging *with* and *into* disability, who resoundingly report the desire to 'age in place'.

In a five country comparison of accommodation support policies for older adults with ID, Bigby (2010) notes that Canada, the U.S., Ireland, the UK and Australia – despite different policy systems – have all shared in common the debate about how to support 'aging in place' owing to a lack of coordination between aging and disability care. She finds that, in all five countries, older adults with DD are more likely to be placed in residential aged care, despite poorness of fit with the resident profile, because the disability sector is consistently ill-equipped to support 'aging in place' – often in group homes – for this population (Bigby 2010, 10). Similarly, Wark (2015) uses interviews with support workers, service providers and policy-makers in the U.S., UK, and Ireland to provide insight into best practices for older adults with DD for implementation in Australia's National Disability Insurance Scheme. Regarding social inclusion, he finds that the best practices for disrupting the 'silos' of aged care and disability care come through providing for appropriate levels of support at home, even for individuals with extensive health care needs (Wark 2015, 97). Similarly, Ellison (2011) identifies a wide range of benefits in avoiding institutional outcomes through the provision of community-based aged care for older adults with disabilities in Australia, including increased access to leisure activities and more opportunities for community involvement and the development of social relationships.

To provide a more concrete connection between public policy, service provision and lived experience of older adults with DD, Maes (2003) conducts a review of international studies that assess life outcomes among this population using QOL methodologies. She finds consensus in the studies reviewed that social services directly affect numerous accepted QOL domains, including social inclusion, and advocates for the more direct involvement of people with DD and their support workers in the monitoring and evaluation of service provision through education and sensitivity to QOL measurement (Maes 2003, 237). This speaks to the concept of person-centred planning, which has become a guiding principle in recent Canadian disability legislation, including the Social Inclusion Act.

Reuzel et al. (2013) examine the practice of person-centred planning by observing the interaction patterns between a sample of individuals with mild DD and their support staff in the Netherlands. They find that, in general, support workers are more likely to dominate conversational interactions with clients with DD, though this asymmetry does not necessarily devalue the client's views. Following a similar design, Antaki et al. (2006) observe interaction between support staff and clients with DD in the United Kingdom, and find that two conversational styles dominate decision-making discussions. They find that both styles treat the client as 'incompetent' in making decisions, and characterize the lack of client voice in decision-making meetings as a dilemma for professional practice. By contrast, Dunn et al. (2009) examine substitute decision-making by support workers on behalf of clients who are deemed legally incapable. They find that substitute decision-making by support workers in practice extends far beyond narrow legal definitions to exert a normalizing influence on client's lives that contradicts the principles of person-centred care. Thus, while there is an asymmetry in dialogical relations between clients and staff in various sites within the international literature, there is no clearly articulated framework for best practices in promoting person-centred planning in service provision with respect to promoting the social inclusion of older adults with DD.

2.4 Relevant Theories of Aging Studies

Two prominent theories of aging have been consistently applied to the aging and disability 'nexus' within the disability literature. The first, 'successful aging', has been interpreted in many ways through its application to older adults with disabilities. It is important to note that the three 'main components' of successful aging as defined by its original authors, are 'avoiding disability and disease', 'high cognitive and physical function', and 'engagement with life' in old age (Rowe and Kahn 1997). The problem, of course, is that if we take these main components as central criteria, then many adults aging *with* a disability are by definition incapable of aging successfully. However, such rigid characterizations of successful aging have been subdued by attempts to reformulate or adapt the concept to older adults with DD. One key element of successful aging that has been noted by disability scholars is the emphasis on promoting environmental features that allow for accommodation and adaptation, such as assistive technology and individualized supports (Schalock 2004, 210). Here environmental features encompass more than a physical environment, as accommodations – such as person-centred care from support workers – can also be used to overcome barriers to individual access to the social and cultural environment.

In their critique of the application of principles of successful aging to older adults with disabilities Minkler and Fadem (2002) draw from the work of P. Baltes and Baltes (1990), whose related theory of optimal aging, they argue, is better suited to the unique physical and environmental needs of the older adult with DD. The authors' critique of successful aging rests on the fact that the binaries constructed to organize the processes of aging with a 'scientific and managerial efficiency' lose sight of the significance of variation in lived experiences by marginalized identities (Minkler and Fadem 2002, 233). While the authors here are referring to severe physical disabilities, their critique is just as applicable, if not more so, when we consider the diverse and marginalized experiences of older adults with DD. Optimal aging has promoted the theory of 'selective optimization with compensation' which proposes that, through different life stages, different outcomes become desirable. The theory suggests that different resource allocations are required to support the increased focus on maintenance and repair in later life and to maintain a balance between the expectations placed on different generations (Baltes and Smith 2003). While this idea of relativity and adaptability of desired outcomes can be applied to physical and intellectual impairment (Ibid. 132), optimal aging treats these variations as corresponding to the general expectations of sequential age categories, leading authors to claim that the theory is not seamlessly transferable to DD acquired in early life (Bigby 2004, 245).

A second theory of aging that has been frequently applied to disability studies is the 'life course perspective on aging'. A central premise of the life-course perspective is that development does not cease as adults enter into old age, and that many of the experiences that are tied to aging are embedded within specific historical contexts, and influenced by social and cultural conditions, such that no two cohorts experience life course stages the same way (Settersten 2003, 17). Thus cohorts may share common experiences of structural pressures, but may experience different outcomes. For example, Dannefer (2003) has shown that advantages and disadvantages corresponding to identity or 'social class' within cohorts are magnified over the life-course, such that by old age inequalities imprinted on different socioeconomic identities from birth are at their most magnified.

This focus on structural disadvantage has been applied to disability theory, which argues that by situating individual lives of disabled persons within the structural context that 'disables' them, more can be learned about the precise nature of these structural forces (Priestley 2001, Irwin 2001, Breitenbach 2001). Irwin (2001) proposes that in order to effect positive changes to these structural forces, 'social claims' must be put forth to act against the social hierarchies that, ironically, can act to reduce the ability of marginalized groups to effectively place claims in the first place, by privileging some groups over others (p.24). Thus, structural forces reinforce inequality, and this process is magnified according to the number of intersecting social disadvantages, such as aging and DD, that are imposed upon individuals within a given cohort.

As such, the life course perspective is useful in demonstrating the pervasiveness of social attitudes, and thus emboldens the suggestion that social barriers are more daunting than environmental barriers. Moreover, it serves to emphasize the ‘double jeopardy’ of aging with a DD, particularly among the cohort who are now entering old age to contend with these disadvantageous social constructions along with the cumulative effects of a lifetime of social exclusion (Walker and Walker 1998). Indeed, this segment of the population is likely the most ‘disabled’ cohort in Canadian society. Yet, disadvantage need not be all-encompassing. Darling (2013) suggests that older adults ‘aging with disability’ benefit from the absence of holding stigma and prioritizing a medical model through the life course. Consequently, she argues that those who ‘age into disability’ later in life are more likely to be affected by declines in self-esteem, owing to their sudden embodiment of the subjective disabled identity, most commonly leading to what she labels as a ‘resignation orientation’ in self-identity (Darling 2013, 139). However, while positive self-identity may be a useful tool in managing one’s personal experience of disability, it is insignificantly related to the broader, culturally embedded constructions of disabled identity that ‘Social Model’ theorists have claimed create the disabling condition.

2.5 The Social Model of Disability

The social model has been prominent in the disability policy literature since the early 1980’s, existing generically as a perspective that identifies socially constructed barriers as the ‘the disabling conditions’ that structure widely held attitudes and expectations about the limitations that accompany physical and intellectual impairment (Barnes and Mercer 2010). However, given its ubiquitous presence in the disability literature, the social model has been subject to frequent critique and revision (Rapley 2004, Barnes and Mercer 2004). While a detailed account of the evolution of this model is beyond the scope of this analysis, an important distinction has emerged between different social formulations of disability that have been brought to light by Canadian disability policy. Rioux and Valentine (2006) identify two distinct streams within the 'social pathology' perspective on disability emerging from the social model: the environmental approach and the human rights approach. The human rights approach focuses on the revision and adaptation of public policy to provide political and social entitlements, while the environmental approach seeks to place increased control of supports in the hands of individuals with disabilities so that they can overcome embedded social barriers (Rioux and Valentine 2006, 49). The former approach conforms to the types of sweeping national rights entitlements forwarded by the UNCRPD and the *In Unison* report, while the latter more closely aligns with the person-centred approach promoted by Ontario's Social Inclusion Act, and Québec's Disability Integration Act. Differentiating these provincial policies through their almost oppositional position relative to national disability policy may help uncover intergovernmental tensions that can act to compromise the effectiveness of both approaches in promoting social inclusion outcomes.

2.6 Trends in Canadian Disability Policy

Numerous texts on Canadian disability and aging policy have explored the tension between federal and provincial governments, as well as regional service centres, and developmental agencies in issues of funding and governance of service provision domains. By analyzing and assessing the growing trend of 'disentanglement' through the increased authority of community support systems, Bach (2002) stresses that in order for these systems to succeed in achieving the goals broadly identified by federal documents such as *In Unison*, they require assistance from federal and provincial governments in the form of funding and the enforcement of accountability mechanisms, in addition to policy direction. Power et al. (2013) attribute this trend of increasingly downloading central authority to developmental services organizations to an emerging paradigm shift toward a 'developmental welfare state' in public services delivery among western nations who have signed the UNCRPD. This 'personalization paradigm' shares a common orientation towards promoting 'choice' and 'innovation' among organizations operating under the guiding hand of strategic objectives emerging from the centre, and is differentiated by the unique political conditions within which the paradigm operates. For instance, in Ontario they find a strong orientation towards involving stakeholders – including developmental services organizations, academic researchers, and individuals with disabilities – in the development of policy instruments, as evidenced by the development of the Social Inclusion Act (Power et al. 2013, 104).

However, while it may be forthcoming, this paradigm shift has yet to be fully realized in either Ontario or Québec. Carney (2013) points to the persistence of paternalistic practices in supported decision-making that have survived major policy shifts due to the resilience of the custodial care model in legal definitions of supported decision-making in both provinces. He contends that without matching changes in legal definitions of competence in capacity for decision-making, or greater oversight of support services to address grievances with quality of care, attempts to facilitate person-centred planning will be compromised by the influence of support workers. Similarly, Joffe (2010) finds quality of support work provision is an obstacle to the person-centred approach promoted by Ontario's Social Inclusion Act, and advocates for rights education for PSWs and adults with DD, in addition to more external oversight of service provision. Tremblay (2015) finds that Québec's system is also steered away from person-centred planning through professional interference, as 10 out of 30 adults with DD in her sample were referred to inappropriate services and supports owing to inconsistent practices within Québec's three-tiered governance structure. Yet, while each of these authors identify shortcomings of the current structures in Ontario and Québec, they do so without any concrete or replicable measurement of how these same structures have advanced social inclusion. Without such measurement, it is not possible to advance beyond general sketches of the services system to compare precise service outcomes for different types of disabilities and different cohorts within the life course.

2.7 Social Inclusion

In the interests of providing a foundation for this type of comparison, numerous authors have set out to conceptualize and measure social inclusion. For example, Prince (2009) advocates for the development of a Canadian index on social inclusion, following a wide trend of macro social indices to measure policy and service outcomes. He proposes that this would aid in the comparison of services across jurisdictions, and demographic dimensions by measuring distribution and levels of social inclusion (p. 96). This possibility has been the subject of significant attention within the QOL literature pertaining to life outcomes for individuals with DD. Schalock (2004) specifically addresses what he calls the 'emerging disability paradigm', that he claims has shifted assessment of service delivery towards four primary focuses: functional limitations, personal well-being, individualized supports, and personal competence and adaptation. To facilitate measurement of services and support outcomes within each of these emerging focuses, he connects them each to one of the eight domains identified by the 'Schalock model' of QOL measurement. He situates the 'social inclusion' domain within the 'personal competence and adaptation' focus, and suggests that it can be assessed through measures of community integration and participation, community roles, and social support services (Schalock 2004, 207).

Through frequent replication in the academic literature, the Schalock model has become increasingly viewed as the preeminent system for measuring social inclusion outcomes, and the eight domains that it identifies are reflected in the eight domains set forth by the UNCRPD (Wang et al. 2010, 229; Shogren et al. 2009). Most importantly, its conceptualization of social inclusion as a QOL domain has been attributed to quality of service provision in studies linking social support to social inclusion. For example, Maes (2003) links user satisfaction in relation to disability services and supports with QOL outcomes among persons with DD in Australia to find that users are underrepresented in support planning. Similarly, Schalock et al. (2002) highlight the increasing use of the Schalock model of QOL among developmental services agencies to conduct internal evaluation of the services they provide. Given the continued popularity of these measures, it is likely that support for older adults with DD has, and will continue, to reflect a commitment to promoting social inclusion, in keeping with the principle defined by the Schalock model. As such a viable precedent has been established in the academic literature to reinforce the conceptual model that I have set forth in this study.

2.8 Conclusion

This review of the current literature has identified the key streams of literature with which this project engages, in addition to several gaps that this thesis attempts to fill. First, there is very little literature on the implications of public policy or the influence of structural designs on social inclusion outcomes, particularly where evidence is provided by support workers for older adults with DD. The sparse existing literature on support workers in Canada has focused on sectoral differences in wages or philosophies of care, rather than on the workers themselves as part of a multileveled system targeting specific outcomes. Emerging applications of the Schalock model, in concert with the multilevel governance conceptual framework discussed in the next chapter, provide a promising avenue for creating this linkage in the specific issue area of social inclusion outcomes through yearly planning for older adults with DD.

In addition, there is room to test whether person-centred approaches to planning yearly support objectives have begun to emerge in place of practices of supported or substitute decision-making, which have been reported to persist despite the clear orientation of Canadian disability policy towards the ‘personalization paradigm’. This represents an important area of emphasis in this project’s focus on the connection between policy and practice. To this end, this thesis will test whether the ‘siloization’ of disability and aging services reported in the international literature is also present in developmental services systems for older adults with DD in Ontario and Québec. This represents a key area of comparison for the structural designs of the Type I and Type II MLG systems; as Québec’s expected advantage in responsiveness should create less siloization through more integrated service delivery at the local level. To further this type of comparison, this thesis now shifts to a review of the MLG literature, and exploration of the conceptual framework as applied to the Ontario and Québec developmental services systems.

CHAPTER 3. MULTILEVEL GOVERNANCE

3.1 Introduction

Much has been made in political science of the transition from government to governance. This transformation in the way political systems are studied has been facilitated by the emergence and identification of new ‘spheres of authority’ at supranational and subnational levels that have eroded the dominance of national governments as the primary locations of oversight (Rosenau 2007). In part, this has been the result of a trend towards decentralization that dates back at least as far as the 1970s, when increasing pressures of globalization, combined with the potential for improved public service delivery, chipped away at the dominance of the traditional central state apparatus (Cheema and Rondinelli 2007). In Canada, this period of decentralization has resulted in shifting intergovernmental relations, with authority increasingly seated in the hands of the provinces rather than the federal government. Moreover, the transition from government to governance in Canada has also seen the emergence of non-governmental actors in the areas of policy design and implementation, thus seizing a share of authority offloaded from the central government (Bakvis et al. 2009). These system level trends have led many authors to posit and test theoretical expectations pertaining to probable outcomes owing to the precise jurisdictional designs of governance structures.

I derive my theoretical expectations from a burgeoning stream of literature that is tied together by a broad conceptual framework of Multilevel Governance (MLG). Specifically, I draw from Hooghe and Marks (2003) who explore two distinct types of MLG, which they label ‘Type I’ and ‘Type II’. I have chosen the MLG theoretical framework over other more traditional ones, such as federalism or intergovernmental relations, because these other frameworks do not account for the more decentralized, non-governmental levels of governance in Québec and Ontario's developmental services systems. Specifically, this project is interested in how developmental agencies and the support workers they employ act as distinct levels of governance. To define a 'sphere of authority', Rosenau (2007) indicates that it is distinguished by "the issuance of directives by its leadership and the compliance of its adherents" (p. 89). As such, this thesis treats this as the primary criteria for identifying governance levels in jurisdictional design. By establishing that these levels constitute specific 'spheres of authority' within the developmental services landscape, it becomes necessary to account for their role within the MLG structures in both provinces. To this end, the MLG conceptual framework is very useful in both explaining differences in jurisdictional design, and providing theoretical expectations as to the types of outcomes that these designs should produce. This emphasis on jurisdictional design will be instrumental in addressing the puzzling fact that these two most similar provinces are pursuing similar social service objectives (promoting social inclusion outcomes through person-centred care) using demonstrably different governance structures.

As this chapter will make clear, the MLG conceptual framework is well suited to the project of comparing Quebec and Ontario' developmental services systems because it is the theoretical approach that best describes, and posits expectations in accordance with, the increasingly nuanced relationships between multiple levels of authority that have accompanied the "resurgence of territorial politics" (Alcantara et al. 2016). Given Ontario and Quebec's conformity to the Type I and Type II designs respectively, MLG is an important tool to trace the influence of these contrasting jurisdictional designs on achieving policy outcomes within their unique service structures. However, as this thesis will ultimately demonstrate, these outcomes are also dependent on factors which are unique to the specific issue context of developmental services for older adults, and are thus beyond the rather limited conceptual focus of the Hooghe and Marks MLG framework. Chapter 5 presents findings related to these unique factors, which reflect broad social constructions of the 'aged' and 'developmentally disabled' identity categories. In this way, this thesis echoes a popular critique that MLG is conceptually underspecified, and difficult to apply to specific contexts owing to the complexity and distinctness of relationships between authorities at different levels (Piattoni 2009; Alcantara and Nelles 2014; Curry 2015). Nonetheless, by identifying the conceptual limitations of MLG, this thesis does not reject the utility of the framework altogether. Indeed, the purpose of this project is to provide a deep engagement with the work experiences of small sample of workers in both provinces, rather than a broad engagement with every outcome each system produces. To this end, the MLG framework is not used to predict the entire range of outcomes produced by each system, but rather to predict how the interaction between differently organized spheres of authority within Quebec and Ontario's contrasting architectures will differently affect the potential for support workers operating within these systems to deliver specific outcomes for the older adults with DD who they support. This is consistent with what Alcantara et al. (2016) label the 'instances' approach to MLG, which is more promising for practical application owing to a more refined focus than the more problematic 'systems' approach.

The primary purpose of this chapter is to lay the groundwork for the use of the MLG conceptual framework in this thesis. It begins by elaborating a schema for differentiating Type I and Type II systems according to their jurisdictional design, which is consistent with the key areas identified by Hooghe and Marks (2003). To this end, three central criteria are presented by which MLG types are differently designed: jurisdictional levels, membership and responsiveness. Each of these three features of MLG systems is separately addressed in the three subsequent sections of this chapter. In each of these sections the specific feature is defined, and then operationalized in accordance with the Québec and Ontario governance structures. This serves the dual purposes of supporting the claim that Ontario is a Type I and Québec is a Type II structure, while also presenting the divergent theoretical expectations that accompany these designs. These theoretical expectations are synthesized in the penultimate section of this chapter, and are then applied to the specific developmental services governance structures in Québec and Ontario in the concluding section.

3.2 Multilevel Governance: Type I and Type II Designs

The typology that Hooghe and Marks propose distinguishes between MLG types through the specifics of their jurisdictional designs. Moreover, by proposing two distinct types of MLG, the Hooghe and Marks typology has been applied to governance structures at various levels or 'spheres' of authority, from the local or subnational, as with Canadian indigenous peoples' self government (Alcantara and Nelles 2014), up to supranational, as in the case of the European Union (Hooghe and Marks 2005). For the purposes of this thesis, the largest level of analysis is the provincial level, as I propose that Ontario and Québec meet the design requirements of Type I and Type II respectively. Therefore, before discussing the theoretical expectations that accompany this classification, it is necessary to establish the justification for it. Table 1 lists some of the key distinguishing features of Type I and Type II structures that provide an organizational structure to the justification that I propose for classifying Ontario as Type I and Québec as Type II.

Table 1. Hooghe and Marks' Typology of MLG System Designs

	Type I	**Type II**
Jurisdictional Levels	Few	Many
Membership	Non-intersecting	Intersecting
Responsiveness	Embedded Institutions – Resistant to reform	Flexible Design – Adaptable to specific needs

Within the literature, the concept of MLG has been applied to the following three areas: political mobilization, state restructuring and policy making (Piatonni 2009). Each of these distinct areas has unique implications for how the MLG conceptual framework is employed. For the purposes of this analysis the focus solely rests on policy-making, specifically the analysis of outcomes produced by the divergent MLG systems for developmental disability supports in Ontario and Québec. To establish this divergence, I will demonstrate how Ontario and Québec separately conform to the design characteristics of Type I and Type II governance structures respectively. In the above representation of the Hooghe and Marks typology, I emphasize the three main areas upon which I base this comparison. In the proceeding sections, I will address each of these areas separately to provide a nuanced description of the Hooghe and Marks typology and to identify the ways that the governance of developmental disability supports for older adults in Québec and Ontario conform to these criteria.

3.3 Jurisdictional Levels

At the heart of the difference between Type I and II structures as defined by Hooghe and Marks is the notion that Type I structures represent traditional, institutionally embedded political authority, while Type II structures reflect the more recent shift towards decentralization, where unconventional governance levels have appeared to address the shortcomings of previous structures. This is evident when the authors claim that federalism is the ‘intellectual foundation’ of Type I governance, given that power is distributed between multiple – but not many – levels of government (Hooghe and Marks 2003, 236). Canada’s type of federalism diverts significant independence to the provinces, both in terms of jurisdictional authority over specific issues, and in terms of financial transfers to fund this oversight. This independence is magnified in large, highly populated and resource-rich provinces like Ontario and Québec[7], which are better situated to leverage their own interests against those of the central government (Bakvis et al. 2009, 51). Given provincial autonomy in numerous issue areas, including disability support services, this thesis treats Québec and Ontario as separate MLG systems nested – through intergovernmental relations[8] – within Canada’s federal system.

Hooghe and Marks emphasize that both Type I and Type II systems can coexist within MLG systems, often complementing each other due to their unique capacity for accomplishing different types of tasks (2003, 240). As such, MLG can describe a political system (Canada) while Type I and Type II structures can exist in many forms within that system (Alcantara et al. 2016, 37). Therefore, the comparison of two provincial level structures proposed by this thesis is appropriate because of the jurisdictional authority that both provinces have over their developmental disability support structures. In both Ontario and Québec the provincial governments act as an important central power, with a significant ‘sphere of authority’ in this specific issue area that is bounded by their jurisdictional borders. This spatial demarcation, in addition to the provinces’ autonomy in the issue area of regulating support work practice means

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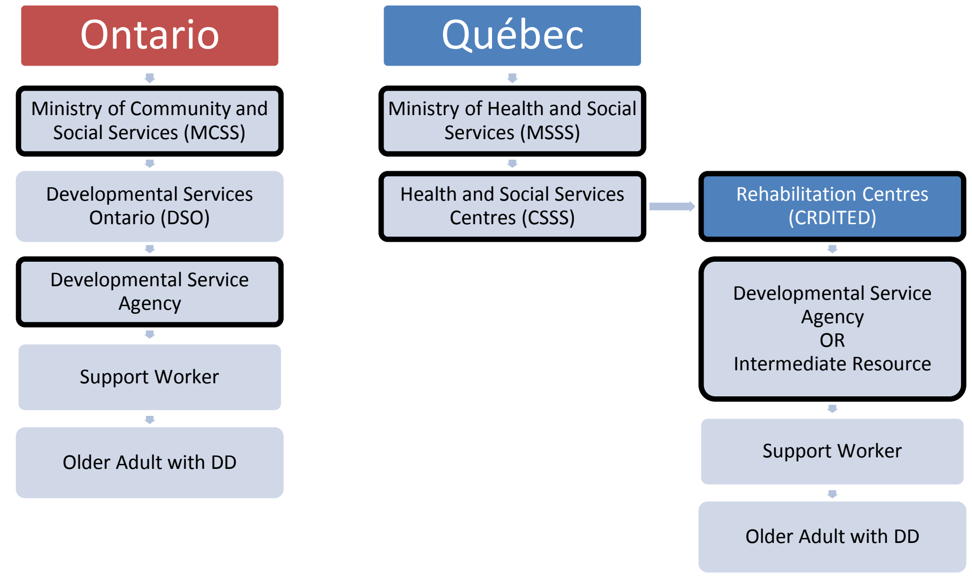
[7] Although Québec falls below national averages in some economic measures, it undoubtedly belongs among the major provincial players in terms of intergovernmental relations for many reasons. These are outlined later in this chapter, but it is important to emphasize that below average performance in economic indicators such as GDP and fiscal capacity does not significantly hinder Québec’s resources

[8] Regarding where federalism fits within the MLG concept, Alcantara et al. (2016) provide a schema that differentiates MLG from Intergovernmental Relations as mutually exclusive forms of multilevel politics (39).

that Ontario and Québec have what Skelcher (2005) labels as ‘jurisdictional integrity’, where a governmental body oversees both the spatial and policy domains. In this sense, Québec and Ontario are similar. In Ontario, support work provision is overseen by the Ministry of Community and Social Services, while in Québec it is overseen by the Ministry of Health and Social Services.

Figure 1. Examples of DD Support Governance Structures



* Black outline denotes separate governance level

However, what distinguishes the two provincial governance structure types is the appearance of another jurisdictional level in Québec in the form of CRDITED (see Figure 1). The addition of this one additional level significantly changes Québec’s governance structure. The CRDITED have issue-specific jurisdiction in areas of support services for people with developmental disabilities, including residential care, rehabilitation, adaptation and social integration (MSSS 2006). This means that within their jurisdictional boundary, each CRDITED has central authority in these areas giving them influence over which support services are received by clients with developmental disabilities of any age within their jurisdiction (Tremblay 2015). Moreover, this makes the CRDITED a unique player in the context of intergovernmental relations. Depending on the situation, CRDITED can interact with government policies at the local (e.g. adapted transit issues), provincial (e.g. income support issues) or federal (e.g. subsidized employment accommodations) levels. More importantly, when it comes to assigning and overseeing service provision, CRDITED are afforded significant responsibility to regulate the organizations operating within their service area. Because of this distinct authority, they can be seen as a level of government.

CRDITED are in fact one of multiple centres of power in the DD services landscape in Québec. Primary care is offered by regional 'health and social services centres' (CSSS), which serve as an entry point to other services, while highly specialized care (e.g. for mental health patients in crisis) is provided through the hospital system (Tremblay 2015, 163). As such, CRDITED can be seen as a secondary level of care (Ibid.), although this might understate the extent of their responsibility in relation to the other levels within this specific issue area. Nonetheless the 'polycentric' nature of the Québec structure's multiple levels clearly fulfils this first criteria of Type II MLG, and also serves to starkly differentiate it from Ontario's more traditional, centralized authority structure.

In Ontario, DSO's operate at the same position in the governance structure as the CRDITED in Québec. However, DSOs have only very recently appeared, and their role within the provincial governance structure is very different. In contrast to the jurisdictional authority held by CRDITED, DSOs effectively operate as administrative branches for referral and data collection under the authority of the MCSS. Following the enactment of the Social Inclusion Act in 2011, nine DSOs were set up in separate regions of Ontario as 'access points' for adults with developmental disabilities (often with the assistance their family/support network) as a means to centralize the processes of application and assessment for services in demand across the province (Saaltink and Ouellette-Kuntz 2014). To complement this policy, the MCSS also introduced a ‘Quality Assurance Measures’ (QAM) regulation that aims to improve and standardize service provision in the developmental services sector. Following consultation from an outside consulting firm, the QAM component called for by the Social Inclusion Act outlines ‘core competencies’ to be introduced into the human resources framework across the province. (Hay Group 2009). This policy-led standardization is consistent with the top-down architecture of the Ontario system, and of a ‘rights-based approach’ more generally, where significant accountability mechanisms are installed in order to protect the overarching interests of the central government (Joffe 2010). The outcomes promoted by this architecture are more thoroughly examined in the ‘Responsiveness’ section.

By comparing the positioning of DSOs and CRDITED within the governance structure, an important distinction becomes apparent. Unlike CRDITED, which are afforded significant independent authority within Québec’s system, DSOs in Ontario have been created to fulfil a specific regulated role as access points, or ‘application entities’ as they are identified in the Social Inclusion Act (MCSS 2008, 7(2)). Therefore, while CRDITED can be considered a separate level of governance within Québec’s polycentric structure, DSOs are embedded within the Ontario provincial government’s overarching ‘sphere of authority’. Type II systems are theorized to employ functionally-specific jurisdictional levels designed to most effectively provide the specific public service for which they exist (Hooghe and Marks 2003, 238). As such, we should expect that Québec’s system will be more ‘flexible’ to the specific needs of the users within its various jurisdictions. However, in order to establish the appropriateness of this expectation, it is important to first examine how jurisdictional membership is differently defined within the two MLG types.

3.4 Membership

According to the Hooghe and Marks typology, Type I and Type II structures are expected to differ with respect to the nature of jurisdictional membership. Type I regimes are theorized to have traditional territorial or 'non-intersecting' memberships, while Type II regimes are theorized to have intersecting memberships, with overlapping borders that diverge from more conventional hierarchal structures. In fitting with this feature of Type II structures, the geographical jurisdictions of CRDITED vary significantly among the twenty centres active in the province. For example, within the city of Montreal alone, there are four CRDITED, while in less populated areas of the province CRDITED serve multiple large rural regions with numerous municipalities therein (MSSS 2014, 206-211). This is typical of Type II jurisdictions, where there is no prescribed 'fixity' based on population or geographic size, but rather membership boundaries are devised with the specific function of the jurisdiction in mind (Hooghe and Marks 2003, 236). This structure has been elsewhere defined as prioritizing "single purpose jurisdictions with overlapping memberships" (Piattoni 2009, 170). In the Québec case, the specific function is the oversight and delivery of specific social services including residential and respite supports to individuals with DD living inside the specific jurisdiction. This single purpose for the CRDITED can significantly intersect with other jurisdictions, such as regions designated to health and social service centres (CSSS) (Tremblay 2015), as part of a separate provincial governance structure.

To emphasize the difference between membership patterns within these two governance structures it is important to once again return to the concept of 'jurisdictional integrity'. A fundamental part of what makes jurisdictions overlap is the precondition that they are not hierarchically linked to one another (Skelcher 2005). This is a key distinction between the Ontario and Québec systems, because there are several surface-level similarities between the two structures that can make them seem more alike than they are in practice. As with CRDITED in Québec, DSOs serve regionally separate jurisdictions within Ontario[9]. Moreover, they exist to fulfil a singular purpose within these jurisdictions: providing access to developmental services. However, this function is decidedly more specific and limited than the more expansive list of responsibilities held by CRDITED. Within Ontario there is a definitively hierarchal structure linking support work practice to government oversight through detailed policy mechanisms, and DSOs exist to uphold this structure rather than to hold any distinct jurisdictional authority.

In the specific case of support workers, this hierarchal relationship is apparent through the introduction of QAM, which has meant significant provincial policy regulation of hiring, professional advancement, and daily work practice (Cobigo et al. 2014). Indeed researching, understanding, and aligning with ministry priorities have been identified as necessary parts of the administrative work involved in interacting with DSOs to gain access to developmental support services in Ontario (Saaltink and Ouellette 2014, 49). Through detailed policy instruments, the MCSS restricts both DSOs and community providers province-wide by imposing standards on the support work industry that are in line with governmental priorities. As such, membership is non-intersecting because the governance architecture is 'system-wide', thus reflecting two key criteria of Type I systems (Hooghe and Marks 2003). Moreover, the 'interscalar' relationship

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[9] The nine DSOs in Ontario have different jurisdictional borders than the fourteen Local Health Integration Networks (LHINs) which serve as access points for health care services in the province. However, the nature of this overlap is quite different, owing to the fact that LHINs operate under the purview of a separate ministry, the Ministry of Health and Long-term Care. Moreover, the LHINs have far broader responsibilities and organizational designs than DSOs, with both the agenda and the authority to act responsively to meet the needs of membership (Gutmanis et al. 2015)

between regional DSOs and the central MCSS is consistent with MLG rather than other similar governance forms (Alcantara et al. 2016, 40). Finally, that the Ontario structure consists of one large sphere of authority contrasts significantly with Québec's polycentric, intersecting membership structure.

3.5 Responsiveness

The third major system design domain that separates Type I and Type II structures is their responsiveness to the demands of their constituents. Type I structures are proposed to be resistant to reform, owing to the embeddedness of multi-purpose institutions within their durable system architecture, while Type II structures are proposed to be more flexible to change and adaptation owing to the forces of demand exerted upon them by constituents for whom membership is a choice (Hooghe and Marks 2003). Thus change in Type I systems is proposed to occur rarely, and incrementally, in accordance with popular understandings of systemic resilience (see for example Lindblom 1979). Conversely, Type II change is thought to be more dependent on the preferences of members who exert consumer-like forces on the governance structure. Indeed, Type II structures are designed to produce desirable local outcomes, owing to their superior efficiency and effectiveness in the designated issue area (Skelcher 2005, 99). Catering to the specific needs of the jurisdictional membership is an important reason that Type II structures have emerged to replace more traditional Type I designs.

By its very design the MLG system in Québec is set up to address the twin objectives of 'population responsibility' and the 'structuring of services' as the two principal objectives of regional CSSS offices operating within the broader MSSS governance structure (MSSS 2005, 10). It stands to reason that more localized and unimpeded jurisdictional authority has the potential for greater responsiveness, specifically when one of its principal objectives is responding to the unique demands of its membership. However, when spheres of authority are limited to specific issue areas, problems that overlap into multiple spheres can complicate responsiveness by requiring cooperation between separate task-specific architectures. Hooghe and Marks label this the 'coordination dilemma' drawing from Scharpf's (1997) work on the transaction costs of interjurisdictional coordination among multiple parties. They offer that the best options in order to decrease these transaction costs in Type II structures is to either 'limit the number of autonomous actors' that require coordination or to 'limit interaction among actors' by designating total functional authority within each governance unit (Hooghe and Marks 2003, 239). Therefore, where these conditions are not met it is reasonable to expect coordination problems.

There is also potential for variation in responsiveness between different jurisdictional designs within Type II systems. Unlike Type I designs which employ standard governmental organizations within their more traditional multilevel architecture, Type II designs can distribute authority to numerous different types of organizations. To this end, Skelcher (2005) distinguishes between three different entities that can exist within Type II systems: club, agency, and polity-forming. Within this typology, CRDITED conform with the criteria of the 'agency' entity because their jurisdictional authority is legitimized by existing within the mandate of the MSSS, while they nonetheless are flexible to target their specific support strategies to their unique jurisdictional membership (Ibid, 98). Understanding the precise form of organization as it pertains to the sharing of authority is important to predicting the transaction costs that can be expected. Mapping the organizational design, or the relationship between the top level of the governance structure and the levels existing below it, allows us to understand the specific solutions that these structures are created to provide in response to the common problems of decision-making and agenda-setting that emerge, specifically where behaviour is seen to be motivated by bounded rationality and self-interest (March 2008, 57). In the Québec case, the flexible design should allow CRDITED to act as 'agencies' with more ability to adapt and respond to specific demands of their membership, while still operating under the broad legislative mandate of the MSSS.

As for Ontario's structure, the Type I design has the advantage of reducing the transaction costs associated with coordination. When assessing more traditional Type I designs, it is important to remember that while coordination problems do exist between separate agencies and departments within federal structures, these are not levels in the sense of multilevel governance (Doern et al. 2014, 71). What is more, the issue areas encompassed by these bodies are often quite broad, and so while coordination problems might influence the local level, they are less likely to occur there. For example, in Ontario the MCSS has clear and uncontested oversight in the domain of disability supports, with DSO offices operating squarely within this overarching sphere of influence. As such, the DSOs themselves should not be considered a separate level of governance. Indeed, they were created specifically to facilitate more top-down control of service allocation for older adults with DD by the MCSS, which represents the top level of the Ontario governance structure (Saaltink and Ouellette-Kuntz 2014). Moreover, the QAM introduced by the Social Inclusion Act have significantly increased ministry influence on both the hiring practices and the specific work practices of support workers and other employees within Ontario's developmental services system. However, it is important to acknowledge that just because there is a large 'sphere of authority' at the top level of Ontario's governance structure, in addition to the fact that DSOs should not count as separate levels, does not mean that no spheres of authority exist at lower levels within the structure.

For example, at the level of the developmental service agencies, or even at the individual level of support workers providing services to people with DD, there are distinct spheres of authority. Moreover, these can be characterized by a significant degree of responsiveness to the unique demands of the individual, so long as it conforms to the guidelines of operant policies. For example, in ‘substitute decision-making’, where the support worker must act on behalf, and in the best interests, of an individual who is deemed to lack the capacity for decision-making, is frequently part of the job description (Dunn et al. 2009). In this case, a substantial sphere of authority is entrusted to one individual support worker in order to respond to the best interests of the individual.

Responsiveness is also exemplified by the numerous support strategies that can be differently employed by developmental service agencies in order to promote social inclusion outcomes. In this area, despite the more top-down architecture, there is evidence that developmental service agencies employ different tools to monitor and evaluate yearly planning outcomes for their clientele. One recent study finds that 37.2% participating developmental agencies in Ontario had developed their own planning tool, and a majority of the others were using a mix of multiple different tools to measure outcomes (Martin et al. 2012). This likely represents a response on the part of developmental agencies to fill in the gaps that are left over from strict adherence to the broad QAM regulations in the monitoring and evaluation areas of yearly planning. In this way, developmental agencies in Ontario assume responsibilities for regulating planning outcomes that are situated one level higher in Québec under the authority of the CRDITED. Thus, while DSOs do not represent a separate level of governance, their lack of authority in specific areas, such as monitoring of yearly plans, affords greater authority to developmental agencies in Ontario than their counterparts in Québec.

A primary focus of the Social Inclusion Act (2008) is to crystalize Ontario's commitment to allowing developmental service users significant latitude in choosing individualized supports through direct funding, though no program for this purpose has been implemented yet. The proposed program is modeled after the Self-Managed Attendant Services in Ontario Direct Funding Program that has been in place for broader disability services since the late 1990's. While this ongoing program has been critiqued for neatly conforming to, and perhaps stabilizing, the neoliberal agenda, as well as the turn towards austerity in health and social services in the wake of the 2008 recession, by limiting the potential of DSOs to diversify their services, it has also been acknowledged for its enduring commitment to the independence and autonomy of people with disabilities (Kelly 2016). If and when a program is put in place for providing direct funding to developmental service users, DSOs would take on greater responsibility as an access point for the administration of direct funding (MCSS 2011, 19). However, given that deficiency or loss of independence and autonomy are typically associated with both old age and DD, it is unlikely that the Social Inclusion Act (2008) will deliver a comparable program capable of circumventing the administrative hurdles that are associated with installing adequate safeguards (Kelly 2016, 113).

Therefore, even this introductory comparison of the responsiveness of the two governance types has revealed some potential problems for theoretical expectations based principally on system design. While Québec's structure should offer increased flexibility at the regional level owing to the separate authority of CRDITED, this flexibility advantage may not result in substantive differences with respect to the specific tools, or indeed the dynamics of the relationship between developmental agencies/support workers and the older adults with DD whom they support. That is, even though its Type II structure is designed to be more flexible, various factors which may disrupt the flexibility advantage with respect to the outcomes the system produces. This fissure between design and outcomes may be even more pronounced in Ontario, where greater authority is seated centrally, at the ministry level of the governance structure, and thus further away from the outcomes promoted by support workers at the lowest, most decentralized level of the Type I MLG structure.

So why then does this thesis derive theoretical expectations from a conceptual framework that is based on system design? It must be emphasized that the Hooghe and Marks MLG framework does not treat Type I and Type II as static, predictable categories. On the contrary, jurisdictional designs emerge to maximize the outcomes they produce, and thus can significantly vary within types, while still conforming to the broad criteria which distinguish them. This is emphasized by Skelcher (2005) who writes:

> "The mission of the new quasi-governmental and partnership bodies is to perform. The traditional public administration imperatives to conform to procedural norms are relaxed." (p.102)

In this sense, outcomes are vital in tracing whether the systems designed to produce them are working. To this end, responsiveness is the most important of the three criteria comprising the MLG typology with respect to the theoretical expectations that this project will employ in its analysis of the influence of contrasting governance structures in Québec and Ontario on social inclusion outcomes for a specific population from the perspectives of support workers who, at the most decentralized governance level in both provinces, act to promote these outcomes.

3.6 Theoretical Expectations for Type I and Type II Systems

Having reviewed the primary areas of difference between the two types of MLG systems, it is now possible to elucidate how these two systems should differently affect support work practice in Québec and Ontario. It is important to acknowledge that given how these governance structures have been extended to the level of direct support work provision, these systems may not apply to all older adults with DD, particularly those who do not make use of developmental supports. Instead, the task at hand is assessing the influence of these demonstrably different structures on the social inclusion outcomes targeted and delivered by support staff for service users in this population. To this end, the interview data in this study will not only provide information on how these structures act to affect support work practice, but will also test whether the governance structures operate as they are intended to.

The first frontier of difference proposed by the MLG framework pertains to the number of jurisdictional levels. As mentioned, Ontario's Type I system has fewer jurisdictional levels in keeping with more traditional federal, top-down structures. To facilitate the broader sphere of authority at the top end of the governance structure, we should expect elaborate policy mechanisms that stabilize central control. While the Social Inclusion Act and the subsequent QAM are evidence of far-reaching policy mechanisms, the mere existence of these policies does not speak to their influence on support work practices. To understand how these two systems can be expected to differently affect the practice of support workers, it is necessary to define the sphere of authority for the support worker in relation to overarching levels of governance such as the ministries (MCSS and MSSS), the developmental agencies, and in the case of Québec the CRDITED. To this end, it is unclear whether support workers in Ontario and Québec will have significantly different amounts of authority at the individual level when it comes to planning and decision-making with respect to social inclusion outcomes. This is the hole that the analysis undertaken by this thesis seeks to fill, and is a key area of focus in the interviews.

In addition, based on the MLG literature it is possible to establish theoretical expectations for the higher governance tiers. Specifically, there should be a pronounced difference between Québec and Ontario in terms of the flexibility of developmental agencies. This should be evident in the types of services provided in relation to the needs of the jurisdictional membership. For example, Québec's more flexible Type II structure should result in the delivery of services and programs that are more responsive to the regional demands of the CRDITED. On the contrary, Ontario's more rigid system should result in more standardization of services and programs, owing to its large multipurpose policy domain. At the heart of this difference lies the question of 'who establishes and oversees priorities in these contrasting systems?' Clearly, in Ontario we expect that this will be the MCSS. Yet, Québec's system appears more ambiguous. This multi-tiered, polycentric Type II structure should disperse issue authority, and create tension between levels.

The benefit of Québec's system is that CRDITED should provide extra flexibility in their responsiveness to their jurisdictional membership, but this may come at the expense of efficiency, specifically where coordination with other tiers is required. Drawing from Hooghe and Marks' 'coordination dilemma', the efficiency of CRDITED in Québec should be tightly linked to the functional authority that they have in structuring developmental supports for their given jurisdiction. There is evidence that at least in one area – service referral – CRDITEDs are inefficiently organized when it comes to coordination with either CSSS or specialized hospitals to promote optimal outcomes for service users (Tremblay 2015). Interestingly, the specific task of service referral is the sole domain of DSOs in Ontario, which occupy similar jurisdictional spaces to CRDITEDs despite not operating as a separate tier in the governance structure.

Finally, we should expect that variation between provinces in similar developmental services tasks will be legible through the connection between system design and desired outcomes. That is, because the specific outcomes (social inclusion for older adults) are similar in both provinces, any differentiation in the tasks (such as yearly planning) to achieve these outcomes should correspond to different system designs. For example, in Ontario's Type I system we should expect more standardization in the process of creating yearly plans, and thus greater similarity between respondents' accounts of devising and monitoring yearly objectives. Conversely, we should expect Québec's Type II structure to give support workers greater flexibility in matching their objectives to the available resources within their region, matching the greater influence of regional governance bodies (CRDITEDs).

3.7 Conclusion

This chapter has aimed at two clear purposes. The first is to establish the difference between Type I and Type II MLG systems, and to demonstrate the conformity of governance structures in Ontario and Québec respectively to these types. The second purpose is to derive theoretical expectations from the existing literature that can help answer the research question set forth by this thesis: 'Does more decentralization in Canadian provincial developmental services governance increase the potential of support workers to promote social inclusion for older adults with DD?' To this end, by examining three different domains of difference, two key areas have been identified in which each provincial governance structure is expected to have a clear advantage over the other. In the area of 'responsiveness', the Québec structure should be more flexible, due to the task-specific jurisdictions under the authority of CRDITED. This should enable CRDITED to prioritize services targeted to the needs of the users who comprise their sub-provincial membership. Conversely, with respect to 'efficiency' the Ontario structure, with its embedded institutions and system-wide architecture, should be more resilient to problems of coordination in providing consistent outcomes. This should provide a more consistent quality of developmental services in Ontario.

These two developmental services governance structures have been the subject of significant policy intervention. The Québec system, as represented here[10], was structured in 2003 to specifically promote the integration of social services across multiple levels (MSSS 2009). Moreover, the Ontario system has been significantly restructured following the introduction of the Social Inclusion Act in 2012, which introduced DSOs to monitor service access, and QAM to improve efficiency in the area of support work. In light of this significant policy focus in each province, and in addition to the structural differences and their theoretical expectations, as outlined in this chapter, another important question emerges: do these two specific, contrasting MLG systems produce significantly different social inclusion outcomes for older adults with DD in Québec and Ontario? Given that Ontario's Type I and Québec's Type II jurisdictional design are theorized to have distinct advantages, and that both provinces are targeting social inclusion outcomes via person-centred care through policy architectures structured around support work provision for older adults with DD, comparing these provinces by the exact outcomes produced should have important implications for best practices in the governance of developmental services.

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[10] The Québec system is undergoing another significant restructuring with implications for the governance of developmental disability supports in 2016 at the time of this thesis' publication.

CHAPTER 4. FINDINGS (A): THE INFLUENCE OF QUÉBEC AND ONTARIO GOVERNANCE STRUCTURES ON SUPPORT WORK PRACTICE

4.1 Introduction

This chapter begins by returning to a question posed at the end of Chapter 3: ‘do these two specific, contrasting MLG systems produce significantly different social inclusion outcomes for older adults with DD in Québec and Ontario?’ To address this question, this thesis first seeks to examine the connection between policy and practice in each province. In both Québec and Ontario, across multiple levels of the respective governance structures, there are policies and rules in place that aim to shape the practice of personal support workers for older adults with DD. Specifically, Ontario’s *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities* (“The Social Inclusion Act”) and Québec’s *An Act to secure handicapped persons in the exercise of their rights with a view to achieving social, school and workplace integration* (“The Disability Integration Act”) have emphasized the promotion of social inclusion outcomes through person-centred care. By interviewing respondents about their support work practice, it becomes possible to assess the influence of the rules and policies operating throughout the contrasting MLG structures as ‘relations of ruling’. In keeping with the institutional ethnography methodology that this thesis employs, interview respondents’ in-depth accounts of their work experiences, with a focus on the specific tasks which frame their practice, will speak to the influence of operant policies which frame these experiences and the location of issue authority throughout the respective governance structures. This corresponds with the first objective of this thesis, as introduced in Chapter 1:

Objective 1: *To assess the influence of governance structures on ‘framing’ the work practices of personal support workers for older adults with DD.*

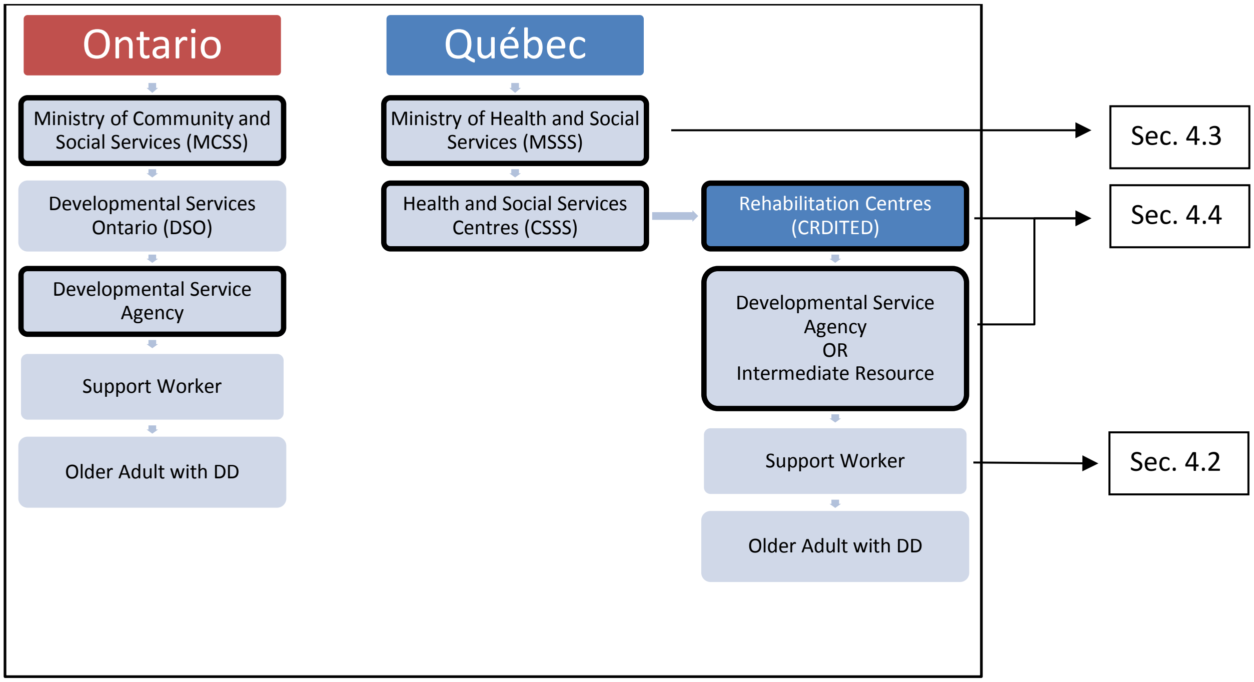
PUBLIC POLICY → SERVICE PROVISION
DD Services Governance *Personal Support Workers*

The primary finding of this thesis is that, despite the contrasting governance structures that shape developmental services in Québec and Ontario, these structures are producing remarkably similar outcomes. Specifically, the evidence presented in this chapter will demonstrate that social inclusion objectives are either being assigned low priority, or being ignored altogether in the yearly planning efforts of primary support workers, despite the fact that recent policies in both provinces have sought to prioritize these outcomes.

To this end, the chapter begins by presenting findings related to the specific practices of yearly planning. While other job tasks are analyzed later in this chapter, the most important aspect of support work in this chapter, and in this thesis more generally is yearly planning, particularly with respect to the pursuit of social inclusion outcomes. As section 4.2 explains, yearly planning, as a practice mandated by policy in both provinces, represents the most relevant area to analyze individual outcomes, both to assess whether social inclusion is being prioritized, and whether these outcomes are being facilitated in a person-centred manner. The findings presented in this chapter reveal numerous fissures between policy and practice, specifically in the area of yearly planning. Therefore, to situate job tasks within Québec and Ontario's broader governance structures, in both cases comprised of multiple spheres of authority at different levels of centralization, this thesis begins by focusing on the practices of support workers at the most decentralized level.

This chapter is organized so that each section corresponds to specific 'spheres of authority' within the governance structures of Québec and Ontario (see Figure 2). In keeping with this structure, section 4.3 shifts from the support worker level to address respondents' interactions with the ministries at the top level of Québec and Ontario's governance structures. By tracing the frequency and type of interaction with the ministries, it becomes possible to assess their influence from the 'centre' of the governance structure. To this end, this section tests the theoretical expectation from the MLG literature that support workers in Québec's Type II system are less encumbered by regulations from the centre than their Ontario counterparts, and thus operate more flexibly to pursue objectives for their clients. Interestingly, section 4.3 demonstrates that primary support workers in Québec do have more responsibilities, however this is partially due to the effects of recent cutbacks in reducing the labour force. This introduces an important intervening variable, the financial capacity of developmental services systems, which is demonstrated to have pronounced impact on support work outcomes. Nonetheless, this section also presents findings supporting the theoretical expectation that there will be more regulatory intervention in support work practice in Ontario than in Québec, in keeping with their contrasting MLG types, by comparing regulation oversight of medication administration.

Figure 2. Representation of Governance Levels and Corresponding Sections in Ch. 4



Next, section 4.4 addresses the role played by developmental agencies in both provinces, as well as the role of CRDITEDs as an extra governance level in Québec. This section presents findings related to the greater number of jurisdictional levels in Québec than in Ontario, which is a key area of difference between Type I and Type II systems identified in Chapter 3 (sec. 3.3). First, this section compares the influence of developmental agencies over the job task of creating and filing progress notes which document important information concerning the daily progress of service users. The extent to which progress notes are accessible across the support network provides evidence of the coordination of developmental services, an area within which the Hooghe and Marks MLG framework predicts that Ontario’s Type I structure will have an advantage. To this end, the findings reveal that Québec’s multiple, overlapping jurisdictions tend to create coordination problems for primary support workers in communicating with the broader support network, as predicted by the MLG framework. Conversely, among the Ontario sample, coordination problems were more commonly confined to the immediate support environment within the developmental agency.

By addressing each of the levels identified within the two provincial structures, the findings demonstrate that jurisdictional design does not tell the whole story. To this end, an important additional finding that becomes apparent in this chapter is that system capacity can significantly impede structural designs to limit the potential of public policies promoting social inclusion for older adults with DD. Section 4.5 addresses respondents’ appraisals of system capacity in both provinces to find that the increasing burden of austerity measures in Québec, in contrast to substantial recent financial infusions by the government of Ontario into the developmental services system has problematized comparisons based on jurisdictional design. This points to a persistent criticism the MLG conceptual framework: that it becomes vague when it is extended from conceptualization to analytical application in real world cases (Alcantara et al. 2016; Rouillard and Nadeau 2013). The chapter concludes by addressing this criticism in light of the evidence that has been introduced, and a reappraisal of the theoretical expectations set forth in Chapter 3.

4.2 Support Workers and the Task of Yearly Planning

This thesis, perhaps controversially, treats primary support workers as a separate sphere of authority within the MLG structures in Québec and Ontario. However, it is necessary to qualify this treatment by emphasizing that it is only applied to primary support workers, and not support workers more generally. Moreover, primary support workers are not treated as a separate governance level. Instead they are seen as occupying a distinct sphere of authority in relation to other employees of developmental agencies. In both provinces primary support workers – called primary direct support professionals in Ontario and special care counsellors in Québec – are the support workers in charge of preparing yearly planning documents for a given service user in the developmental services system. As outlined in the research design (Sec 1.3), the main selection criterion for interview respondents was that they acted as the primary support worker for an older adult with DD. This criterion was chosen because within the yearly planning process primary workers issue directives to the broader support network and, indeed, to the individual they support, as part of the process of promoting yearly planning outcomes. As mentioned in Chapter 3 (sec 3.1), Rosenau (2007) defines a sphere of authority by “the issuance of directives by its leadership and the compliance of its adherents” (p. 89). I propose that by devising, planning and documenting the main yearly objectives for older adults with DD, primary support worker constitute a distinct sphere of authority within the issue area of promoting social inclusion outcomes for this population.

Before comparing the effects of these two MLG types on the specific promotion of social inclusion objectives in yearly planning, it is reifying to first present findings related to respondents' explicit understandings of which policies frame their practice. For example, Ontario's Social Inclusion Act (2008) contains an important section entitled 'Rules Governing Service Agencies' that outlines several additional policy mechanisms which exert central control over developmental agency practices, including Quality Assurance Measures (QAM), the funding agreements between the MCSS and developmental agencies, and subsequent reporting requirements which affect multiple levels of developmental agency employees. However, despite this textual evidence of top-down control present in the policy, the Social Inclusion Act was not mentioned by any of the five Ontario respondents during the interviews. Given, that interview respondents were informed that this project was concerned with public policies promoting social inclusion (see section 4.3), the lack of direct reference to this policy suggests that primary support workers are unaware of the specific provincial policies which shape their practice.

Indeed, the only one of the above listed instruments that was mentioned was QAM, which was implemented as a subsequent regulation to the Social Inclusion Act. What is noteworthy about this singular mention is that it references a very specific aspect of support work practice that is affected by QAM: the language used within developmental agencies:

> "Core competencies, this agency the Hay Group conducted a survey and has been asked by the ministry to do that. They want to sort of like standardize the language for all agencies working with people with disabilities." (ON3)

Here the respondent identifies the key component of the QAM policy: core competencies. In the lead up to the enactment of the Social Inclusion Act, the MCSS contacted Hay Group, an international consulting firm, to play a lead role in the development of an accreditation model that would outline 'core competencies' for six positions within the developmental services sector (Hay Group 2009). The purpose of this strategy was to improve both the consistency and quality of staff through better hiring practices and a standardized rubric for promotion. However, when this respondent discusses core competencies, they focus only on one specific aspect of standardization: the language. This reveals an important way that policy influences support work practice. By shaping the language that support workers use, operant policies act to frame their job tasks.

In institutional ethnography, this is referred to as 'institutional language', and is used to map the 'conceptual schemes' that organize work practices (DeVault and McCoy 2006, 37). The effect of institutional language was ubiquitous in the interviews in both provinces. This is best exemplified by the words that respondents used to identify older adults with DD (see table 2). In Québec, respondents unilaterally used the word 'client' to refer to developmental service users, perhaps reflecting the more user demand driven service landscape of its more flexible Type II governance structure. By contrast, in Ontario respondents preferred the term 'individual' to refer to service users, likely owing to the more person-centred, individual choice model forwarded by the Social Inclusion Act. This is supported by the use of the term 'individuals with developmental disabilities' within the final report offered by the Hay Group (Hay Group 2009).

Table 2. Words Most Frequently Used by Respondents to Refer to Older Adults with DD

	Québec					Ontario				
	QC1	QC2	QC3	QC4	QC5	ON1	ON2	ON3	ON4	ON5
"Client"	73	39	89	84	52	1	0	0	0	0
"Individual"	3	1	0	0	1	39	38	49	44	60

While this kind of surface level analysis of word usage may indicate that policy influences support workers' speech, it does not speak to their specific job practices. To extend the analysis beyond trends in language usage, it is necessary to look at the way that language is employed, and what that says about the larger spheres of authority. In institutional ethnography this is accomplished by observing textual practices. Through texts, especially standardized reports and forms, ruling relations are 'activated' by their coordination of activity between human agents – in this case support workers – who must engage with these texts according to standard practice (Campbell and Gregor 2004, 33). To this end, I asked respondents numerous questions pertaining to the various texts that are part of their work.

One area of great interest was the development, implementation and monitoring of yearly personal plans for the older adults with DD whom they support, which is a ministry requirement in both provinces. These individual plans are important because they reflect the major outcomes that are targeted by a service user and their support network for each year. As such, they provide important insight into the types of objectives targeted by support work, the means to achieving those objectives, and the role of policy instruments and MLG tiers in shaping these processes.

Evidence from Regulated Yearly Planning

Yearly planning for people with DD requiring residential support is quite different in the two provinces, despite some commonalities. Ontario's individualized support plans (ISPs) and Québec's intervention plans (IPs) are both provincially mandated to be created, implemented and monitored by developmental agencies. In Québec, they are legislatively mandated by 'An Act to Respect Health Services and Social Services' (Chapter S-4.2 1990), as they are in Ontario by the QAM regulation added to the Social Inclusion Act (O. Reg. 299/10). Both of these policies contain sections indicating that service users should be involved in the development of plans wherever possible. Moreover, both of these documents acknowledge social inclusion/integration as an important domain for individual planning. However, despite these similarities, the interviews revealed that there are stark practical differences in yearly planning practice in the two provinces. While these differences owe in part to the divergent MLG structures in the two provinces, it is necessary to frame a discussion of these structures by first addressing the fact that, in both provinces, respondents identified significant fissures between policy and practice.

For example, Ontario's ISP emphasizes a person-centred approach, where the service user is intended to be as involved as possible in the development of support plans. However, multiple respondents reported a broad disconnect between the policy's intent and the practice of fulfilling its requirements. Specifically, some respondents emphasized how lower functioning older adults with DD might be unable to participate in selecting or working towards goals due to the severity of their impairments, thus making it more viable to 'do *for*' rather than 'do *with*':

> "I'm not supposed to be doing them. I'm supposed to be assisting them to do it, if it's a real ISP. But, again, reality does not lend itself to that." (ON1)
>
> "I am doing for, I am not doing with!... The 'do for' and the 'do with' thing and the hand over hand where they want to do it on the ISP, I hate it." (ON2)

To add further emphasis, two of the five Ontario respondents made mention of the fact that the ISP asks that the goals be written in the first person, despite the fact that some older adults with DD possess very limited communication skills. As a result, not only are support workers required to choose the goal, but they are often also required to record the goal on an official document by pretending to be the person that they support. In this sense the fissure between policy and practice is created by what respondents perceived as unrealistic demands being imposed by the policy on their job tasks.

In the Québec sample, respondents were more at ease about discussing the involvement of service users in the development of IPs, in part because the Québec support workers were given more individual authority in the development of more clinical and scientific plans. From this position, involving older adults with DD and their broader support network in planning occurred at the discretion of the primary support worker, rather than in accordance with a policy mandate. This is evident by the more assertive manner in which the Québec respondents spoke about individually developing their clinical objectives:

> "So, I'm choosing the need, then I come up with the target behaviour first, then my long-term goal, then my short-term goal, then I'm creating my teaching method, I'm doing my methodology plan, then I am submitting it to my specialist in clinical activities, then I am doing my Intervention Plan, show it to the curator, have it signed, and then I am starting. Oh, and somewhere in there I did my (baseline) first…" (QC1)

Here the respondent uses technical language to identify numerous specific steps that they personally complete in the process of developing and monitoring the yearly plan. This intensive process involves revising the set objectives every 90 days, with the aim of achieving multiple benchmarks of the IP during the year. The contrast with Ontario's less intensive development and monitoring procedure is evident by comparison:

> "Well, we have an (agency plan) that we do every week. We can do it more often, but every week is because you are tracking how many times this goal has been achieved this

> week. Are they doing it or not doing it? And then you can track this. And as time goes by, you can see if they are progressing."(ON1)

This coincides with previous research that finds that Ontario's more centrally regulated structure demands less in terms of monitoring and revising annual objectives, leaving developmental agencies to devise their own methods of planning outside of the ISP (Martin et al. 2012). Whereas in Québec, the various steps of the planning and monitoring process comprise a significant amount of the work done by special care counsellors, who devise, implement and monitor these plans. This allows these support workers to assume the role of experts in the planning process, independently determining when the involvement of service users is appropriate:

> "I definitely have clients who are involved in their planning. Like, they are going to say 'I want to do this, I want to move' – it is sometimes not realistic. Like, 'I want to move out on my own'. Ok, but you live in a wheelchair, you need an adapted environment, you are not able to cook or bathe yourself." (QC2)

This latitude afforded to Québec workers in determining the appropriateness of client involvement appears in stark contrast to the Ontario cases, where even when workers are not involving service users in ISPs, they are pretending to in order to fulfil policy requirements. While the actual outcomes in terms of the involvement of older adults with DD in annual planning may be quite similar in both systems, these outcomes are arrived at through different practices, which also vary in their adherence to operant policy structures.

Yearly plans contain the most important support objectives for individuals within the developmental services system, making them vital to understanding how these systems operate.

The evidence here reviewed indicates that there are notable differences between the person-centred intent of the policy and the substitute decision-making that occurs in practice. This intervention of the individual agency of support workers, their ‘sphere of authority’, complicates this analysis as it pertains to the outcomes produced by entire developmental services systems. It raises the possibility that substantial interventions in social inclusion outcomes are occurring in an ‘institutional void’ (Hajer 2003), where the influences of the various legitimate levels of governance are being minimized on the ground by support workers, who are acting independently within the unique conditions of their interpersonal relationship with the service user.

This is problematic for the MLG conceptual framework, which treats jurisdictions, rather than individuals as the level of analysis. However, this is not insurmountable. To the contrary, the ‘tension’ created by the imposition of individual-level preferences on the pursuit of system-level outcomes has been identified in the MLG literature as something to be incorporated into institutional design, and thus legible within the broader governance structure (Skelcher 2005, 102). In this way, the fact that Type II systems afford more agency to support workers choosing effective avenues for the performance of the social inclusion outcomes is consistent with the flexibility advantage that they are theorized to have in the area of responsiveness. Similarly, the imposed pretence of person-centred planning through the first-person reporting of goals in Ontario’s Type I system is consistent with the disadvantages that arise from imposing single policies in large jurisdictions with heterogeneous populations (Hooghe and Marks 2003, 235). That is, while some older adults with DD might benefit from designing and recording their yearly objectives, the evidence from the interview sample indicates that this is not the case for all. Therefore, as this analysis now shifts to more directly address the multiple levels of governance within each system, it is necessary to be cognizant of where these fissures between policy design and actual practice occur, and how they are accommodated by the MLG systems.

4.3 The Influence of Central Authority

Having situated the support workers' accounts of their 'spheres of influence' in yearly planning within the contrasting governance types in Québec and Ontario, this thesis now shifts to examine the influence of the sphere of authority that originates from the ministries at the top of each governance structure. In addition to yearly plans, there are numerous other ways that ruling relations are articulated through texts that support workers engage with. While some of this paperwork is created by the developmental agencies, most of the documentation completed by support workers is mandated in some way by the MSSS in Québec and the MCSS in Ontario. In this manner, the sphere of authority extends from the centre to affect the daily practices of support workers. By asking interview respondents to describe their interactions with the ministry through these various textual relations, important insights were gained regarding how the ministries at the top level of these two MLG structures operate.

Interaction with the Ministry

The previous section established that the support workers comprising the sample had very minimal explicit knowledge of the policy instruments that shaped their practice. Similarly, respondents in both provinces reported infrequent interaction with the ministry, outside of textual relations, such as mandatory documentation. Interestingly, some respondents from the Québec sample were able to provide concrete examples of their communication and coordination with ministry officials, while the Ontario sample provided none. One Ontario respondent explained that support workers and their supervisors would have little reason to directly interact with representatives of the MCSS, and that instead this would be more appropriate for managers within the developmental agency (ON3). In Québec, it was more common for respondents to interact with representatives of both the MSSS and the Ministry of Employment and Social Solidarity (MESS), owing to their larger personal role in the coordination of services for their clients:

> "It's time-consuming, because in my department we didn't used to have all of these responsibilities. We once had social workers doing all these jobs. Dealing with welfare, dealing with (medical care), all these… Then I came here and it is like I am really a social worker, and an educator at the same time" (QC5)

In this quote, the respondent indicates that their work responsibilities have increased owing to a scarcity of funding resources coming from the province, leading to fewer jobs both in the departments in charge of income support and other reimbursements, and in the developmental services sector. A recurring theme that emerged when the Québec respondents discussed their interaction with ministry representatives was the need to advocate for their clients in order to maintain the financial support to which they were entitled. This was highlighted as a significant challenge in preserving the often limited personal finances of older adults with DD. To this end, the Québec staff were more burdened than their Ontario counterparts with respect to preserving the financial supports owed to the older adults with DD whom they supported:

> "Yeah, lots of work with welfare. Everything that is, all the needs for reimbursing transport, the monthly cheque, their diapers, all of that needs to be reimbursed" (QC1).

This burden is magnified by the punitive practices that surround income supports, which are structured such that if a service user's account exceeds a certain amount, their access is cut:

> “And, if I do not get that information in the right time, and send it in the right time, the client will be cut from welfare. And then it is a totally different process. It is a harder process to reapply again, and explain to the welfare department why he had extra money because he had some expenses that should have been paid, but they were not paid.” (QC3)

These same types of clawbacks and funding issues have been documented in the Ontario system (Stapleton et al. 2011), but they were not mentioned by any of the respondents interviewed. In one sense, this evidence conforms to the theoretical expectation that coordination problems would be more frequent in Québec’s Type II system. The broader responsibilities of primary support workers in the Québec system, which are seen as a benefit in providing responsive service outcomes, are here seed to create disadvantages when it comes to coordinating with ministry officials who represent different spheres of authority. Ontario’s more defined hierarchy appears to leave absolve primary support workers of much of this responsibility. Yet the evidence provided in this section also raises the possibility that the differences between the two provinces may have more to do with structural capacity than the specific jurisdictional design. That is, the extra responsibilities with which the Québec workers were burdened was also attributed to recent cuts to services, leading to fewer jobs both within ministry’s bureaucratic apparatus, and in the developmental services sector. The intervention of capacity factors is given closer attention in section 4.5.

Medication

Another stark difference between the two provinces relating to influence from the top of the governance structure that was apparent in the interviews concerned the work practices around medication. In the Ontario sample the administration of medication to older adults with DD was something that respondents frequently identified as an important element of their work practice. Respondents made reference to the strict guidelines that they are given in yearly medication trainings provided by the developmental agency, and the detailed process of documenting the administration of medication and observing for negative interactions between different drugs:

> "My only concern is that always we have lots of questions regarding medication, you know for my (family) it's one thing, but for the guys it's totally different, you know? You have to follow the (agency) policies and procedures, but we always end up with some questions about something. It is the area that I feel less comfortable." (ON5)

Four out of the five Ontario respondents reported that they had anxiety around medication administration due to the dangers associated with interaction between the different types. Indeed, this was identified as one of the key areas where employees face strict oversight and discipline from supervisors: "You only get spoken to when it comes to health and safety or medication" (ON4). This evidence suggests that because medication has been identified as a key priority in the policy that guides support work practice, it has been internalized and made more important to staff. Indeed, medication administration is emphasized repeatedly in the QAM regulation, with 'Health promotion, medical services and medication' serving as one of the eleven measures legislatively enshrined by the document, with numerous provisions outlining developmental agencies' various responsibilities for documentation and accountability.

By comparison, the Québec sample mentioned medication less frequently with only two of the five respondents making reference to anxiety regarding medication interactions. Interestingly, though, one respondent indicated that they believed medication administration becomes a more pressing concern as people enter old age: “But in the aging population, our guys have taken so much medication their whole entire life, that I think it should be investigated a little bit more when we see behaviours. It could be something more serious.” (QC2). Despite the possible health problems associated with interactions or overmedication, there were far fewer accountability mechanisms reported by the Québec sample. While it was clear that some developmental agencies have medication protocols that are implemented at their own discretion, there is no policy governing home owners or the staff working for them in intermediate resources:

> “So there’s problems around the medication. For me it is a deception, because I was thinking that the nurse should be more implicated, but they treat the home manager in the (group home), they treat it like it is being at home. So they do what they want. But me, I never managed medication this way” (QC4)

The lack of mandatory training or documentation of medication administration in Québec comes in stark contrast to the strict regulations in Ontario. This is evidenced by the more frequent anxiety about issues related to medication in the Ontario sample. In this case, the stronger reach of medication policy in Ontario points to the stronger sphere of authority originating from the centre where provincial policies are generated.

The evidence reviewed in this section has pointed to some key distinctions regarding the reach of central authority. Ontario’s Type I system appears to have much stronger regulatory reach extending from the centre, in keeping with the theoretical expectations derived from the fewer jurisdictional levels. Interestingly this reach does not appear to be enforced through direct interaction between MCSS employees and primary support workers. Instead, this interaction was revealed to occur higher up the professional order, at the management level. As this authority trickles down to Ontario support workers, the evidence suggests that it is concentrated in priority areas such as health and safety, and medication administration, where unregulated practice presents the greatest risks to the well-being of service users.

The case of medication administration specifically highlights a key distinction between the two systems, as Québec's system appears to have relatively less oversight and documentation involving administration than Ontario's. This may result from differences in accountability between the two MLG designs, where Type II systems, such as Québec's, are theorized to have less institutionally-embedded avenues for accountability in service delivery owing to their more amorphous architectures at the organizational level (Skelcher 2005, 106). This would seem to imply that greater accountability mechanisms are required at the CRDITED level to govern medication administration. However, given that the interview sample is derived from only one CRDITED, it would be erroneous to draw conclusions about the medication practices in the other nineteen CRDITEDs throughout the province. Indeed, comparing the active models of medication administration governance across the province is an interesting avenue of future research, given the important correlation between proper medication administration and well being for older adults with DD. Nonetheless, the important distinction that the findings from this project provide is that this same type of regional disparity is not possible in Ontario's system, owing to the significant regulation of medication administration that is enshrined in provincial policy through the QAM regulation.

4.4 Developmental Agencies and Québec's Extra Levels of Governance

As was evidenced in the last section, Québec's Type II structure distributes much of the oversight over support work tasks that are regulated at the ministry level in Ontario to

CRDITEDs which exert substantial regional authority. As this analysis now shifts to compare spheres of authority at the developmental agency level, it is necessary to once again frame this comparison by accounting for Québec's extra levels of governance. Since the transition towards the community-based services model, developmental agencies have been integral partners in service innovations brought on by partnerships with provincial governments across Canada (Levesque 2012). However, in the Québec case this relationship is complicated by the significant regional authority given to CSSS in determining service priorities, and integrating health and social services. Following the December 2003 enactment of the *Act respecting local health and social services network development agencies* (Bill 25), Québec's CSSSs were required to orient services to the specific demand profiles of their jurisdictional membership, with broader, integrated service priorities for specific issue areas set out in action plans (MSSS 2009). For example, following the introduction of the 'Disability Integration Act'[11] in 2004, the MSSS published a broad strategy outlining key priorities for disability services, which reaffirmed the provinces commitment to 'social integration' of all disabled persons (MSSS 2008).

Given that in the Québec case developmental agencies are overseen by spheres of authority at three higher governance levels – the MSSS, the regional CSSS, and the regional CRDITED – it is reasonable to expect that their role will vary significantly from that of developmental agencies in Ontario. Specifically, MLG theory posits that Type II structures like Québec's will incur disadvantages in coordination, as authority is diffused to lower levels (Hooghe and Marks 2003, 234). To test this theoretical expectation, this section presents findings related to primary support workers' appraisals of coordination, as it is required in the tasks of their daily practice.

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[11] Recall that this is the short form this thesis uses to identify the *'Act to secure handicapped persons in the exercise of their rights with a view to achieving social, school and workplace integration'* (2004)

Before moving to a more general discussion of coordination in the provision of developmental services, this analysis of the roles of developmental agencies begins by returning to textual relations as a key data source, in adherence with the institutional ethnography research design. In addition to forms submitted to provincial ministries, support workers also provide paperwork to developmental agencies as part of their practice. In this way, textual relations track the interaction between support workers and the agencies that employ them, constituting another separate tier of the MLG system. The evidence provided by the interviews in both provinces suggests that a primary function of paperwork mandated by developmental agencies is coordination between staff in different departments and at different levels of the developmental agency. To this end, daily progress notes are important because they allow support workers to provide dynamic records of important information.

Progress Notes

In both provinces the participating developmental agencies had switched from paper copies of user's progress notes to versions submitted via computer over a secure network as part of province-wide initiatives. Respondents reported that this seemingly minor change had a significant impact on their daily practice. Positive accounts of the increase in efficiency were indicated: "working with computers it lessens the job a little, so I am able to spend more time with the individuals" (ON3). However, these were tempered by dissatisfaction that 'computer time' was not always available given the dynamic nature of the job tasks:

> "But the only problem with (software for note entry) is that we have to be near a computer, and if you work, like in … the workplace where you have the clients where you have to do something during the 8 hours while they are staying with you, you have

> no time to do it, so you have to stay after work to enter your notes, or do them the following day, or keep them until the last day of the week on Friday afternoon" (QC3)

Limited access to computers acts to reduce the efficiency advantage that electronic notes can provide. While evident in both provinces, this anxiety was more pronounced among the Ontario respondents, three of whom reported that while, in principle, the networked documentation system provides advantages in the areas of security and efficiency, in practice these advantages are outweighed by problems in the area of accessibility. As with the Québec respondent quoted above, an Ontario respondent identified the problems with inefficiency owing to limited computer access:

> "Yes, I will go on in the evening, and I will read what happened that night. Which is bad for me because I only get computer time in the afternoon, so when this person comes in in the morning, unless I can see something with them, I have no idea" (ON1)

Here the respondent points out that without access to these notes, there is a shortage of information vital to daily planning. This problem is exasperated when services users receive support from multiple agencies:

> "Well with the other agencies communication is a bit hard because we are not logged on to the same system. So it is a bit of a struggle, so we just – word of mouth, talking to each other, or in the communication book, the old fashioned. But now we just… with computers, you wish we were all logged on to the same thing, so I can see what you did last night." (ON3).

Interestingly, this respondent reveals that some Ontario support workers have established informal verbal communication links to compensate for the shortcomings of agency-specific software in order to share vital information about people they support. This is another example of support work practice significantly diverging from the intent of policy – in this case, the developmental agency's policy on online progress notes.

Another obstacle to accessibility that was mentioned in both provinces was lack of computer expertise among support workers. Respondents expressed that they and others in the field felt inadequately trained during the transition from paper notes to software:

> "I can help myself to the computer, but not the best. And, if that is the case, where you are coming out of paper, and you are going to bring in computer, then I think to the ones who are computer dummies, they would be saying, ok here… you are going to go and learn the basic needs for computer" (ON2).

Without the skills to navigate the software, coordination with other staff in the support network through progress notes is made more difficult. That staff are willing to create informal links to foster coordination points to the importance of communication across the support network in providing developmental support services. This need for communication extends beyond progress notes, to encompass the broader objectives sought by support work. As such, the capacity that developmental agencies generate for coordination provides important insight into the relations of ruling that they provide as a separate level of governance within the MLG structure.

Coordination involved in Developmental Supports

Within developmental agencies in both provinces there are often numerous departments offering different types of specialized services for adults with DD. These include respite/day program supports, education and vocational training, and residential supports including group homes, long-term care, semi-independent living, and private residences. It is common for older adults with DD to use many of these services at the same time, thus necessitating coordination among the support team. While respondents in both provinces identified coordination problems, the dynamics of these problems were very different. In Ontario, issues with coordination identified by respondents were localized mostly to the immediate support team. Conversely, respondents in the Québec sample identified more pervasive coordination problems occurring between different developmental agencies, and outside professionals who were part of the support network for individuals with DD. This difference is consistent with the theoretical expectations from the MLG literature concerning the difference in responsiveness between Type I and Type II systems.

In the Ontario sample, the most commonly identified area of coordination problems was among the immediate support team. Four of the five respondents indicated that there are stark differences between staff in terms of their commitment to sharing information to provide effective support. They emphasized that, given the importance of experiential knowledge with specific service users, and the added importance of communication regarding behavioural and health updates with older adults specifically, there was insufficient communication between both residential and respite support staff:

> “No. No, it doesn’t happen often enough. Sometimes it is hard to get staff to even call you back. So I don’t know, maybe people, some people might not have the skill, they might forget, or maybe I am being nice by saying they are forgetting, giving them the benefit of the doubt” (ON4).

Here the respondent implies that interaction with other primary staff in the support team at times may not occur due either to forgetfulness, or deliberate efforts not to keep communication channels open. This tension between different members of the support team was echoed by another Ontario respondent when discussing the lack of involvement of recreational support staff in yearly planning for some service users:

> "…which is really, I think, insulting or distrustful on their part because I am here spending like six hours with this guy every single day, and you are at home with them, but I'm not included to share what they do in the good part of the morning and the afternoon with you. You have no input on this whole chunk of their life." (ON1)

It is revealing that the Ontario sample was more focused on differences in proficiency among support workers at the same level of qualification, given the emphasis that has been placed on quality assurance generally, and core competencies of support workers specifically. First, this is more evidence that the priorities established by policies at higher levels of the MLG structure have a significant influence on the attitudes of support workers. Second, it suggests that the core competencies focus of the QAM regulation is addressing an area of significant need within the Ontario structure by attempting to provide consistent standards for positive staff performance.

In Québec, the coordination problems that respondents identified pertained to coordinating with different positions in the support network, rather than with other support workers specifically. In part, this reflects the tendency of the Québec system to favour private ownership of small group homes which act as 'intermediate resources', with oversight and funding handled by the CRDITED (MSSS 2009a). As defined in section 302 of 'An Act Respecting Health Services and Social Services' (S-4.2 1990), intermediate resources are "operated by a natural person as a self-employed worker or by a legal person or a partnership" and "participating in the maintenance of users otherwise registered for a public institution's services". This creates challenges to coordination between support workers employed by the public institution (CRDITED) that oversees social services, and the home owner as a 'self-employed worker'. This is evident in one respondent's description of the home manager's role: "Ok, so these homes are people under contract. They are not hired by the (agency), they are not hired by the government, so it's their business. So we don't have any say over staff over there." (QC1).

Diversity in the support network that is overseen by the CRDITED extends beyond home managers in the intermediate resources to include the whole support team. Unlike in the Ontario, where developmental services are more likely to be provided by one agency, in Québec the oversight of services occurs in CRDITEDs at a level higher than the developmental agency level, potentially resulting in a support network comprised of professionals from multiple agencies. This can create administrative obstacles when attempting to coordinate meetings of the support network, as is necessary when setting and evaluating yearly objectives:

> "The obstacles are like organizing team meetings when there's nine people involved… getting times when everybody can come... It's making requests – because you need a request for the OT to be involved, you need a request for the nurse to be involved in a case, for a social worker. A lot of administrative stuff to get everything organized, sending out times over and over and over again. All of the sudden someone will change a time, and then you will have to start all over again" (QC2)

These barriers act to complicate coordination, and thus the capacity of support workers to set and work towards objectives. In this way, the Québec system conforms to the theoretical expectations set forth by the MLG literature in that its polycentric structure leads to coordination dilemmas in interactions between spheres of authority at different levels of the governance structure. The CRDITED is charged with the difficult task of having to merge disparate professionalized 'silos' from various tiers of the Type II system, such as public curators at the ministry level, therapists at the regional or CSSS level, support workers from separate developmental agencies, and home owners from the intermediary resource level. This type of coordination involves multiple perspectives owing to the unique professional knowledge as part of the support network:

> "That's a big problem. No one has the same perception of a problem… So this, sometimes, can make us work in a circle again, where we are explaining to everybody, and at the end no one understands the same way, so the perception of the people when they talk, when they hear, when they think. No one thinks the same way, so it is difficult to be on the same page." (QC4)

In this way, the effect of coordination problems on support work practice creates a tension between different levels of the Type II MLG architecture, in keeping with the theoretical expectations. Moreover, the evidence from the Ontario sample suggests that coordination problems in the Ontario system are more commonly confined to the level of the developmental agency, where consistent, standardized expectations provide a clear rubric for staff roles, and create tension between staff at the same level. In this way, the Ontario evidence suggests that the system is more efficiently organized, with support workers occupying specifically defined roles within the developmental agency hierarchy. The next section situates these theoretical expectations within the broader project of comparing these two structures in their promotion of social inclusion outcomes for older adults with DD.

4.5 Other Factors Affecting Structural Capacity to Deliver Social Inclusion Outcomes

This chapter has presented support workers' accounts of their interaction with multiple levels of the governance structures in both provinces to test adherence with the theoretical expectations set forth by the MLG literature. The purpose of this format was examine the influence of these higher levels of governance on the direct practice of support workers, who themselves represent a tier of governance at the 'frontline' level. Indeed, this is in keeping with the conceptual model set forth by this research project. However, analysis of the interviews revealed a significant intervening factor which must be included in the discussion of the governance structures and operant policy instruments within the two provinces: the system's capacity to deliver the outcomes targeted by the policies operating within it.

During the interviews, there was a notable difference in the appraisals of system capacity by respondents in both samples. In Ontario, respondents tended to be more optimistic in their appraisals, while in Québec there was more pessimism about the future capacity of developmental agencies and CRDITEDs to deliver on their service objectives. At the root of this difference was concern over the effect of ongoing austerity measures in reducing the capacity of the developmental services framework in Québec. Scarcity of financial resources was also a theme that emerged among the Ontario sample; however, notably, respondents did not express concern about future reductions in funding or in accessibility of current services. In the Québec sample, the effect of these reductions was apparent in two areas that are indicative of the capacity of the developmental service structure: availability of programs and financial support.

Given the importance, reported in both samples, of day programs in supporting social inclusion outcomes, the number and availability of these problems is a valuable indicator of system capacity for promoting these outcomes. To this end, every respondent in the Québec sample identified access to appropriate day program supports as a major problem at the system level.

> "I mean we hear it all the time in the news, 'they turn 21, what do we do with them?'… Waiting lists are so long that you need to get creative, and whenever you find a spot somewhere you need to jump on it, even though it may not be exactly what the client needs at the moment, sometimes you just need to make it work." (QC5)

> "Day program, even if there's a lot, over time it changed because we have more clients and less resources, right? So better accessibility to programs that are better fitted to specific clients." (QC1)

This is consistent with a Québec Ombudsman's report, which indicates that CRDITED's are increasingly being encouraged by the MSSS to close down day programs in order to focus on super-specialized services, while responsibility for this critical social inclusion area is passed either down the ladder to developmental agencies, or up the ladder to the CSSS (Québec Ombudsman 2012, 54).

While, increases in life expectancy and more effective diagnosis of DD are increasing the number of service users, these demographic changes are also changing the demand profile of day program users, as older adults represent an increasing share of the DD population. Another concern raised by Québec respondents was that day programs, where available, were not tailored to the meet the specific needs of older adults with DD, instead favouring a younger clientele:

> “Ah, it’s not for old people, it’s for everybody who wants to go, with different types of levels. So sometimes it is not appropriate, because all of the levels of (DD) are all mixed up together, and it is not the perfect thing to do.” (QC4)

In the literature on aging and developmental disability services, there has been a consistent emphasis on the incompatibility of these separate ‘silos’ of service provision (Putnam 2014, Bigby 2010, Washko et al. 2012). In accordance with this literature, and with the predominance of the DD service silo in the developmental services landscape, the failure to target services to the specific needs of older adults was identified as a system-wide problem:

> “Once you have taken these clients into service, we are basically responsible for their whole entire lifespan, and we are not necessarily equipped and trained for a geriatric population” (QC2)

> “They are trying to put money in early intervention, so eventually kind of reducing mild or moderate intellectual disabilities. So there’s less resources being put for the older adults, where they are kind of put in maintenance, or left to their own devices…There is just more money being put into the children’s services.” (QC5)

This calls into question the flexibility of the Québec structure. While Type II structures are designed to be more responsive due to their smaller, single purpose jurisdictions, in the Québec case this flexibility appears to be constrained by the depletion of financial resources dedicated to preserving or adapting system capacity. That is, although Québec’s Type II jurisdictional design is expected to be advantageous in tailoring services to meet the needs of regional demographic profiles, financial constraints can limit this potential, thus forcing CRDITEDs to prioritize certain groups of service users. Given these financial conditions, and given that CRDITEDs are responsible for service delivery across the 'whole entire lifespan', it is plausible that early intervention, and an emphasis on younger service users could appear to be the most efficient and effective use of scarce resources at the regional level.

Among the Ontario sample, issues with capacity were also raised, but these were focused more on the status quo. While two of five respondents indicated that increased funding for staffing would improve social inclusion outcomes, none of the respondents discussed cuts in funding or program access. This in part reflects Ontario's status as one of the wealthier provinces in Canada, where better access to 'core funding' from provincial and municipal governments allows its developmental agencies significantly more financial capacity than counterparts in 'have not' provinces (Levesque 2012). In addition, Ontario is following through on a commitment from the 2014 provincial budget to increase spending by $810 million on developmental services over three years with the explicit purpose of eliminating waiting lists and increasing system capacity[12]. This significant increase in financial support to the provincial system comes in stark contrast to the austerity measures reported by the Québec sample. As such, a direct comparison between the Ontario's Type I and Québec's Type II systems from a structural perspective must be sensitive to these divergent financial circumstances, which should be expected to disrupt Québec's capacity to fully realize the advantages of its Type II structure as proposed by the MLG literature.

4.6 Conclusion

The findings presented in this chapter have both confirmed the theoretical expectations set forth in Chapter three, and introduced intervening factors which serve to challenge the

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[12] Source: Ontario Budget 2016, Chapter I, Section E. Retrieved online from: http://www.fin.gov.on.ca/en/budget/ontariobudgets/2016/ch1e.html

application of the MLG conceptual framework. First, in the area of responsiveness, Québec's system was seen to be provide support workers more latitude in using their professional expertise to select yearly planning objectives. Moreover, these objectives had a more clinical focus, and were monitored through a more complex and multifaceted assessment process than in Ontario's system. However, for older adults with DD Québec's responsiveness advantage was constrained by a systemic bias towards younger adults, specifically with respect to the structure and availability of recreational day programming. This finding was consistent with existing literature on the disability 'siloization' of developmental services for older adults, where developmental agencies and their employees demonstrate limited capacity for providing supports for older adult service users. The impact of siloization is further explored in Chapter 5. Finally, responsiveness was further constrained by broader deficits in system capacity that have accompanied austerity measures, resulting in significant shortages in staffing and programming resources in the Québec developmental services system.

The second theoretical expectation tested by these findings was that Ontario's Type I system should have advantages in efficiency and coordination owing to its more traditional, top-down architecture, with greater power seated in the hands of the ministry. The findings largely supported this expectation, with evidence of greater coordination among the support network and more defined roles for support workers within the Ontario structure. Additional evidence of Ontario's more centrally regulated structure was apparent in the area of medication administration, where the Ontario sample identified monitoring and documentation protocols which were less strenuous or non-existent in Québec according to respondents there. Moreover, evidence from 'institutional language' use revealed that Ontario respondents were highly aware of, and influenced by the priorities and specific nomenclature set forth by prominent policy documents, even when they were unfamiliar with the documents themselves. However, as with the Québec sample, Ontario support workers did not always act in strict adherence with the person-centred focus of prominent policy, specifically in the areas of yearly planning where they emphasized that some degree of substitute or supported decision-making was often necessary.

In both cases, the evidence demonstrated that primary support workers are exerting significant agency within their distinct 'sphere of authority' with respect to what outcomes they are pursuing with the individuals that they support. The fact that such significant authority is being exercised in this 'institutional void' may explain why social inclusion outcomes were assigned lower priority relative to other yearly planning outcomes for older adults with DD by support workers in both provinces, despite the emphasis on social inclusion outcomes in prominent public policies. The attitudes that lead to this prioritization are the primary focus of the next chapter, which addresses the effects of social constructions of aging and disability on support work practice.

Finally, a major finding of this chapter has been that structural capacity factors must be considered in the comparison of MLG systems. The evidence presented here suggests that Québec's system is significantly impeded in realizing the advantages of its jurisdictional design by a lack of financial capacity to promote responsiveness in developmental services, particularly when it comes to the social inclusion needs of older adults with DD. This is particularly apparent in the areas of day program availability, where access is limited by prohibitively long waiting lists, which exasperate the exclusion of older adults in a service model that is already biased towards younger users.

This finding has potential implications for the MLG conceptual framework, as it suggests that Type II structures may be less capable of acquiring necessary resources to meet common priorities through funding agreements with governments at the top of the governance structure. This fits with existing literature that suggests that as issue authority is dispersed down the governance structure to entities at lower levels, so too is accountability on delivering objectives, even if these are consensus priorities for collective action (Skelcher 2005; Piattoni 2009). Moreover, it is confirmed by recent events, as at the time of this study Québec is implementing significant reforms to centralize the governance of health and social services in the province to promote greater accountability and integration with MSSS structures at the regional level (MSSS 2016). It remains to be seen if these reforms will address the capacity problems identified here, and this represents a promising avenue for future research in developmental services governance. Furthermore, future application of the MLG framework would be well served by a deeper treatment of the connection between funding agreements with central governments and structural capacity for collective action in Type II structures.

CHAPTER 5. SOCIAL CONSTRUCTIONS OF AGING AND DEVELOPMENTAL DISABILITY IN THE WORK EXPERIENCES OF SUPPORT WORKERS

5.1 Introduction

The primary reason for basing this thesis on the experiences of personal support workers for older adults with developmental disabilities (DD) is examining the influence both of public policy and of social constructions of 'aged' and 'developmentally disabled' identity categories on the precise outcomes that are produced by support work practice (see Objective #3 in Chapter 1). The primary finding of this thesis is that despite the contrasting governance structures that shape developmental services in Québec and Ontario, these structures are producing remarkably similar outcomes, as evidenced by the experiences of support workers in both provinces. This broad finding is bolstered by two supporting findings:

i) System capacity factors can significantly impede the potential of public policy to promote social inclusion outcomes for older adults with DD.

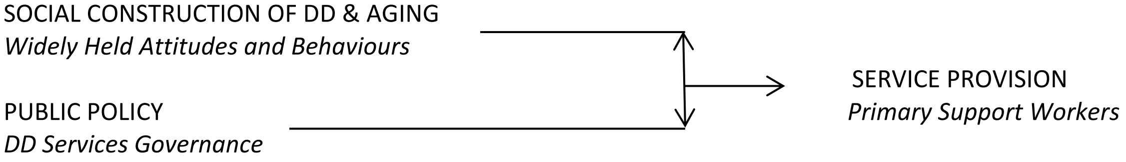
ii) Persistent exclusionary social attitudes have stalled the changes that prominent policies have sought to produce in the social constructions of aging and DD.

Of these two supporting findings, this chapter is more concerned with the latter, while Chapter 4 presents evidence that is more oriented towards the former. To conclude this thesis, Chapter 6 summarizes the interrelationship of these findings, in a discussion of the implications for developmental services in Québec and Ontario. By synthesizing these findings, it becomes possible to address the puzzling fact that these two neighbouring provinces, pursuing similar outcomes, use diametrically different MLG structures. Through this synthesis, it becomes clear that despite the pronounced structural differences – which are based on divergent strategies for governing social services providing individualized outcomes – both Québec and Ontario appear to be failing to promote social inclusion for older adults with DD in similar ways.

Rather than further test the theoretical expectations set forth by the MLG conceptual framework, this chapter exists to present findings related to the intervening factors that have problematized the application of MLG to the specific cases of developmental services in Ontario and Quebec. While the interview respondents did identify structural features consistent with the two types of MLG, as evidenced in the previous chapter, the influence of these designs on the promotion of social inclusion outcomes in both provinces was limited by the alternative factors that are reviewed in this chapter. Specifically, this thesis finds that exclusionary social constructions limit the potential of structural designs to produce desired social inclusion outcomes both within the disability services sector, and in terms of the engagement of older adults with DD and their support workers with broader society. This has implications for the use of MLG, as it suggests that the expected differences between Type I and Type II structures are more pronounced when these structures are performing properly, by delivering the outcomes that they have set forth. As such, this chapter exists primarily to explain why both provinces are failing to deliver social inclusion outcomes from the evidence of support workers. Through this explanation, the practical implications of system design in this specific issue area can be teased out, which will embolden the discussion of policy implications presented in the final chapter.

As has been mentioned, part of this explanation has to do with the persistence of exclusionary social constructions at the intersection of aging and DD. To explore this relationship, this chapter addresses how person-centred outcomes targeted by recent public policies in both provinces must contend with attitudinal barriers that result from the intersection of socially constructed ‘aged’ and ‘developmentally disabled’ identity categories. These social constructions are not statically defined, but rather are dynamic, and dependent on the context of the broader governance structure, and the precise service relationship (Walker and Walker 1998). They act to 'produce' identities that are coherent within a fluid categorization of membership to accepted identity categories (Rapley 2004). Just as social model theorists have defined disability as social organization that perpetuates exclusion and disadvantage by imagining otherness that is unrelated to an individual's precise impairment (Barnes and Mercer 2004), exclusionary constructions of 'older adulthood' and being developmentally *disabled* are similarly fabricated independently of the precise experiences of older adults with DD. In this way the intersection of aging and DD can be differently constructed by public policy, developmental agencies, support workers, and the broader public. Therefore, identifying these social constructions from the specific perspectives of the support workers interviewed is in keeping with the second objective of this thesis project:

Objective 2: *To assess the mutual relationship between social constructions of 'aging' and 'disability', and public policy in Ontario and Québec by tracing their influence on support work practice.*



To this end, this chapter presents findings from the interview data related to the social constructions of these two identity categories within the context of support work practice. It begins by exploring support workers' accounts of what differentiates support provision for older adults with DD from their experience supporting younger adults with DD or older adults without DD. The findings demonstrate that in both the Québec and Ontario samples, developmental services workers feel anxiety around a lack of capacity throughout the governance structure in dealing with issues related to aging in the support of older adult clients. This conforms to the expectations forwarded by previous studies on the 'siloization' of disability and aging support services, which represent a significant barrier to the promotion of social inclusion for older adults with DD who are service users in either system.

By first addressing the unique realities of supporting older adults with DD, a foundation is established upon which both to direct the analysis towards how support workers define and operationalize social inclusion for this population, and to situate these practices within broader social constructions of aging and DD identified in the academic literature. Next the chapter will shift to discuss the community-based service model that currently frames support work practice in relation to the previous custodial care model as employed in residential institutions (for people with DD), and nursing homes (for neuro-typical older adults). By situating the current model of care in relation to the previous model, the changes in attitudes that have been attributed to this transition– such as greater tolerance for social inclusion of older adults and people with DD – are given context, and tied to the different outcomes produced by the newer model of services. Again, this section demonstrates that the correlation between policy and outcomes is weakened by the intervention of social attitudes and system capacity factors, which act to create a 'siloized' disability services landscape that is underprepared to meet the specific needs of older adults.

The third section explores support workers' definitions of social inclusion by comparing them using the principles of the most popular model of social inclusion for people with DD: the Schalock model. This model is closely linked to the definitions, indicators and applications of social inclusion that have served as fundamental principles in important policy documents, namely the United Nations Convention on the Rights of Persons with Disabilities (Shogren et al. 2009). As such, the Schalock model enables a comparison between support worker's personal definitions of social inclusion and the definitions set forth by the most prominent rights policy currently in place in Canada. The relationship is further examined in the fourth section of this chapter which compares support workers' operationalization of social inclusion through yearly planning objectives to the support work applications of social inclusion indicators that are set forth by Schalock et al. (2002) in a study which presents consensus principles of conceptualization and measurement of 'quality of life' for people with DD. In this way, this outcome-based model provides a useful tool to assess the relationship between definition and operationalization of social inclusion by each respondent. To this end, I find that social barriers act to significantly intervene in support workers' potential to deliver inclusion outcomes, thus limiting the correlation between the practices of promoting social inclusion and the definitions of social inclusion that frame them.

5.2 Developmental Services for Older Adults with DD

Given that developmental services are provided across all stages of the life-course – from behavioural interventions in infancy to palliative care for the oldest old – it is not surprising that each of the respondents interviewed had experience supporting people with DD both above and below the threshold of 50 years of age. Moreover, given the numerous theoretical perspectives that emphasize the factors that act to differentiate the experience of older and younger adults with DD (see Chapter 2) it is not surprising that support workers in both provinces identified major differences between supporting these two populations. The difference between the two groups that was most reported by the sample was the decreased functional autonomy of older adults with DD:

> "I guess the need to be able to sit down throughout the day, the physical stamina. It is not fast-paced, there is someone who can help monitor someone who needs reminders to go

> to the washroom, with their food, heating up their meals. It is people who have less autonomy in general, and who have lost some of their autonomy and independence as they are aging." (QC2)

This is consistent with the fact that physical disabilities are far more prevalent among older adults with DD. Preliminary results recently released by Statistics Canada from the 2012 Canadian Survey on Disability indicate that 96.3% percent of the population of people with DD 65 years of age and older have a physical disability, as compared to 49.3% aged 15-24, and 74.9% aged 25-64 (Statistics Canada 2015, 5). While issues of functional decline are faced by all older adults as they move through the life course, physical and cognitive declines for older adults with developmental disabilities are often more limiting, thus leading to greater support needs, and are compounded by decreasing access to resources, both financial and relational, such as support from parents (Doka and Lavin 2003). The transition towards functional decline in older adulthood was a major area of emphasis for support workers in both provinces when characterizing the implications for supporting this population, in contrast to supporting younger adults with DD:

> "So I think in the team meeting, with someone younger you might be saying what fantastic programs can we do out in the community and inside? What can we plan organize and implement for this younger individual? Within the team meeting we might talk about programs a lot and getting them involved as much as possible so that they feel like they are taking ownership in their life and people are not doing things for them. You want the person to feel normal, like normalization. You want them to feel like a regular human being, and like they can do it on their own. You can let them do it on their own.

> For someone who is older you might be speaking about their care a little bit more in the team meeting, and doctor's appointments" (ON4)

> "A lot of them its maintenance. Maintaining any of their abilities, whether it be their independence – a lot of it is their independence, well for me at least. It is not because they get older that we can't teach them new skills or anything like that, but a lot of it is maintaining, because some of them are maybe not in day program, so they are not moving around as much, or they don't get to make as many choices." (QC5)

Apparent in the above quotes is an anxiety that was ubiquitous in the interviews, where respondents were deeply concerned about missing some of the tell-tale signs of the declines in functional autonomy and health that are associated with older age. At the root of this anxiety was a lack of professional training directed toward support practices specifically targeted to older adults. This is consistent with literature that has found that disability organizations often lack the professional and organizational capacity to support client populations with unfamiliar disabilities, or that are older in age (Sparks 2000; Putnam 2011). This includes an emphasis on early intervention therapeutic techniques, such as applied behavioural analysis for autism spectrum disorder, which are tremendously effective for children, but are not designed for applications with older adults.

This emphasis on catering services to younger users extends beyond specific techniques to typify whole programs of disability services. For example, respondents in both provinces indicated that day programs are not structured to meet the specific needs of older adults with DD, with a dominant model of services that favours younger clients. As a result, older adults with DD can be forced to withdraw from day program supports – which often provide their primary access to social interaction and community engagement – because these programs are not designed to accommodate their needs:

> “I mean, a lot of the adults now are maybe falling through the cracks a little bit in terms of having the services they should have because of the way the model of services is now.” (QC5)

> “And even trying to give them choices, sometimes they don’t want to wake up in the morning. So that little leeway, just allowing to say “you know what, today X didn’t want to come to work” I wish there was even more of that because I know of another agency who have really set up like an evening day program.” (ON3)

In the second quotation, the Ontario respondent indicates that even the idea of all-day, five days a week programming does not necessarily reflect the preferences of some older adults with DD. The implication is that many who would choose to take mornings or full days off when they are fatigued or feeling ill are nonetheless encouraged to attend day programs because there is often insufficient staff to monitor them if they would rather stay home to rest instead. This is consistent with the general theme of the first quotation, in which the respondent claims that the current model of services is catered more towards younger persons with DD, resulting in older adults with DD ‘falling through the cracks’ by not receiving the same quality of care.

This emphasis on the failure of the overarching model of care to account for the specific needs of older adults with DD as service users has long-persisted in the literature (Wolfensberger 2000, Walker and Walker 1998). Specifically, the phenomenon of day program models gearing services towards younger age groups has been frequently identified in research on the disability services sector (Sparks 2000; Bigby 2010; Doka and Lavin 2003). As such, there is preliminary evidence of the ‘siloized’ nature of developmental supports in both provinces, where support staff are operating within a service landscape that is tailored more to disability rather than to needs resulting from aging. However, there is also evidence that many older adults with DD may choose to remain in the disability services ‘silo’ because the community-based model allows them to ‘age in place’ and remain more engaged in the community than similar services in the ‘aging’ services silo (Ellison et al. 2011). To better situate the community-based disability services model relative to the operant care models in other residential settings, the next section will review evidence provided by support workers with experience in both settings.

In summary, the evidence in this section provides support for the notion that disability services in Québec and Ontario are oriented more towards younger users. Indeed, in some cases this occurs out of necessity, as strategies such as early interventions in ABA for children on the autism spectrum can be crucial to establishing core capacities that will improve outcomes throughout the life course. Nonetheless, the broad orientation towards younger users in the disability services sector has troubling implications. First, staff frequently expressed anxiety about being unprepared for declines in health and functional autonomy as a result of aging. For the respondents in the sample, this anxiety was compounded by supporting clients with limited or no verbal communication skills. Older adults with DD who have difficulty disclosing symptoms are not only at risk of rapid health deterioration, but also of maladaptive behaviours, which can complicate social inclusion (Ouellette-Kuntz 2005, 117). Second, recreational supports, such as day program services, which are critical to promoting social inclusion through community engagement and participation, are dominated within the disability services sector by a model of care that is oriented towards younger users. This puts older adults with DD in a disadvantaged position relative to younger users in the developmental services landscape, and thus provides incentive to compare this model of care to others.

5.3 Community-Based Disability Services in relation to Other Care Settings

Nursing Homes

Several of the staff interviewed had experience providing support services to individuals in aging services (nursing homes) and in the previous custodial care model of developmental supports (residential institutions). Three of the ten respondents reported prior experience working in nursing homes, which gave them unique insight on the types of aging services that are available to the broader public outside of the developmental services system. When comparing disability supports to nursing home supports, one respondent indicated that the residential and recreational support offered by developmental services is superior in numerous key domains:

> "I have worked in a nursing home before I came to (agency)… and it's just terrible. I think the guys here have a better quality of living, they have more resources here, it's a more friendly environment, they have things to do." (ON1)

This quote contrasts with those provided in the previous section, where support workers negatively appraised recreational supports in the developmental services model for forcing older adults into being overly active. Here, the respondent cites the availability of resources and opportunities for activity as a benefit of developmental services when compared to nursing homes.

Staffing ratios also emerged as an area where the developmental services system has an advantage. In moving away from the institutional model of services, community-based developmental services have emphasized smaller staffing ratios that are designed to promote greater flexibility to meet individual needs. Another Ontario respondent highlighted differences in the general model of care implemented in both settings, where staffing resources were much scarcer in the nursing home setting:

> "And I liked the community-based setting better than the nursing home. One of my main reasons is, I found that when I was doing the training part in the nursing home, I found the ratio of the staff to the individuals was a back-breaking piece." (ON2)

Here the respondent indicates that their prior experience in the nursing home was more physically demanding than their experience in a group home. While problems of understaffing were also reported by respondents when discussing the current developmental services models in both provinces, this quote suggests that understaffing is more pronounced in the nursing home setting. Nonetheless, given the potential for greater support needs among older adults with DD compared to those without DD, it is problematic to directly compare the staffing models used in these two environments. However, comparing individual work experiences within these two environments through institutional ethnography reveals how these experiences are 'socially organized', and can thus clarify some of the identity constructions that underlies this organization (Campbell 2000). In this case, the evidence suggests that nursing homes have insufficient resources and staffing to support the diverse needs of older adults with DD. As such, the services offered by the disability services 'silo' appear to be better prepared to meet the needs of this population. Further analysis is enabled by comparing respondents' experiences supporting this same population in the previously dominant custodial model, which is typified by residential institutions.

Residential Institutions

While only one of the respondents had prior experience working in a residential institution, eight out of the ten respondents reported that older adults for whom they are the primary support worker had once resided in them. The negative conditions endured in these settings were reported to have had pronounced impacts on the behaviours of former residents, thus changing their support needs.

> "Some behaviours – like survival of the fittest. If you put food in front of them, (they) wants to eat as fast as possible, because otherwise someone will grab it – so trying to slow them down. 'It is ok, it is your lunch, nobody will take it away from you'" (ON3)

Here the respondent identifies the impact of living in residential institutions on the eating habits of an older adult with DD whom they support. It is interesting to note that the respondent observed an impact not only on the behaviours (in this case eating habits), but also on the attitudes that institutional survivors have towards fellow residents (in this case the fear that if they do not eat quickly someone will take their food). This supports evidence from the academic literature that the traumas endured during extended stays in residential institutions or psychiatric hospitals have distinctive impacts on individuals, which then influence the nature of corresponding disability supports (Barken 2013; Malacrida 2015). One respondent in particular provided compelling evidence from their experience that individual traumas left over from internment in residential institutions can act to significantly limit the potential for person-centred approaches given the routinized denial of autonomy in decision-making that was common in these settings:

> "So those clients went into a place where it was a unit, they were living in a unit, 12 people all the time with no or little choices, life choices. Like they don't have a choice for who they live with, what they're going to eat, what time they are going to eat, are they going to take a bath or shower, what they are going to wear, who is washing – to a more open, more choices, being allowed to say 'I don't like this food may I have something else?', 'I would like to have a bath not a shower', 'I would like to wear this', 'I would like to take a walk to the park', even if you are not verbal you are able to, as you are working with a person you are able to know what she likes, and what she doesn't like, and so on." (QC1)

Given that institutionalization has been associated with social isolation, and that the community-based services model exists to advance social inclusion, the transition between settings has been seen to present significant obstacles to support staff, particularly when supporting individuals with 'challenging behaviours' (Lemay 2009). Indeed, residential institutions for people with DD were designed in such a way that "even the smallest details in the architecture spoke to assumptions about the dangerous nature of those to be confined behind its walls" (Abbas and Voronka 2014, 123). In this way, social constructions of sub-humanity and deviance were built into the physical structures of residential institutions, acting to reinforce the processes of exclusion that these buildings represented.

While the residue of social constructions based around exclusion can be seen to challenge the support work mandate of 'rehabilitation' with the end goal of social integration, they are not insurmountable. As evidence of this point, two respondents in the Québec sample indicated that they had seen quick and dramatic improvements in targeting challenging behaviours among survivors of residential institutions who had transitioned to community-based residences:

> “I had a client who was living in one of the psychiatric hospitals – (they were) living there for two years, and the way I saw (their) personality and (their) general emotional health just evolve once (they were) placed in a group home, and it was more of that family feeling, family aspect. Being able to go to the movies and go to the mall, and like, go to restaurants and what not. I mean that is a need for anyone. You need to have that. It is quality of life. So an institution: those were, that is the past.” (QC5)

> “I will say that in my personal experience I saw half of the behaviours go away within the first few months by changing the setting. So it was a big improvement. There’s also the way things were in the 80’s, 90’s and even before, the traumas that those people suffered that we don’t know very much of them because they are not allowed to – they are not able to express them, which comes with an institutional setting.” (QC1)

These testimonials provide evidence that supports the already popular assumption that the community-based support model provides tremendous advantages in key functions of social inclusion over the custodial care model. The first quote emphasizes the advantages in the areas of community visibility and participation, stressing that these are fundamental ‘needs’. Of particular interest is the emphasis the respondent places on the ‘family feeling’ of the group home, which is a stark contrast to the isolation experienced by institutional residents, many of whom were separated from their families at very young ages. Similarly, the second quote expresses that the isolation of the institutional setting served to deny institutional survivors the potential to give voice to their trauma, with the implication that the community-based setting both allows expression, and does not inflict this type of trauma.

However, despite referring to community participation and expression, which are key components of popular conceptions of social inclusion (discussed in the next section), the support workers in this case do not explicitly refer to these components as social inclusion outcomes. Moreover, while it is apparent that the community-based model provides advantages in promoting social inclusion, the role of support workers in this pursuit remains unclear. While this section has identified some general ways that the institutional model created and reinforced social exclusion, it is necessary to move further to establish how the community-based model promotes inclusion, as a means to understand the role that intervening factors such as persistent exclusionary constructions of older adults with DD interfere with this potential. Therefore, in order to provide greater clarity as to how social constructions of older adulthood and DD affect support work practice, this thesis will now address how support workers define and operationalize 'social inclusion' for this population.

5.4 Support Workers' Definitions of Social Inclusion for Older Adults with DD

In order to develop an understanding of how support workers define and operationalize 'social inclusion', I first asked each respondent to define the concept. Later in the interview, I asked them to provide an example of a social inclusion goal that they had worked into support planning for an older adult with DD. This was done, in part, to address whether there were any differences between how social inclusion is defined and operationalized by public policies, developmental agencies and support workers themselves. To establish a baseline, I turned to the most prominent existing definition of social inclusion that is specifically applied to developmental disability supports, which is found within the Schalock model of quality of life (Schalock 1990; Schalock et al. 2002; Schalock 2004; Wang et al. 2010). The Schalock model identifies 'social inclusion' as one of eight consistently recognized quality of life domains.

Furthermore, Schalock identifies three primary indicators for measuring social inclusion as personal well-being outcomes for individualized supports provided to persons with disabilities (Schalock 2004, 207):

i) community integration and participation
ii) community roles (contributor, volunteer)
iii) social supports (support network, services)

Interestingly, the social inclusion definitions provided by respondents almost entirely corresponded to the first indicator 'community integration and participation'. However, when they were asked to provide examples of social inclusion goals, and as they went into greater depth at other points during the interviews, they presented examples that correspond to the second and third domains. This thesis will examine findings from the interview data related to defining and operationalizing social inclusion by systematically working through each of the three indicators of social inclusion proposed by the Schalock model, beginning with the first: community integration and participation.

i) Community Integration and Participation

When asked to define social inclusion, 8 out of 9 respondents provided definitions that were thematically closest to the community integration and participation indicator[13]. In one sense, it is intuitive that this indicator would most closely align with support workers' definitions, because it has the broadest application of the three indicators in the social inclusion domain of the Schalock model. To fall under the thematic orientation of 'community integration and participation', a respondent's definition merely needed to make mention of promoting some

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[13] One of the ten respondents did not provide a social inclusion definition

form of community activity that an older adult with DD could participate in[14] (Schalock et al. 2008, 184). This is noteworthy given the emphasis that this indicator places on ‘activity’ in the promotion of social inclusion, particularly in light of the anxiety expressed by respondents about the energy levels of the older adults as support recipients. As the following quotations demonstrate, respondents tended to emphasize the capacity for activity and engagement among people they supported when providing definitions of social inclusion:

> “Bringing the guys into the community, and really showing the community that the individuals with developmental disabilities are as part of the community as people who do not have developmental disabilities are with one another. So you and I are part of the community as much as myself and an individual with a developmental disability.” (ON4)

> “I think social inclusion is really, you know, moving away from all of the institutionalization, integrating them into the community, whether it be working, or you know if it’s a day centre in the community, or just community outings, you know, doing leisure-type activities in the community, not being shunned away at home just because you have a disability. So it is really just being fully included using all of the resources that are offered in the community.” (QC5)

In both of these definitions there is an emphasis on the active process of working against the barriers of social inclusion through enabling community participation. In this way the respondents are defining social inclusion while also describing a way to promote it. The second quotation specifically ascribes value to activity, where more frequent and active engagement with the community is evidence of greater social inclusion. This is in keeping with the way that

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[14] To measure variation of social inclusion with this indicator, Schalock et al. (2008) suggest that researchers directly observe the frequency with which an individual is involved in community activities (p.184)

the ‘community integration and participation’ indicator is defined in the Schalock model, where more frequent activity in the community is sufficient to more social inclusion. It is also consistent with popular concepts from literature on older adulthood, specifically the notion of ‘successful aging’, which emphasizes ‘engagement with life’ as a key domain of success in old age, and productive activity as a key indicator of this engagement (Rowe and Kahn 1997, 438). In this way, the preponderance of participation-based definitions may reflect an inherent devaluation of the unique needs of older adults that I have previously identified in the disability ‘silo’ of services.

As such, the preponderance of responses forwarding a ‘participation’ definition of social inclusion suggest that this is the most viable and appropriate application of developmental services from the perspective of support workers. What is most problematic about the participation-based definitions is that they do not explicitly defer to the agency of the service user in determining both the frequency and the precise nature of the community participation that is to define *their* social inclusion. Moreover, definitions that normalize the frequency and type of individual action may inherently limit the social inclusion outcomes that are available to people with multiple or more pervasive functional limitations, specifically older adults. These implications will be further examined at the end of this chapter, however they are important to bear in mind when relating definitions that are oriented towards ‘community integration and participation’ to other definitions and applications of social inclusion by support workers.

ii) Community Roles

Only one respondent specifically articulated a community role when providing their definition of social inclusion. It is noteworthy that even this articulation of a community role was seated within a definition that was more closely aligned with the participation domain of the Schalock model:

> “I see my individuals just like any other taxpayer in the community, right? Privy to going to the grocery store, going to the doctor’s office like anybody else, going banking, going to the theatre or going to a place of religious, whatever, inclusion of their choice” (ON3)

As is evident in the quote, ‘community roles’ are employed in this social inclusion definition as a means of justifying broader participation, therefore signalling closer adherence to the first indicator of social inclusion identified in the Schalock model. In this sense, the community role of ‘taxpayer’ is used by the respondent to defend the freedom of supported individuals to participate by gaining equal access to specific public places. However, beyond justifying participation, this usage is also in keeping with one application of social inclusion within the concept of quality of life specified by Schalock et al. (2002), which is to enable community roles as ‘contributors’ or ‘volunteers’ by promoting integrated environments (463). Here the barriers to inclusion are broader social attitudes, which are seen to act against the performance of these roles by people with DD. In this case the specific constructions of difference and devaluation are acted against by assuming roles that are valued by society.

This is consistent with Wolfensberger's (1983; 2000) ‘social role valorization’ approach, which is an emancipatory action schema for people with DD that has evolved out of the ‘normalization’ paradigm to promote the attainment of valued social roles as a means of challenging exclusionary constructions. In this approach, people with DD are devalued by existing outside of social norms; therefore, by demonstrating competence in the *normal* performance of accepted social roles, they can destabilize the constructions of incompetence and difference that are at the root of exclusion. Indeed, ‘social role valorization’ has become deeply intertwined with the fundamental principles of the community-based model with respect to promoting social inclusion through support work practice. This is evidenced by the ‘new’ definition of social inclusion (participation sociale) forwarded by the Office des personnes handicapées du Québec (OPHQ), which emphasizes that the exercise of ‘social roles’ (rôles sociaux) will be key outcomes in a more person-centred approach to disability services in the province moving forward (OPHQ 2009, 12).

Despite the prominence of ‘social role valorization’ in policy definitions of social inclusion in the era of deinstitutionalization, this concept has been critiqued both for structurally reinforcing the dependence of older adults with DD by creating a role for support workers in promoting social roles (Walker and Walker 1998) and for underspecifying the full range of factors that maintain social exclusion, including the intervention of professionalized authority in determining the social needs of supported individuals (Barnes and Mercer 2010). Interestingly, this echoes the ‘structured dependency’ critique that emerged in the politics of aging literature to identify the web of social and economic factors that act to limit the social roles available to older adults by creating and reinforcing their dependency (Townshend 1981). These same factors have been identified in the shift from institutional to community-based services for people with DD (Oliver and Barnes 2012,137). In this light, it is possible that when support workers actively work to help older adults with DD to pursue ‘normal’ social roles, the mere act of supporting these individuals in public may reinforce their dependence in the eyes of the broader community with whom they are interacting. Given that the support workers in the sample were very sensitive to community perception of the people they supported, this might explain why support workers were less likely to include ‘social roles’ in their social inclusion definitions. Chapter 6 presents a more thorough account of the social barriers encountered by support workers through community interactions with older adults with DD.

In addition to social barriers, physical environmental barriers can also act to impede the social inclusion of people with DD, particularly older adults. To this end, another way to promote integrated environments and thus, in accordance with the Schalock model, allow older adults with DD to assume functional roles in the community is through integrated environments. The implication is that, beyond social barriers, there are a number of interrelated factors that affect each individual's 'adaptive behaviour': a fundamental component of their broadly constructed 'competence' (Schalock 2004). This is reflected in the sentiments of one Québec respondent, who emphasized the importance of adapted environments when asked to define and operationalize social inclusion for older adults with DD:

> "Well I would like to see more places that are adapted to their needs, their aging needs. And more flexible schedules. I don't necessarily think that everybody who is over a certain age should be going five days a week to programming because we think 'oh it's fun, they like it'. I would like to see a more flexible schedule. And I don't know if everyone should be working on specific clinical objectives and needs throughout their whole lifespan – we don't." (QC2)

In this quote the respondent stresses the importance of adapting physical spaces and planning processes to match the specific needs of older adults, specifically within the field of developmental supports. Due to the higher prevalence of physical disabilities among older adults with DD (see section 5.1), they are more likely to require adapted environments. Therefore, the lack of accommodations in the pursuit of community roles through flexible planning and accessible environments suggests again that support services for older adults with DD are firmly seated within the disability services silo, rather than the aging services silo, which is consistent with research findings from other countries (Putnam 2014, Bigby 2010). Moreover, the emphasis on clinical objectives addressed by QC2 suggests that existing models that are designed to promote roles as ‘students’ supported by ‘educators’ may be catered to younger developmental service users. This theme is further explored in the next subsection, which addresses the availability of appropriate social supports as the final indicator of social inclusion.

iii) Social Supports

The Schalock model defines social supports as a means to achieve social inclusion outcomes. To this end they are theorized to include the full range of developmental services and include the entire support network, which extends beyond just the primary support worker (Schalock 2004, 207). The support network includes anyone providing any kind of support to an individual, including family, social workers, therapists, educators, medical professionals and other support workers. Despite holding only one position in the support network, primary support workers are expert informants on this broadly defined category of social supports, due to the interaction with other supports that is necessitated by their role in coordinating services for their clients. To this end, they can situate their specific role within the entire web of developmental services designed to promote social inclusion for older adults with DD.

Because of their unique roles in coordinating supports, primary support workers have valuable insights into the role of support workers in the broader project of promoting social inclusion for older adults with DD. In assessing this role, it is necessary to acknowledge that there is variation on a client-by-client basis in terms of what types of supports are needed, and who in the support network is best situated to meet these needs. From the interview data it is clear that respondents had different strategies, plans and procedures depending on the needs of the specific individual they supported, thus demonstrating that some degree of person-centred care is occurring in both provinces. However, to provide greater depth, the interview respondents were asked to describe the role that they play on a case-by-case basis as support workers in promoting social inclusion outcomes. Given the emphasis that support workers placed on community participation in their definitions of social inclusion, it is not surprising that the roles that they described had mostly to do with facilitating participation by supporting their clients in overcoming their individual challenges. This is evident in the following quote from a Québec support worker:

> "Or sometimes, some of my clients, they speak but they have slurred speech, and it's harder for somebody to understand them. I'm letting them talk, whatever, and I see that the person does not understand. I just repeat, or ask the person to repeat and then I say it after, to give the person occasion to still use (their) verbal skills, but also to make sure that (they are) understood." (QC1)

In this quote the role of the support worker as a mediator is represented. Here the support staff indicates that rather than speaking for the supported individual, they instead attempt to provide an authentic replication of typical conversation by asking the supported individual to repeat themselves when they are not understood, or repeating for them after they have spoken. A strikingly similar sentiment was also expressed by an Ontario staff:

> "I'm really there to help with when this person runs into a stumbling block. When they are trying to express something, or maybe they are nervous to talk to somebody, or the person is not understanding them" (ON1)

These quotes speak to how important familiarity and prolonged experience supporting specific individuals are to support work practice. Through familiarity, the support worker is able to understand and translate the ‘slurred speech’ of the person that they support, which is difficult to understand for the person who has, presumably, just met them. In this way, the support worker has the potential to assist in confronting social constructions of DD and aging that can act to impede social inclusion, specifically where the older adult with DD is not understood in their interactions with other members of the public. Yet, importantly, given the tremendous power wielded by the support worker as a mediator, where they can essentially interpret for the person they support based on their experience with that person, this mediation must itself be both unencumbered by stigmatizing social constructions, and consistent with the authentic wishes of the supported individual.

Throughout the sample, particularly among the longer tenured staff, the importance of experience with service users was emphasized with respect to promoting the authentic interests of clients. This was often contrasted with anxiety about staffing turnover, or the reliance on temporary staff from outside of the developmental agency, whose transient roles often do not allow them to forge meaningful relationships with service users, based on a lack of continuous experience supporting them. Experience in the support relationship has also been identified in the academic literature as being of vital importance to support work practice, specifically when supporting individuals with limited communication skills. In fact, it has been noted that the model of supported decision-making, as opposed to substitute decision-making, for people with DD originated in the Ontario developmental services system (Kelly 2016, 153). This model, which respects the capability of people with DD to make decisions that concern their well-being as a human right, was apparent in one Ontario respondent’s appraisal of the importance of experience to support work practice:

> “I would say knowledge is power. I know them, so I might know what ticks them off and what makes them happy. I might know, you know, not to play this type of music because it might set a behaviour for somebody, or this particular individual likes the soft music. So just having that wealth of information is a strength for me to work with someone.” (ON3)

This quote speaks not only to the importance of the support worker’s knowledge of the person they support, but also to the importance of their role in mitigating or intercepting stimuli that can trigger adverse behavioural reactions, which can be very distressing for persons with developmental disabilities. This has been reflected in studies that have addressed developmental service users’ evaluations of barriers to social inclusion, with ‘negative community attitudes’ and ‘staff not acting in their best interests’ as commonly reported barriers (Abbott and McConkey 2006; Maes 2003). However, by including the perspectives of support workers, the picture becomes more complete.

It is clear from all three subdomains of social inclusion that have structured this section that there are distinctive, overarching trends in how support workers in both provinces define social inclusion. A recurring finding is that support workers most commonly define social inclusion as ‘community integration and participation’, thereby conforming closest to the first domain of the Schalock model. Indeed, the evidence from this small sample suggests that this is the most important domain of social inclusion to support workers in Québec and Ontario. This could be related to the prominent place that ‘participation’ is given in public policy on social inclusion, including Québec's current 'social participation' concept (OPHQ 2009) and Ontario's Social Inclusion Act (2008), where 'community participation services and supports' is the terminology used for applications targeting social inclusion outcomes. However, as with the 'institutional language' observed in section 5.1, while uncovering the influence of 'relations of ruling' in 'textual relations' may suggest that policies frame work practices, it is necessary to analyze the practices themselves in order to understand the extent of their relationship to overarching policies. To this end, the next section will move beyond definitions to examine how social inclusion is operationalized in the planning and practice of promoting social inclusion in the field.

5.5 Social Inclusion Operationalized in Yearly Planning

In the interview data there are striking differences between how respondents defined social inclusion and how they operationalized it in the practice of support work. While definitions of social inclusion tended to emphasize community participation, the examples that respondents provided of job tasks to promote social inclusion often did not thematically conform to any of the common indicators of social inclusion. To explore this incongruence between definition and operationalization, this section will focus specifically on social inclusion goals that support workers created in the process of yearly planning for older adults with DD. To address the relationship between definition and operationalization, this section will follow the guidelines set forth for support work applications of quality of life concepts by an expert panel on measuring outcomes for people with DD (Schalock et al. 2002). Importantly, these guidelines provide a framework for connecting definitions of social inclusion (specifically the three indicators identified in the Schalock model) with applications that are suitable for developmental services structures that seek to promote social inclusion outcomes (see Table 3). Quality of life concepts are increasingly being applied to individualized planning objectives, given their capacity for producing measurable and replicable outcomes for support work applications (Schalock et al. 2008, 185). By referring these broad categories of application to the domains of social inclusion to which they are connected, it becomes possible to assess whether similar connections are being made by support workers and the older adults with DD who they support.

Table 3. Support Work Applications of Schalock's Social Inclusion Domains

Social Inclusion Domain (Schalock 2000; 2004)		**Support Work Application** (Schalock et al. 2002)
i) Community Integration and Participation	→	Participation (e.g. attending community event)
ii) Community Roles (contributor, volunteer)	→	Integrated Environments (e.g. vocational support)
iii) Social Supports (support network, services)	→	Natural Supports (e.g. supported interaction with peers)

Given the emphasis on the 'community integration and participation' area in respondents' definitions of social inclusion, we should expect that the majority of social inclusion goals identified by support workers would involve promoting participation in some way. From a planning perspective, this could include any activities that encourage social membership through community activities and engagement with both disabled and non-disabled people (Maes 2003, 228). However, of the eighteen different examples of yearly goals provided by interview respondents, only two goals satisfied this very broad definition of community participation. Moreover, there were only five planning goals identified by the respondents that were oriented towards social inclusion more generally, with community roles and social supports left absent from the goal-planning altogether. Yearly planning in both provinces was oriented more towards behavioural objectives (addressing challenging behaviours and teaching social appropriateness), activities of daily living (ADLs) or instrumental activities of daily living (IADLs), and objectives aimed towards maintaining functional autonomy and health.

While this project's respondent confidentiality requirements prohibit the direct quotation of many of these goals[15], the broad thematic orientations of yearly planning goal examples provide sufficient evidence of the influence of social constructions on support work practice. To this end, Table 4 organizes the eighteen goal examples provided in the interviews by their conformity to four of the eight QOL domains that comprise the Schalock QOL supports framework (Schalock 2008, 185). However, it must be emphasized that 'social inclusion' was the only QOL indicator for which I asked respondents to provide a goal example during the interviews. That is, I did not ask support workers to provide specific examples of any of the other thematic orientations, but I did ask respondents to provide examples of social inclusion goals.

Table 4. QOL Orientations of Yearly Planning Objectives

Goal Type				
Social Inclusion	Self-determination (Behavioural)	Personal development (ADLs or IADLs)	Physical well-being (Health and maintenance)	Total
5	6	6	1	18

In light of this, it is very surprising that only five out of eighteen goals are sufficient to a broad thematic orientation of social inclusion. Moreover, two of these five goals barely met the most general thematic criteria of social inclusion, and did not provide any specific objectives related to suitable applications in accordance with the Schalock model. Both of these goals were to attend an annual outing to view specific entertainment spectacles. While, in broad terms,

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[15] Due to the small demographic presence of older adults with DD, including direct quotations of yearly planning goals would jeopardize the confidentiality of both respondents and the older adults with DD who they support.

attending an entertainment spectacle that one would otherwise not attend could suffice as social participation, it does not explicitly entail community interaction. That is, it is plausible that a supported individual could attend an event with little or no community interaction. Furthermore, these outcomes were only delivered once a year, making them as infrequent as possible for a yearly planning objective. Hypothetical examples of higher frequency goals include volunteering once a week for a local charity, or attending an educational program three times per week, in both cases producing more frequent and more promising opportunities for community interaction and participation.

Drawing from the interview data, the most likely explanations for the lack of social inclusion outcomes in yearly planning is that support workers regard them as less important or less attainable than other types of goals. Given that yearly planning in both provinces involves focusing on one or two isolated objectives, it follows that the thematic orientations of stated objectives will accord to areas of perceived importance in support work practice. Although the sample size of this project is too small to draw generalizable conclusions about the nature of goal planning in either province, some of the interview responses suggest that prioritization is taking place:

> "(This individual) has like exhibitionist types of behaviours. So teaching all of that, like about boundaries, and what to be asking strangers" (QC5)

In this example, a Québec respondent discusses a behavioural goal that was prioritized in yearly planning. Here the behavioural objective involves learning socially appropriate behaviour when in public by addressing 'exhibitionist' tendencies, specifically exposing one's body to strangers. It makes sense that this behavioural goal would be assigned high priority, because this type of behaviour – which could be criminal, in addition to socially inappropriate – presents a significant obstacle to social inclusion more generally. Therefore, prior to pursuing social inclusion objectives, particularly where interaction with the broader community is expected, this type of behaviour would require significant intervention.

Yet community interaction is not always required for a goal to be considered a social inclusion objective. Promoting interaction and participation in settings that are exclusive to people with DD can also occur. This is evidenced in the following quote:

> "One of the individuals… (their) goal was just to make new relationships here (at recreational program)." (ON1)

In this case, the yearly goal focuses on expanding interaction with peers in a supported setting. Here priority is given to social interactions occurring in a controlled environment, rather than in the broader community. While this goal was categorized as thematically oriented towards social inclusion, it can also be thematically linked to behavioural support because it is implied that promoting social interaction in this supported environment is educational and socially appropriate. However, the case for social inclusion is bolstered if we consider how the Schalock model is extended to the application of social supports. Table 3 lists the support services application of social supports as 'natural supports', which are defined as relationships existing outside of service provision that act to enable integration and participation (Schalock 2004, 207). By encouraging the development of new friendships in a day program setting, the support worker is also encouraging the development of new natural supports, which contribute to social inclusion as measured by the social supports indicator. Therefore, while this specific goal does not explicitly present any opportunity to challenge exclusionary attitudes in the broader community, by building relationships among older adults with DD it adds to the individual's social supports, and thus suffices as a social inclusion objective.

While the yearly planning outcomes reviewed in this section meet the broadest criteria of social inclusion outcomes, they are thematically different and more general than the definitions that respondents provided. Support workers' definitions emphasize community integration and participation, and are more in line with how current policy documents in Ontario and Québec define social inclusion, while their examples reveal that other objectives are given higher priority. It bears repeating that the examples quoted in this section were part of only five out of eighteen goals that met even the broadest criteria of social inclusion, and that these examples were provided when respondents were asked about social inclusion objectives. So why, then is there this apparent lack of emphasis on social inclusion in yearly planning? This chapter has presented numerous interrelated explanations, which I will summarize briefly.

The first explanation that this chapter has discussed is that support workers, and the broader support network, are assigning greater priority to other goal types rather than social inclusion goals. In this light, one possible reason for this lack of emphasis on social inclusion planning may be that these objectives are too resource-intensive. In addition to responding to each service user's areas of perceived need, yearly objectives also must be feasible given quality and quantity of available supports. Therefore, because social inclusion outcomes require greater resource inputs (see Section 5.4) and better quality of staffing (see Section 5.3) than the system currently provides, this could explain why the disjuncture between definition and operationalization of social inclusion goals exists.

Another explanation suggested by the findings presented in this chapter is that support workers are less likely to target social inclusion outcomes with older adults than younger adults, owing in part to the ‘siloized’ nature of developmental services in both provinces. This is consistent with a phenomenon identified in the literature, where support workers associate yearly planning with skill development, and stereotype older adults as unable to develop new skills, thus causing them to devalue implementing meaningful support objectives for older adults with DD (Bigby 2004, 57). This explains why existing programs and practices for promoting social inclusion are often geared more towards younger service users, given that they are the primary targets of services and funding. Moreover, this explains why support workers for older adults are more likely to seek yearly objectives that target declines in health and functionality related to old age, because i) the broader disability services landscape is not designed to identify and provide rehabilitation to counter these declines, and ii) without immediate action functional declines can accelerate quickly. These problems were magnified in support workers’ accounts of working with older adults with DD with limited capacity for verbal communication. That is, the perceived unreliability of service users to identify important health declines – echoing a recurrent and dehumanizing socially construction of people with DD (Rapley 2004, 29) – compounds the fears of support workers that these declines will go unobserved. This was evidenced by the anxiety that respondents consistently reported when discussing the importance of monitoring for signs of age-related declines.

Finally, the findings presented in this chapter have raised the possibility that social barriers that are encountered through interactions with the broader community may significantly limit the potential of support workers to promote inclusion-related objectives, specifically those related to participation and community roles. Given that support workers’ definitions of social inclusion were most frequently oriented towards ‘community integration and participation’, difficulty in traversing exclusionary social attitudes observed in the community at large might explain why social inclusion outcomes so rarely made mention of participation. This possibility is explored further in the next chapter.

5.6 Conclusion

By focusing on the roles of primary support workers, and situating them within the community-based model which frames developmental services in Ontario and Québec, this chapter has emphasized that social barriers faced by older adults with DD appear to be more pervasive than those faced by younger developmental services users. This is evident in the findings related to the transition of institutional survivors into community-residences and group homes. In support of the community-based model, respondents identified rapid decreases in challenging behaviours, and improvements in emotional health following the transition out of the social isolation of residential institutions, as successes of the current model. However, they also explained that institutional survivors deal with deep and often incommunicable trauma that causes socially isolationist behaviours, such as the hoarding of food for fear that it will be taken. Given that deinstitutionalization has made this the last cohort of institutional survivors, and given the general orientation towards younger developmental service users, it is not surprising that respondents did not identify any initiatives at either the developmental agency or provincial level focusing specifically on promoting social inclusion for this segment of older adults with DD. This conforms to existing critiques of the failure of the community-based model to promote adaptation to the new care environment during the transition from residential institutions (Lemay 2009). In this way, this specific cohort of older adults with DD appears uniquely underserved, or *excluded,* in the current context of developmental services.

Deinstitutionalization and dramatic increases in life expectancy have made older adults with DD a visible ‘new’ population within the developmental services landscape. This is reflected by the lack of public policies in Québec and Ontario specifically targeting *their* inclusion. The evidence presented here suggests that existing policy frameworks, and the multilevel structures that implement them, are not presently constructed to deliver social inclusion outcomes for this ‘new’ population. Support workers in both provinces provide detailed definitions of social inclusion, which are consistent with the principles emphasized by public policy (participation in particular), but identify significant obstacles to promoting outcomes through practices that operationalize these definitions. These obstacles significantly intervene with the performance of policy outcomes, and thus dilute the expected divergence owing to jurisdictional design proposed by the MLG framework. The responsiveness advantages of the Quebec Type II system demonstrated in Chapter 4, are mitigated by the low priority that support workers assign to social inclusion outcomes in relation to other outcome types that they deem more urgent in a resource-scarce environment. Similarly, the coordination advantages that were attributed to Ontario’s Type I system are attached to a large system architecture that consistently prioritizes services for younger users. This is reflected in scheduling and staffing models that are unsuitable to the specific needs of older adults, and thus decreases the potential for promoting, or even planning social inclusion outcomes.

To explain the broader fissure between policy and practice, this chapter has investigated the biases that are apparent in the orientation of developmental services towards younger service users, in addition to the problems of structural capacity identified in Chapter 4; but this thesis has not yet turned attention to the wider public attitudes that are instrumental to social inclusion. The next chapter analyzes support workers’ appraisals of these attitudes as a means of completing the conceptual model set forth by this thesis. This enables a concluding discussion of the implications of system design on the specific, yet complex, tasks of planning and implementing social inclusion outcomes for older adults with DD.

CHAPTER 6. CONCLUSION

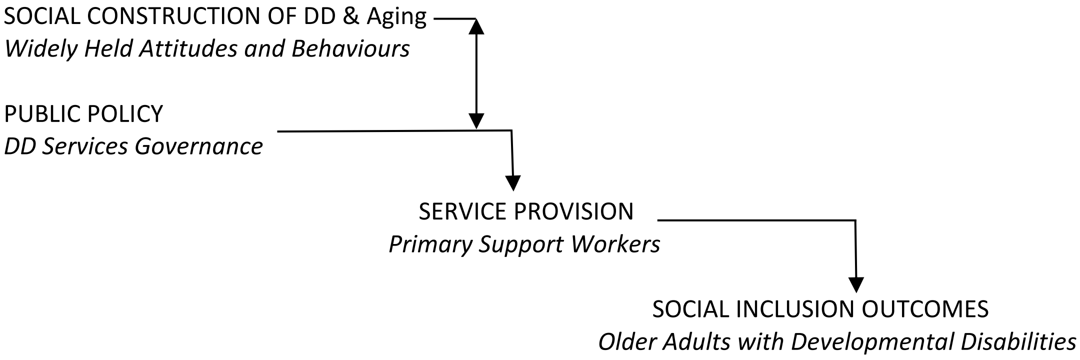
6.1 Introduction

The findings presented in the previous two chapters suggest that two broad categories of influence 'public policies governing developmental services' and 'social constructions of aging and DD' are exerting opposing influences on support staff in the provision of services to enable social inclusion. While public policy in both provinces has facilitated a shift towards the community-based model, which promotes person-centred care strategies designed to meet the objectives of promoting social inclusion, resilient social constructions of disability and aging act to stabilize social barriers that exist to maintain marginalization. Specifically, the 'siloized' disability orientation of developmental services for older adults acts to deny or de-emphasize services and supports that target social exclusion based on the social construction of older adulthood. In this way, existing programs and services designed to promote social inclusion have demonstrated a bias towards younger service users. In this concluding chapter, this thesis gives a more thorough treatment to the question of why this bias exists in both Québec and Ontario's developmental services structures, by examining the influence of broader social attitudes towards aging, DD, and the intersection of these identity categories through support workers' observations of the interaction between older adults with DD and the general population.

It would seem obvious that social constructions of aging and disability among support workers who advocate for older adults with DD should be less exclusionary than in the general population. After all, according to the social model of disability, it is these broader exclusionary attitudes that act to disable people, by constructing expectations and imposing activity limitations that are disconnected from the precise condition of impairment (Barnes and Mercer 2010). By extending the social model, disability scholars claim that discriminatory attitudes based on the social construction of disability act to manufacture the dependency that is the basis of community services for people with disability (Oliver and Barnes 2012, 137). To test this explanation, and thus test for the presence of exclusionary constructions in the 'microsystem' of individual level outcomes, this chapter will explore support workers' accounts of their interaction with the broader community through their experiences supporting older adults with DD.

By examining community reactions to the participation of older adults with DD, the findings presented in the next section help to connect the separate parts that comprise the conceptual model set forth by this project. Support workers in both provinces consistently emphasized increased visibility as the best way to counteract exclusionary social attitudes, and therefore the most important strategy for promoting social inclusion. As such, the analysis presented in this chapter, in concert with the evidence from previous chapters, addresses the final objective set forth by this project:

<u>Objective 3:</u> *To assess the effects of disability services governance structures on the promotion of social inclusion outcomes for older adults with DD from the perspectives of the support workers in charge of planning and implementing these objectives.*



The definition of disability as an 'activity limitation', which originates from the social model of disability, is now enshrined in important policy documents at the supranational (UNCRPD), national (*In Unison)*, and subnational levels (Ontario's 'Social Inclusion Act' and Québec's 'Disability Integration Act') levels. Up to this point, this analysis has treated policy structures and social constructions as separated entities. However, as this thesis has made clear from the outset, we must address the interrelationship of these influences in order to situate support work practice in the context of the 'relations of ruling' that frame it. In light of support workers' claims that the most promising avenue to promote inclusion for older adults with DD is to increase visibility to challenge stigma and discrimination, the penultimate section of this chapter shifts to address the implications of this finding for future policy and governance in developmental services. This discussion of policy implications is presented in the context of summarizing key findings, and is proceeded by a short section concluding the thesis.

6.2 Broader Constructions of Aging and DD

Towards the end of each interview, respondents were asked to identify the most significant barrier to promoting social inclusion outcomes for the older adults with DD who they support. The obstacles identified in their responses are presented in Table 5, and organized in accordance with where they occur. The first two columns correspond to the findings identified in Chapter 4 (Policy and Governance Structures) and Chapter 5 (Developmental Agency & Support Work Practice) respectively. The third column, however, deals with broader social attitudes, which complicate this analysis by existing outside of the MLG structures and localized support work practices that it compares. Four out of the ten support workers identified obstacles related to these broader public attitudes as the main barrier to social inclusion for older adults with DD. This is in line with the academic literature, which suggests that addressing broader attitudinal obstacles to social inclusion for people with DD is the most promising avenue of future research, in order to move beyond the myopic view of individuals and support staff (Amado et al. 2013).

Table 5. Support Workers' Main Barriers to Social Inclusion for Older Adults with DD

	Policy and Governance Structures	Developmental Agency & Support Work Practice	Broader Public Attitudes that Limit Inclusion
QC1	Increased funding to improve availability of day programs and extra support staff for community outings		
QC2			Educating people to curb discriminatory social attitudes about aging with DD
QC3			Sensitizing people and public servants to promote inclusive interaction with older adults with DD.
QC4		Support work profession is overly focused on clinical objectives, to the detriment of promoting simple community participation activities	
QC5	Budget constraints lead to limited staffing and program availability causing social inclusion needs to go unmet		
ON1		Longer, or more flexible day program hours to facilitate longer community outings	
ON2		Ineffective communication and coordination of person-centred objectives between support workers	
ON3			Greater awareness of, and practices catered to, the needs of older adults among doctors and medical professionals
ON4		Rigid developmental agency rules dissuade creativity in program planning/limited requirements for planning and organizing original programming	
ON5			Changing discriminatory social attitudes with visibility through community participation
Total	2	4	4

Observing and measuring these social attitudes is a big undertaking, and is beyond the scope of this analysis. However, situating support work practice within the context of interaction with the broader public is vital to the central question of how the promotion of social inclusion outcomes differs within these two provincial structures. The support workers who identified this interaction as constrained by social barriers also claimed that promoting the visibility of older adults with DD is the way to counteract this barrier. The following quote from a Québec respondent emphasizes that while social exclusion is built on ignorance, visibility through community participation presents the opportunity to educate:

> "Educate people. That's it. Because I feel like people with intellectual disabilities are more stigmatized against than the regular aging population because everyone thinks oh they are so cute. Or when you think of a grandmother you think 'oh, the head of the family', a grandmother a grandfather. People view elderly people as a different role, a different status. But people with intellectual disabilities, they didn't have children – well most of our clients. They didn't necessarily have grandkids… Even at the hospital, the people had a certain status that is acquired with someone who is older, someone who has knowledge and you would think them wise. People don't view people with intellectual disabilities in the same way." (QC2)

This quote also implies that there is no frame of reference, or logic for inclusion. This speaks to the power of 'social role valorization' (Wolfensberger 1983; 2000), where embodying positively valued social roles normalizes the inclusion of older adults with DD (see sec. 5.4).

However, the prospect of 'normalization' is problematic for a number of reasons. First, older adults with DD represent a miniscule percentage of the population of older adults with disability, let alone the general population of older adults. Therefore, promoting visibility in the performance of valued social roles is likely to have limited reach as a strategy to change broader social attitudes. Furthermore, a vast range of diagnoses qualify as DD, and these are characterized by tremendously different behavioural and physical characteristics (see sec. 1.2). These differences are matched by divergent social attitudes and expectations, which are further divided by the intersection of older adulthood:

> "I see a difference between let's say somebody that has autism and somebody who will have trisomy. As if you are somebody with autism, they will almost automatically assume that it has to be a kid. So, when you are out with somebody that has autism and is an adult, there is a bit less comprehension on the behaviours and so on, then as if you go out with somebody who has trisomy, which is visible" (QC1)

Finally, as is evident in the above quote, individuals with DD may not immediately represent as being developmentally disabled. The respondent used the example of autism spectrum disorder, which can have less immediately recognizable signs compared to the trisomy family of DD which includes Down syndrome (Percy and Brown 2003). This tremendous diversity among such a small percentage of the population problematizes the potential for a unified approach to combatting exclusionary attitudes.

Rather than 'normalizing' the aging with DD, a more promising avenue for challenging these social constructions is by targeting the generalizations or stereotypes which they produce. This involves challenging attitudes that construct dependency (Townshend 1981; Oliver and Barnes 2012) and the individualized 'problem' of DD (Rapley 2004), to devalue disability and older adulthood. To social model theorists, disability is itself constructed by the "medium of normality" (Armer 2004, 55), which creates expectations of abnormality for deviation from dominant social values such as independence and individualism. According to the interview respondents this can take the form of expressed exclusion or even revulsion: "Some people don't feel comfortable being in the pool with us." (ON3) However, more often, it takes on a more seemingly benign, but equally as exclusionary tone, where members of the public express sympathy for older adults with DD:

> "When we did the (delivery job) to start, and he went to the door, people would be like 'Poor thing! Why (are they) doing this?' and I'm like 'well (they are) giving back to the community'." (ON2)

The above quote demonstrates how social attitudes can intervene with attempts by older adults with DD to perform valued community roles in the pursuit of social inclusion. In the respondent's account of providing on-site job support doing door-to-door deliveries, multiple people react with surprise and sympathy that the older adult with DD is working at their age. The surprise is based on the cultural expectation that they should not still be working, well past the age of the expected transition to retirement. While modern western cultural conditions have challenged the rigidity of constructions of when transitions should occur in the lifecourse, these challenges still must confront oppressive, ageist expectations (Grenier 2012, 11). Moreover, the multiple interactions described by the respondent in this quote conform to expectations from the existing literature, which states that older adults at DD are more vulnerable to ageism, particularly as it intervenes in services promoting community participation (Bigby 2004, 53).

As I have cautioned, identifying and assessing the influence of broad social attitudes is well beyond the scope of this analysis. However, as is evident in these quotations, and in the fact that nearly half the sample identified broad social attitudes as the biggest obstacle to social inclusion, the governance of developmental services for older adults with DD would be well served by incorporating strategies to counteract these exclusionary constructions, specifically with respect to promoting social inclusion outcomes. Indeed, this is integral to the discussion as this analysis now shifts to address the wider implications of this project.

6.3 Summary of Findings and Policy Implications for Developmental Services

This thesis has provided evidence that policy matters. It has done so by exploring the ways policy frames support work practice, even where this influence is latent. Moreover, it has demonstrated that jurisdictional design differently influences the processes of service provision in MLG systems through a comparison of support work practices. However, this comparison has made it apparent that both Québec and Ontario are similarly falling short of producing social inclusion outcomes. Given that the mandate of this thesis was to compare more and less centralized MLG structures in developmental services based on how they deliver specific outcomes (social inclusion) through specific methods (yearly planning), this analysis was confounded by the fact that neither system was succeeding at delivering these outcomes.

To this end, the Hooghe and Marks (2003) MLG framework fell short of the analytical task, owing to an inability to account for the full range of system factors connecting governance architectures with the outcomes that they produce. This shortcoming is in line with previous critiques of the MLG framework as a comprehensive research approach (Piattoni 2009; Rouillard and Nadeau 2013; Alcantara et al. 2016). The evidence related to the prioritization of services for younger adults with DD in the community-based developmental services model indicates that the comparison of system level architectures must account for differences in outcomes that reflect the more pervasive disadvantages imposed on intersecting identity categories. While the contrasting types of MLG systems may produce different outcomes in the aggregate, these differences may be diluted by the intervention of important social factors, which disrupt the promotion of policy outcomes among demographically small, highly marginalized segments of the population. This thesis has demonstrated that discriminatory constructions of aging and DD in the broader community, which are also reflected in the biases of service provision at the provincial and regional levels, can have this disruptive influence on social services structures.

Despite these shortcomings, the MLG conceptual framework was valuable in identifying structural factors that may be impeding the promotion of social inclusion outcomes. In Ontario, greater centralization, owing to the fewer levels in the Type I governance structure, produces yearly planning practices that give the appearance of being person-centred from the perspective of the MCSS, as with the use of first-person language in ISPs for older adults with DD. However, in practice, it was revealed that support workers are choosing yearly planning objectives themselves, and documenting these objectives from the first-person perspective of the service users. While support workers use experience and knowledge of individuals to create yearly objectives reflecting areas of perceived need, they expressed frustration at being forced to assume the perspective of the individual that they support in order to fulfil documentation requirements. Most importantly, in the area of choosing objectives for yearly planning, the Ontario structure was not effectively distributing authority and resources to ensure that support work practice matched the priorities for targeting social inclusion outcomes in yearly planning set forth by the Social Inclusion Act (2008).

This was contrasted with the area of medication administration, where stronger accountability mechanisms and mandatory training were evident in the ‘ruling relations’ described by the Ontario sample. Interestingly, in this issue area there was significantly greater oversight through ministry and developmental agency requirements. This evidence suggests that while accountability mechanisms exist in Ontario, their effectiveness is compromised by the lack of system capacity. In this light, it is understandable that priority would be given to accountability over medication administration rather than over promoting social inclusion, in a situation where limited service capacity forces this choice. As such, the location of regulatory intervention and effective accountability mechanisms demonstrates where the Ontario developmental services structure is prioritizing resource allocation.

The MLG framework was also useful in investigating the Québec structure's performance as a Type II design. In the area of yearly planning, primary support workers indicated having dramatically more latitude to create, implement, monitor and revise support objectives, as was expected owing to the theorized flexibility advantage of Type II systems in the area of responsiveness. However, in this case, the potential for promoting social inclusion outcomes for older adults with DD was constrained by limited day program availability and insufficient staffing to promote community participation through individual outings. Thus, the Québec case indicates that promoting social inclusion outcomes through yearly planning for older adults with DD is not a significant priority at the CRDITED level, given the oversight of this level over day program distribution and availability, and in providing primary supports for individuals in 'intermediate resources'. As in the Ontario case, support workers in Québec emphasized that the maintenance of functional autonomy and behavioural interventions were more common support work objectives in yearly planning practices.

While this analysis has treated the inability of the MLG conceptual framework to account for differences in structural capacity as a weakness that limits its application, the theoretical expectations stemming from the MLG typology of jurisdictional designs are useful in locating the ‘spheres of authority’ where priorities are established within the larger governance structure. By shifting attention to the way governance structures prioritize and promote specific outcomes, within a defined issue area, this analysis supports a refined application of MLG within academic research, that focuses on ‘instances’ of MLG rather than ‘systems’ (Alcantara et al. 2016). That is, within this very specific policy context, MLG is useful in explaining why these two systems differently locate the specific spheres of authority that, by deprioritizing social inclusion outcomes for older adults within the developmental services landscape, are latently authorizing the continued exclusion of this doubly marginalized population.

This thesis has clear implications should either province wish to extend its commitment to supporting social inclusion beyond broad policy statements toward the actual implementation of regulated measures. The evidence presented here suggests that current outcome planning measures are failing to address the social inclusion needs of older adults with DD as a population whose potential for inclusion is problematized by the intersection of two (or more) marginalized identity categories. Provincial governments in both provinces would be well served by investing in increasing the capacity of developmental services to target their specific needs. Respondents in this project identified greater access to day programs, and the adaptation of current day program services in both provinces to accommodate different scheduling needs, and to optimize community participation according to the different preferences of older adults with DD.

In addition, future policy should take aim at the ‘siloization’ of services and supports within the community-based model of developmental services. This could take the form of collaboration and knowledge-sharing between silos in aging and disability services, which would be consistent with Québec’s ongoing pursuit of integrated health and social services, and

Ontario's ongoing pursuit of quality assurance in the provision of person-centred care. Anxiety related to being unprepared or untrained to meet the needs of older adult clients was consistently reported by the interview sample. Moreover, scrambling to meet these needs was often cited as a major reason that services objectives were directed away from social inclusion goals, despite respondents' acknowledgement that both are areas of need. The increasing potential of people with DD to live into older adulthood will only exasperate this anxiety among support workers if greater efforts are not taken to prepare these staff to meet the health and social services challenges that accompany old age.

Finally, inclusive policy should take aim at the discriminatory attitudes that enable exclusion. In the case of older adults, sympathy/tragedy stereotypes that act to construct their dependency have been preserved by a legacy of social isolation. While financial reparations have been made to institutional survivors[16], less has been done from a policy standpoint to address the persistent attitudes that enabled their exclusion in the first place. Policies to enable greater representation of the intersection of aging and DD should explore providing funding for arts-based or participatory action research that takes aim at the misguided assumptions behind these stereotypes (see for example Raymond and Grenier 2015). Given that discriminatory stereotypes encountered by older adults with DD have many commonalities with those faced by older adults and people with disabilities more generally (Bigby 2004, 50), taking aim at these constructions by promoting the visibility of authentic representations of aging with DD would have added value for the social inclusion other groups.

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[16] In a notable recent example, the Ontario government paid over $60 million in settlements to survivors of three residential institutions following class action lawsuits. Sources:
https://www.thestar.com/news/gta/2013/12/09/premier_kathleen_wynne_two_other_party_leaders_apologize_to_huronia_survivors.html
https://www.thestar.com/news/gta/2013/12/23/ontario_settles_with_survivors_of_two_more_institutions.html

6.4 Conclusion

This thesis has employed a unique research strategy to test the question of how the distribution of authority in jurisdictional design affects the precise outcomes within those jurisdictions. By interviewing support workers, rather than managers at developmental agencies, ministry officials, or older adults with DD who use these services, an emphasis was established on the processes of planning and promoting specific outcomes. The institutional ethnography interview methodology was instrumental in allowing respondents to describe the multi-leveled web of influences that shape their work experiences, specifically in the key area of yearly planning. This served to elucidate the connections between different parts of the conceptual model, and situate spheres of authority within the disparate governance structures, in accordance with specific 'relations of ruling' (Smith 2005). This mapping of the conceptual model, with specific reference to the influence of policy tools on targeted outcomes in the areas of social inclusion was consistent with current applications of 'the Schalock model' (Shogren et al. 2015), such that there is potential for replication and expansion of this design to use actual social inclusion outcomes to measure the effectiveness of specific disability policies.

It is necessary to acknowledge the limitations of this research strategy as well. First, owing to the small size of the interview samples, these results are not conclusive or generalizable, even where there is consensus among all respondents in the sample. Nonetheless, the depth of themes explored will be instrumental to future research that aims to test whether the trends identified in this analysis occur across the developmental services systems in both provinces. Given that these interviews were conducted with support workers working in the single largest urban area in each province, future researchers should compare the responses of rural support workers, specifically polling respondents about coordination, where the advantages of the Québec system could be expected to be minimized over larger geographical jurisdictions.

Importantly, this project has not addressed the question of 'why?' these two structures have different designs. This choice was made to deliberately limit the scope of this analysis to the provision of services in the specific issue area. Addressing the historical origins of these two governance structures involves a deep engagement with the history of federalism and health and social services governance in Canada. Québec, specifically, has long existed in many ways as an outlier compared to the type of federalism present in the rest of Canada. The province's distinct national identity, along with a history of distinct forms of policy collaboration has impacted the unique architecture of MLG structures within the province by comparison to the other Canadian provinces, like Ontario, where national cultural affiliation is very weak (Haddow 2015; Contandriopoulos et al. 2004). This has resulted in a historical distaste for traditional 'layer cake' federalist power orientations, leading to the popularity of 'messier' MLG orientations in the province (Curry 2015, 65). Future researchers would also be well served in tying the governance of developmental services to broader trends in the evolution of governance in both provinces within the Canadian federal context.

Last, as this analysis has warned, both Québec and Ontario's developmental services structures are in states of transition. In Ontario, important sections of the 'Social Inclusion Act' are still being rolled out[17]; and, even changes such as QAM and the use of DSOs are still in their infancy. Québec's structure is in the midst of an even more profound structural transition, where the sphere of authority once held by CRDITEDs is eroding into the broader regional health and

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[17] Most importantly, this includes increasing the autonomy of service users to choose different service providers to match different support needs, as facilitated by their DSO location (MCSS 2011).

social services structures of MSSS satellites CISSS/CIUSSS, and developmental agencies[18]. While this transition, premised on better integrating service delivery at the regional level, could address the 'siloization' of services in the province, it remains to be seen how it will affect specific developmental services outcomes, and whether the resulting structure will distribute jurisdictional authority in keeping with the Type II MLG design. In light of these current transitions, and the others identified in this analysis, such as the shift to the community-based model of services, this thesis contributes value as the snapshot of a moment, or 'instance' (Alcantara et al. 2016) in the history of Canadian developmental services. As the MLG framework is conceptually refined, and the literature on the application of social inclusion principles to support work outcomes grows, the research strategy employed here has great potential in identifying best practices to target developmental services with more *visible* benefits.

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[18] The changes in accordance with 'Bill 10' *'An Act to modify the organization and governance of the health and social services network, in particular by abolishing the regional agencies'* took affect on April 1, 2015

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APPENDIX A: Consent Form

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INFORMATION AND CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Study Title: The Governance of Developmental Disability Supports for Older Adults in Ontario and Québec

Researcher: Daniel Dickson – Master of Arts: Public Policy and Public Administration – Candidate, Concordia University

Researcher's Contact Information: Phone – (514) xxx-xxxx Email – dicksondanield@gmail.com

Faculty Supervisor: Dr. Patrik Marier – Department of Political Science, Concordia University

Faculty Supervisor's Contact Information: (t) 514.848.2424x5187 (e) patrik.marier@concordia.ca

You are being invited to participate in the research study mentioned above. This form provides information about what participating would mean. Please read it carefully before deciding if you want to participate or not. If there is anything you do not understand, or if you want more information, please ask the researcher.

A. Purpose

The purpose of this research is to understand the influence of government policy on the practical work experience of personal support workers supporting older adults with developmental disabilities.

B. Procedures

I understand that:

- This research study involves an individual interview, approximately 1 hour in length.
- My identity will be kept confidential, and none of the information that I provide during this interview will be attributed to me in any way to me.
- The researcher will not share my thoughts or any other information about me with anyone, including my employer or co-workers.
- I will have access to a summary of the research findings after the research project is completed.
- My interview will be audio recorded and transcribed without identifying information.
- All of the data will be stored on 2 USB keys which will be kept along with interview notes in a locked filing cabinet. All of the analysis will be conducted on a password protected computer in a secure research office, which is always locked when not in use.
- After a period of 5 years, all of the project data – including audio files, interviewer notes, and interview transcriptions – will be destroyed. The computer storage devices containing data files will be reformatted, then rendered physically unusable, and all interview notes on paper will be shredded.

C. Risks and Benefits

The questionnaire does not deal with topics that are likely to create any physical or psychological discomfort. Furthermore, the measures in place to protect your confidentiality will minimize any risks to your relationships with others, or to your financial well-being. It is plausible that without confidentiality measures in place you would be less likely to provide a negative appraisal of company rules or work practices because you could risk negatively affecting your relationship with supervisors and management who are involved in the development and implementation of these rules. It is also plausible that being associated with a negative assessment of company rules or work practices could risk decreasing your chances for promotion within the organization. For this reason, only the researcher will know your real identity. Confidentiality measures are detailed in the next section.

This research is not intended to benefit you personally. Knowledge and information generated from this study may help other researchers, policy makers, and support workers by contributing to a discussion of best practices in supporting older adults with developmental disabilities.

D. Confidentiality

The information gathered will be confidential. That means that the researcher alone will know your real identity, but that it will not be disclosed.

We intend to publish the results of the research. However, it will not be possible to identify you in the published results.

In certain situations we might be legally required to disclose the information that you provide. This includes situations where the interview respondent reveals any sort of criminal activity such as abuse or any imminent threat to the safety of any other individual. If this kind of situation arises, we will disclose the information as required by law, despite what is written in this form.

E. Conditions of Participation

I understand that:

- I am free to withdraw my consent and discontinue my participation at any point during and after the interview, until a deadline of April 1, 2016, which is one month prior to the completion of the report.
- I do not need to answer any questions that I do not wish to answer.
- My participation is this research study is confidential, which means the researcher will know my identity, but he will not disclose it.
- The data from this study may be published.
- Participation in this study is voluntary – meaning it is not mandated by the employer. Refusal to participate in the study will lead to no negative consequences in the workplace, nor will it be disclosed to the employer.

F. To Lodge a Complaint

This project was approved by the Ethics Research Committee of the CSSS Cavendish. However, if you have a complaint about the conduct of this research, please contact the Complaints Commissioner of the CSSS Cavendish, at the following number: (514) 484-7878 extension 1383.

I have carefully reviewed this agreement, and I understand it. I have had the chance to ask questions and any questions have been answered. I consent to participate in this study.

Name (please print) ____

Signature ____

Date ________________________

If you have questions about the scientific or scholarly aspects of this research, please contact the researcher. Their contact information is on page 1. You may also contact their faculty supervisor.

If you have concerns about ethical issues in this research, please contact the Manager, Research Ethics, Concordia University, 514.848.2424 ex. 7481 or oor.ethics@concordia.ca.

Signature of the Interviewer

My signature certifies that I pledge to respect the confidentiality of all information communicated to me as part of this research in adherence with the procedures outlined above.

Name (please print) ____

Signature ____

Date ________________________

APPENDIX B: Recruitment Letter

Dear *(Developmental Agency)* staff,

This letter is a request for participation in a project I am conducting as part of my Master's degree in the Department of Political Science at Concordia University under the Supervision of Dr. Patrik Marier. The title of my research project is 'The Governance of Developmental Disability Supports for Older Adults in Ontario and Québec. I would like to provide you with more information about this project that explores the effects of provincial policies on support work practices.

The purpose of this study is to compare how Ontario and Québec's policy structures differently influence the work practices of direct support professionals. Specifically, it focuses on policies that aim to promote social inclusion for older adults (50 years of age and older) with developmental disabilities. Knowledge and information generated from this study may help other researchers, policy makers, and support workers by contributing to a discussion of best practices in supporting this population.

I am conducting interviews with primary support workers in both residential and educational settings for older adults with developmental disabilities to gain insight from their work experiences. The interviews will take one hour, and will occur during a scheduled shift at the work location. At the end of this study, the publication of the thesis will share knowledge from this study with other researchers, policy makers and support workers. All participants will have access to the final report.

To respect the privacy and rights of *(Developmental Agency)* and its employees, as well as the individuals that they support, all information provided during the interviews is confidential. That means that the researcher alone will know your real identity, but that it will not be disclosed, nor will it be possible to determine your identity from any information included in the final report.

Participation is completely voluntary. You will make your own independent decision as to whether or not you would like to be interviewed. All participants will be informed and reminded of their rights to participate or withdraw before – or at any time during – the interview. Moreover, refusal to participate in the study will lead to no negative consequences in the workplace, nor will it be disclosed to the employer. Even after the completion of the interview, participants are free to withdraw any or all of their interview responses up until April 1st 2016, one month prior to the submission of the thesis report.

If you would like to participate please fill in your name below, then place the form in the attached envelope addressed ATTN: Daniel Dickson. Seal the envelope and place it in the location's outgoing internal mail box. Alternatively, you can indicate your interest to participate by contacting me using the information provided at the bottom of this form.

Name and Work Location: ____
For additional questions, or to confirm participation please do not hesitate to contact me.
Sincerely,
Daniel Dickson M.A. Public Policy and Pubic Administration Candidate
(e) dicksondanield@gmail.com (t) (514) xxx-xxxx

APPENDIX C: Interview Guide

Begin by thanking the respondent for their participation and going over and signing consent form.

1. Generally speaking, what is your job?

How long have you had it? Supporting the same client?

Can you tell me about what you do? Tasks, paperwork, plans, schedules.

2. Tell me what kind of goal-setting or planning is involved in your job as the primary support worker for your client?

3. What is unique about planning for your specific client?

4. How has your education or training background prepared you to promote the social inclusion of the individual you support?

5. How does supporting an older adult with developmental disabilities differ from supporting younger persons with developmental disabilities?

6. How would you define social inclusion for older adults with developmental disabilities?

7. What are your client's current goals/desired outcomes for this year?

Follow up: Are these the ones that are identified in the client's yearly plan?

Follow up: Can you give me an example of a 'social inclusion' goal from yearly planning?

8. Does the individual that you support have any goals directed towards achieving greater social inclusion?

9. Are you aware of any government policies (programs or funding) that promote the social inclusion of persons with disabilities?

Follow up: Does your client make use of any of these policies?

10. Are there any circumstances where you act as a substitute decision maker for your client?

Probe: Is your client capable of coming up with and communicating life goals? How about goals related to social inclusion?

Follow up: What makes substitute decision-making necessary?

11. Which other people or organizations are involved in creating plans for the person you support?

12. What is the biggest obstacle to promoting social inclusion for older adults with developmental disabilities?