Against Exclusion:
Intellectual and Developmental Disability Policy in Canada

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ABSTRACT

Against Exclusion: Intellectual and Developmental Disability Policy in Canada

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Within Canada, the social inclusion of people with intellectual and developmental disabilities (IDD) is impeded by structural and social barriers borne from a legacy of systemic discrimination and policies of explicit exclusion. This exclusion is so ingrained that the realization of 'full inclusion' for this population significantly challenges dominant social and political norms. However, despite this challenge, for the past 25 years social inclusion has been at the forefront of the Canadian disability policy agenda. This dissertation poses two related research questions: (1) 'how is social inclusion framed in the design and implementation of policies targeting people with IDD?', and (2) 'how do Canadian provinces differ in the effectiveness of social services that promote the social inclusion of people with IDD?'

These questions are addressed in three phases. The first phase involves a Critical Frame Analysis of IDD policy designs within relevant federal and provincial policy documents, identifying six distinct design frames. In the second phase, IDD policy implementation processes are assessed for how they (re)frame social inclusion. Empirical support is drawn from interviews and focus groups with policy actors, advocates, and service users. While the complex nature of implementation (re)framing in IDD services confounds cross-provincial comparison, this dissertation introduces a novel typology for comparing implementation decisions. It demonstrates that policy effectiveness need not be confined to mechanisms of top-down accountability and can be achieved through empowering implementers to adhere to professional norms or service user preferences.

This empirical analysis of social inclusion policy (re)framing develops a descriptive foundation to select and weight indicators used in the third phase: a multidimensional policy index. The Social Inclusion Services Index (SISI) comprises 10 indicators across 4 domains that capture the effectiveness of Canadian IDD policies in promoting social inclusion. The SISI offers insight into the finding that, despite widespread support for inclusive IDD policy, implementation has failed because of austere spending, stalled policy transitions and inflexible administrative structures, among other factors. Cross-provincial comparison, based on indicators reflecting priorities identified by study participants, highlights areas of emphasis to curtail policy failure in the promotion of social inclusion for Canadians with IDD.

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This thesis is part of a journey that began 15 years ago when I took a job working at an afterschool program supporting teenagers with intellectual and developmental disabilities (IDD). In the years since, I have been blessed with the opportunity to support hundreds of people with IDD in many roles; however, the most important aspect of this professional work has been the friendships that it has cultivated. These friendships have greatly enriched my life, and profoundly inspired this work.

I wish to thank Patrik Marier for his supervision and guidance, and for empowering me to build comfort with a wide range of theoretical and methodological approaches during our collaborations together. I know I will continue to learn from him for years to come. Thanks also to committee members Meghan Joy and Francesca Scala for guiding this research with deeply engaged and thoughtful comments during revision. Political Science at Concordia is a small department without the institutional memory of other bigger departments throughout Canada, but it benefits from an incredible group of faculty, staff and graduate students. I particularly wish to acknowledge the friendship and support of Marina Revelli, Véronique Billette, and Michèle Modin who made it a true pleasure to come to work.

I am forever grateful to my partner Charleigh and our daughter Wallis, who was born just prior to the start of field work. So much of the writing of this dissertation occurred during periods of lockdown in the first years of the COVID-19 pandemic. Through these trying times, I benefitted immensely from the support, companionship, and love of my little family. Thanks to my parents Barbara and Larry for always motivating and guiding me when I need it most. Thanks to my friends, bandmates, softball team, basketball league and golf partners for all the much-needed fun and leisure over the years. This work is dedicated to my grandmother Ruth Bradley whose journey into academia at the end of her life inspired me profoundly.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

LIST OF ABBREVIATIONS

ACA – *Accessible Canada Act 2019*

AISH – Alberta Income for the Severely Handicapped

AODA – *Accessibility for Ontarians with Disabilities Act 2005*

CAMR – Canadian Association for the Mentally Retarded

CDB – Canada Disability Benefit

COPOH – Coalition of Provincial Organizations of the Handicapped

CRPD – *United Nations Convention on the Rights of Persons with Disabilities 2006*

CSD – Canadian Survey on Disability

DIAP – *Canada's Disability Inclusion Action Plan 2022*

DCS – Department of Community Services (Nova Scotia)

DMs – Deputy Ministers

DSP – Disability Support Program (Nova Scotia)

IDD – Intellectual and Developmental Disabilities

ISPs – Individualized Support Plans

MCCSS – Ministry of Children, Community and Social Services (Ontario)

NPM – New public management

ODSP – Ontario Disability Support Program

QAM – Quality Assurance Measures

SAID – Saskatchewan Assured Income for Disability

SISI – Social Inclusion Services Index

SLB – Street-level bureaucracy

CHAPTER 1: INTELLECTUAL AND DEVELOPMENTAL DISABILITY POLICY IN CANADA

1.1 Introduction

Within Canada, the social inclusion of people with intellectual and developmental disabilities (IDD) – such as autism spectrum disorder and Down syndrome – is impeded by structural and social barriers borne from a legacy of systemic discrimination and policies of explicit exclusion. Drawing from disability politics and policy implementation scholarship, this project poses two related research questions: (1) 'how is the concept of social inclusion framed in the design and implementation of policies targeting people with IDD?', and (2) 'how do Canadian provinces differ in the effectiveness of social services that promote the social inclusion of people with IDD?'. To address these research questions, this project entails the construction of a policy index that will compare all ten Canadian provinces based on outcomes across multiple dimensions of services targeting social inclusion. This involves a mixed-methods research design, which devotes significant attention to building descriptive depth through extensive interviews with relevant actors situated throughout the policy subsystem, thereby allowing the observation and analysis of qualitative data that will inform the selection and weighting of indicators for the index.

Social inclusion – defined as *full participation in all aspects of society* – is recognized as a "flagship concept in disability politics" (Prince 2009, 91). It has a central role in the United Nations' Convention on the Rights of Persons with Disabilities, which identifies "(f)ull and effective participation and inclusion in society" as one of eight general principles to be promoted by signatory countries (United Nations 2006). In Canada, social inclusion has been a major focus of disability policy instruments since a vision of 'full citizenship' for people with disabilities was heralded by the seminal *In Unison* report in 1998. This vision paper put forth by Canada's federal and provincial/territorial ministers in charge of social services has informed subsequent social programs for people with disabilities. It has done so by installing a coherent policy vision that involves identifying and addressing social and structural barriers to inclusion (ESDC 1998). In light of this longstanding national policy vision, which has informed full citizenship strategies in provincial programs since its emergence (Prince 2016a), it is important to assess how provincial programs vary in the design and implementation of these strategies. Therefore, to address the first research question, this project will compare specific social service policies in Canadian provinces to determine how they differ in framing social inclusion as an overarching national disability policy priority.

Beginning with disability rights mobilization in the 1970's and continuing with significant policy victories in the late 1990's, there have been modest advances in addressing systemic barriers to inclusion (Chivers 2008; Vanhalla 2014). The shift from the isolative and abhorrent conditions of residential institutions towards community living (e.g., group homes) has been a particularly important advocacy outcome (Lemay 2009; Burghardt 2018). This thesis refers to social services targeting people with IDD as 'developmental services', echoing a common terminology used by advocates and implementers working within both federal and provincial level policy structures. While the thesis compares IDD policy systems more generally, developmental services are a central focus. Figure 1.1(a) provides a simplified model of developmental services governance, with the primary responsibility for each governance organization/actor specified below. This model is useful to broadly conceptualize governance roles; however, in practice, the governance of specific IDD policies can be far more complex. Figure 1.1(b) maps the governance of IDD housing policy in Montréal, Québec, with policies from the federal, provincial and municipal levels impacting services used by people with IDD. Thus, while provincial governments are the primary providers of developmental services, it is possible for governments at all three levels to exert influence on specific IDD policy subsystems.

Figure 1.1(a) Simplified Model of Developmental Services Governance

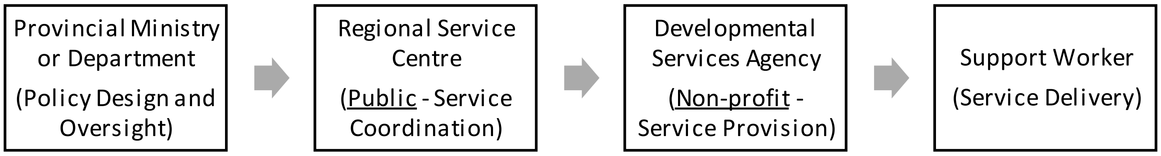
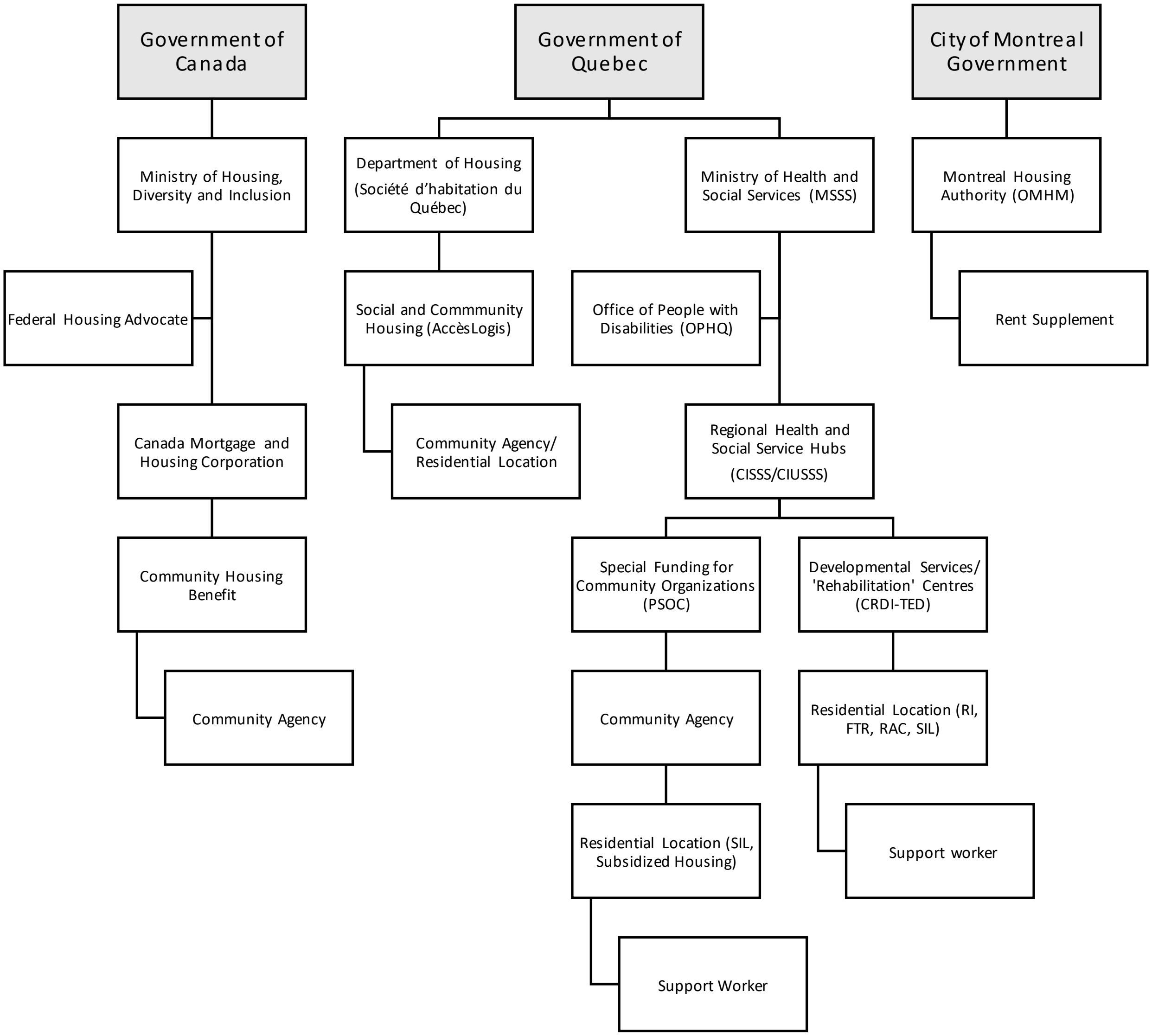


Figure 1.1(b) Governance of IDD Housing Policy in Montréal, Québec.



As a result of deinstitutionalization and improved access to developmental services, prior to the COVID-19 pandemic, people with IDD were increasingly living into older adulthood, with an average life expectancy moving closer to that of the general Canadian population (Shooshtari et al. 2012; Statistics Canada 2015). In this context, older adults with IDD have emerged as a 'new population' in the Canadian social services landscape, caught between the separate silos of disability and aging services. Moreover, in addition to these structural barriers, efforts to promote their inclusion in broader society must contend with the intersection of negative constructions of both aging and disability, which act as persistent and pervasive social barriers (Oliver and Barnes 2012; Rapley 2004; Dickson 2018). This project compares Canadian provinces by the effectiveness of existing policies to promote social inclusion outcomes, with special attention to this doubly marginalized group, who are often overlooked in the policy landscape. While the purpose of the project is to compare inclusion policies for people with IDD across the entire lifecourse, the policy index accounts for additional barriers faced by older adults with IDD. For the purpose of specificity, IDD are defined as permanent impairments that are present at birth and affect a person's ability to learn[1]. Inclusive policies for this population must accommodate neurodiversity by promoting outcomes that reduce the stigma that frequently confronts cognitive difference (Orsini 2012; Scior and Werner 2016; Goodley 2001).

Social inclusion is an amorphous concept. Despite its popularity in policy interventions for marginalized groups generally, and people with IDD specifically, its meaning is dynamic and contingent on a number of factors. For example, unique forms of social exclusion can be faced by different people with similar disability, depending on the nature of their impairments. This is the impetus for Stone's (1984) definition of disability as a socially constructed, formal administrative category, where social institutions – through policy mechanisms such as eligibility criteria – "engage in selective perception and actively shape the way people are treated" (p.27). A key aspect of her argument is that the perception of disability is marked by a contrast between negative social stigma and the perceived political privilege of gaining exit from some obligations of social citizenship, such as contributing to the labour force. It is tenable that both of these factors can act as barriers to social inclusion, however they can also be seen to act against each other. As such, a central proposition of this project is that exclusionary social narratives – also categorized as social barriers in disability studies (Oliver and Barnes 2012, Goodley 2013) – must be assessed not solely for their existence in the public discourse, but also by how they are translated into action. For example, the social construction of disability as pathology, built upon the harmful stereotype that disability is a personal tragedy that *happens to* someone (Oliver 1983; 1990), situates disablement within the individual, and thus favours support strategies that focus on making an individual more *includable*, rather than making society more inclusive.

The primary argument of this dissertation is that the policy project of promoting social inclusion for people with intellectual and developmental disabilities (IDD) in Canada has failed. Since the enshrinement of 'mental disability' as a protected identity category in the *Canadian Charter of Rights and Freedoms 1982*, and more explicitly in the wave of policies that have emerged since the 1998 *In Unison* report (ESDC 1998) detailed a unilateral F/P/T vision for disability policy, social inclusion has been a driving focus of Canadian IDD policy. Indeed, the concept has become so ubiquitous within IDD political and policy discourse that I label the past

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[1] The most common diagnostic criteria for intellectual and developmental disabilities are found in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association 2013) focusing on the identification of deficits in intellectual and adaptive functioning.

25 years the 'inclusion era', where advocacy efforts and the design of policy across levels have been consistently framed by a social inclusion policy paradigm. However, rather than actively advance a practical framework for inclusion, IDD policies in Canada have been trapped in a battle against the ableist and exclusionary ideas that have been embedded within Canadian policy/political institutions since before confederation, when residential institutions and sheltered workshop models were first established (Burghardt 2018; Galer 2012; Prince 2009). This has occurred because social inclusion is a flawed concept when directed towards populations that pose a significant challenge to dominant social norms (Mitchell 2015; Goodley 2001; Ahmed 2012). Specifically, I posit that social inclusion is flawed because it is based on two false presumptions i) that society is power neutral (i.e. that social and political institutions *can* accommodate neutral power sharing among identity groups) and ii) that inclusion is a universal problem[2] (i.e. that all identity groups seek to be included within existing social and political structures). For policy actors working within Canada's developmental services structures, promoting social inclusion for people with IDD often involves highly contingent and individualized decisions and strategies, which may diverge significantly from the intent of overarching policy documents.

Following the argumentative turn in policy studies, policy is now often studied in narrative or discursive terms. However, less attention is paid to performance: how these narratives are translated into action by individuals occupying different positions within a particular policy subsystem or social context (see Newman 2013). Even the subfield of policy implementation studies, which has long focused on how policy designs are put into action (Pressman and Wildavsky 1973; Barrett and Fudge 1981), has advanced a narrow view of performance through concepts of agency and discretion by attempting to aggregate the actions of agents at the managerial (May and Winter 2009) or frontline levels (Lipsky 1980; Maynard-Moody and Musheno 2000). This project aims to uncover the performative variation that can occur by disaggregating, or uncovering the meaning-making and rationale for these actions, in order to identify and analyze dissensus in policy implementation processes. Specifically, by observing both how implementers interpret policy intent and how this informs their actions, we gain greater descriptive insight into how the broader policy system performs, adding valuable context to this cross-provincial comparison. In this way, this thesis connects contemporary streams of implementation literature, which seek to explain implementation across levels of governance (Cho et al. 2005; Schofield 2004; Hill and Hupe 2003; 2009) and contemporary interpretivist scholarship which allows that policy analysis requires 'making sense of local knowledge' (Yanow 2003; see also Bacchi and Goodlaw 2016) to identify how policies are differently understood by individuals or groups of actors throughout the implementation chain.

Crucially, this project takes the position that policy narratives do not occur without context. While it is helpful to analyze the meaning, or causal stories (Stone 1989), that policies represent, these are not the only ideational influences policy on implementation, and certainly

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[2] Disability studies theorists have long questioned the value of social inclusion, given the burden of performative expectations that dominant social norms place on disabled people (Linton 1998; Garland-Thomson 2011). Does everyone want to be included by 'normates' (Garland-Thompson 1997) or must multi-directional exchange occur? As it stands, social inclusion is only urgent and imminent for the excluded.

not on policy outcomes. Connecting policy to outcomes requires taking stock not just of how policy implementers perform or translate a policy into action, but also of social context. Performativity is affected not only by the requirements imposed by institutions, such as government or agency policy, but also by the preferences and expertise of policy actors, including those at the frontline (Newman 2013). I empirically account for these preferences, as a complement to those installed in policy designs, through the development a cross-provincial composite index. Through the selection and weighting of indicators reflecting the preferences of key IDD policy actors, the Social Inclusion Services Index (SISI) incorporates measures of performativity into the broader policy index.

1.2 Research Puzzle

In terms of its contribution to policy studies, this research is guided by two central objectives. First, to address *how* cross-provincial variation occurs, this project compares practical outcomes by their adherence to the explicit goals set forth by provincial policy designs, and the coherence of these designs within broader national priorities for disability support services. Policy design is defined as *the textual representation of a broader mandate within a specific policy area* (Hill and Hupe 2009, 141; Cho et al. 2005). The broader mandate in the developmental services policy area is the focus on promoting social inclusion for people with IDD, which has been at the foreground of disability politics since the growth of the community living movement in the 1970s, and the explicit focus of federal and provincial disability policy in the more recent 'inclusion era' of the past 25 years. At the provincial level, the disparity between the various solutions to the problem of IDD inclusion is puzzling, especially when we consider that the most pervasive barriers to inclusion – ableist attitudes and social stigma – are quite uniform across contexts (Scior and Werner 2016; Verdonschot et al. 2009). As chapter 2 illustrates, policy designs at both the federal and provincial level employ numerous different framings of social inclusion, which are further distinguished by their implementation within divergent provincial governance structures by different constellations of implementation actors.

And yet, the most puzzling aspect is that despite at least a broad, normative commitment to inclusion, manifested in progressive policies such as the recent federal level *Accessible Canada Act 2019*, policies of explicit *exclusion* still persist in all Canadian provinces. Most notably, these include the sheltered workshop model (one which pays workers with IDD far less than minimum wage for repetitive labour conducted in industrial settings out of public view) and the residential institution model (one which confines people with IDD in large human warehouses in rural areas, again hidden from view). Therefore, given the gap between the aspirational policy intent of promoting inclusion and the puzzling persistence of explicitly exclusionary policies, achieving the first project objective requires analyzing the intervening processes between policy designs and outcomes. To this end, this project begins by analyzing the framing of current provincial policy instruments to assess their adherence to national social inclusion priorities for people with IDD. This preliminary framing analysis provides a benchmark for how policies are (re)framed by implementation actors. As such, this thesis complements the textual analysis of policy designs by interviewing implementation actors tasked with delivering these policies. As such, I compare policy designs not only by my interpretation of their thematic content, but also by how they are understood and *performed* by those who engage with policies at various points in the implementation chain. For this reason, the policy index encapsulates a broader scope of policy priorities than those found in policy documents at the federal and provincial level.

As a second primary objective, this project focuses on the role of policy implementers as discretionary agents or 'street-level bureaucrats' who directly engage with service users and influence policy outcomes through "substantial discretion in the execution of their work" (Lipsky 1980, 3). Limits on discretion can take the form of prohibitive regulations, managerial accountability mechanisms or practical considerations such as the number of clients in a worker's caseload (May and Winter 2009). In complex frontline contexts discretion is defined in the street-level bureaucracy literature as *the autonomy that frontline professionals can exercise to dissent from rules governing their practice* (Lipsky 1980). Existing Canadian literature on developmental services has found that social inclusion outcomes are less likely to be pursued where organizations and support workers are more constrained by provincial governments, particularly during austerity (Courtney and Hickey 2016, 83; Dickson 2016). This hypothesis may appear to diverge from early bottom-up theorists, who saw implementation deficits as more likely where more discretion exists at the frontline (Lipsky 1980; Barrett and Fudge 1981); however, these early authors did not apply a universal direction to applications of frontline discretion. Instead, they saw discretion as a way of expanding the scope of implementation studies beyond the limitations of top-down perspectives, to connect and contrast policy designs with practical outcomes. This is reflected by more current treatments of discretion, which find frontline workers able to effectively achieve policy goals by working around the shortcomings of existing policy designs (Ellis 2011; Prior and Barnes 2011). In this way, hypothesizing the direction of discretion vis-à-vis policy priorities requires taking account of numerous contextual factors, including the specific policy issue (social inclusion for people with IDD) and operant institutional configurations (provincial developmental services governance).

In Chapter 5, I engage with this second project objective by proposing a novel typology to analyze how developmental services implementers use their discretion. Specifically, I examine implementation as an act of adherence to a particular framing of the policy problem. Discretion allows implementation actors to choose which framing they wish to adhere to, and how they rationalize their choice elucidates key features of the policy subsystem in practice. Taken together, the two principal objectives of this dissertation aim to address the failure of social inclusion policies and the equally puzzling persistence of exclusionary policies within Canadian developmental services.

1.3 Theoretical Framework

Interpretivist scholarship has been born out of an ontological or constructivist turn in the social sciences more broadly. The construction of meaning surrounding an issue is an important political foundation for the design and implementation of public policy; therefore, processes of issue framing and reframing, and the analysis thereof, are promising for their instrumentality in the connection of political ideas to policy outcomes. Framing is a process of meaning making. At the front end of the policy process, this is well understood, as framing was originally conceived as an analytical approach applied to the policy stages of problem definition (Goffman 1978), agenda setting (Snow and Benford 1992) and policy design (Schön and Rein 1994; Stone 1989). However, within policy implementation research, this dictum has been more problematic to scholars because framing at the frontline is more contextual, nuanced, and personalized than the broadly aggregated framings that occur at the front of the policy process (van Hulst and Yanow 2016). In implementation research, which has traditionally focused on how the actions of implementation diverge from policy intent, more emphasis is often placed on meaning *breaking* rather than meaning making. By treating implementation as an act of policy reframing in adherence with alternative action frames further down the implementation chain, this dissertation advances the theoretical literature by proposing a novel schema for understanding the decisions and actions of implementers.

Drawing from policy implementation literature, this dissertation merges top-down and bottom-up approaches to public policy by emphasizing the interrelation between policy formulation and implementation (Mazmanian and Sabatier 1989; Hupe 2011). Early authors in the implementation tradition favoured a top-down approach that assesses how the implementation of policy outcomes is affected by numerous joint-action problems dynamically imposed upon the policy goals prioritized in policy formulation (Pressman and Wildavsky 1973). In this original articulation, an 'implementation deficit' emerges where tight cooperation does not occur between all administrative actors. However, this perspective was critiqued for ignoring both the managerial skill, and the potential non-conforming priorities of implementing agencies, which may result in a 'reformulation' of policy goals (Mazmanian and Sabatier 1989). While reaffirming the value of identifying the policy goals from a top-down perspective, this expanded approach adds a bottom-up dimension by encompassing agency priorities. This synthesis of perspectives is reflected in Hill and Hupe's (2009) concept of 'multi-layered policy (co)formation', which suggests that as a policy moves through numerous political-administrative layers (such as federal and provincial governments, and implementation agencies/actors), the original policy goals must contend with the goals of each other layer within the system.

Within the bottom-up camp of the policy implementation literature, attention is paid to the roles of frontline workers as street-level bureaucrats, who can significantly shape policy outcomes in the last stages of implementation (Lipsky 1980). Research on street-level bureaucracy (SLB) uses two key variables to assess the influence of workers on policy outcomes: i) the amount of 'discretion' that workers are afforded, and ii) the degree to which their combined individual actions converge with or diverge from policy priorities (Hill and Hupe 2009; Gofen 2014). Moreover, a more current stream of SLB literature finds that 'management matters' in the analysis of SLB outcomes, by addressing the influence of agency priorities on worker discretion (Keiser 2010; May and Winter 2009). Thus, in situations where agency and government policy priorities conflict, and where street-level bureaucrats are afforded greater discretion, an implementation deficit is more likely to occur. Current scholars in the SLB tradition have become more interested in the motivations of frontline workers (Brodkin 2020; Møller and Stensöta 2019; Ellis 2011). While in Lipsky's (1980) early work he theorized that street-level bureaucrats used their discretion to act in their own self-interest, others suggest that discretion is most often used to act in the best interests of service recipients (Maynard-Moody and Musheno 2000). Still others emphasize how frontline workers routinely work to subvert social policy objectives in their daily work, conceptualizing these acts of 'resistance' as part of the policy process (Prior and Barnes 2011). Therefore, in order to mediate between these competing theoretical accounts, understanding the service priorities that street-level bureaucrats use to make calculations of service recipients' best interests is integral to understanding their use of discretion.

a) Canadian Priorities

Canadian disability policy literature identifies a fissure between policy priorities and the priorities of support workers in practice. Mahon and Mactavish (2000) note that support workers are more likely to emphasize the barriers to social inclusion than to develop person-centred strategies with the support recipient to overcome them. Moreover, Hickey (2012) finds that the increasing tendency towards direct funding for developmental services in Ontario has resulted in lower wages, poorer quality of service provision, and less emphasis by support workers on promoting social inclusion outcomes. Similarly, Kelly (2016) expresses concern that the broadening influence of neoliberal policy agendas on support work practice in Canada both negatively affects working conditions and deprioritizes the provision of care for support workers. While each of these texts shares a common pessimism about the potential of support workers to effectively promote social inclusion outcomes in the current Canadian policy climate, there is a lack of consensus as to whether this could be remedied by operating within the confines of existing rules. Pedlar et al. (2000) shift the focus to the agency level to find that developmental service agencies have very divergent service orientations, and that not-for-profit agencies are more likely to promote social inclusion than for-profit agencies. Their contribution thus gives some insight into the effects of governance architectures on the likelihood of effective social inclusion promotion, however it is limited by a top-down approach to implementation that does not account for the significant discretion of implementation actors to reframe inclusion policies.

A common thread in these contributions is the recognition that distinct priorities correspond to different 'layers' within provincial developmental services structures. This speaks to the importance of interviewing actors at various levels of implementation. Second, with the exception of Kelly (2016), there is minimal emphasis on how the distinct service needs of older adults with IDD might diverge from or converge with priorities at various levels within this system. This is particularly surprising given the emphasis that developmental services policy and scholarship places on person-centred approaches to service delivery. Finally, neither these works, nor any other work within the current Canadian IDD policy literature has addressed implementation systems broadly or SLB specifically, nor have these concepts been applied to the comparison of developmental service structures in Canadian provinces. As such, this project targets an important gap in the existing Canadian literature.

b) Tracing policy meaning across levels

Policy implementation literature has focused on the directionality of influence on outcomes (bottom-up, top-down, or hybrid), or on the performance of policy agents through concepts of agency and discretion, which aggregate experiences across levels in the implementation chain (e.g. street level, or managerial level). However, disaggregating the performativity of these agents requires accounting for variation in the meaning of key policy concepts. Simply put, social inclusion – as a policy directive – can *mean* different things to different actors. Adopting a Foucauldian approach to power/knowledge, Prince (2016a) demonstrates the multiplicity of forms of meaning and knowledge production in both disability advocacy communities and in disability scholarship in the Canadian context. Moreover, he compellingly argues that the dominant narratives of disability seek to aggregate experiential knowledge into generalized narratives, which have the effect of minimizing unique lived experiences of people with disabilities, thereby denying them a baseline entitlement to social citizenship (p.15). Identity narratives come to dominate when they acquire what Miller (2019) calls 'subscribers', who in the service of performing in adherence to a dominant narrative, thereby legitimate it. This makes it vitally important to both explore the content and trace the influence of dominant identity narratives to understand the effects of policy design and implementation on promoting social inclusion for people with IDD.

Interpretivist approaches to political science provide useful tools in the pursuit of identifying dominant narratives. Crucial to this pursuit is the discovery of observable objects – or artefacts (Yanow 1996) – which signify particular interpretations of meaning. Yanow (2014) identifies three categories of human artefacts: language (signifying narratives or causal stories through policy text, for example), acts (where meaning is performed), and material objects (referenced by language or used in an act) (p.138). These categories are not mutually exclusive and can be used together to trace meaning constructions among groups of individuals. This is apparent in the literature on policy performance, which fits most neatly into the category of 'acts', but also employs language and material objects in the signification of meaning. Indeed, Newman (2013) argues that performances of public policy can often be seen as translations of the language in policy texts. This position is echoed in a recent edited volume (Clarke and Bainton 2015), wherein the contributing authors find the translation of policy texts by implementors to be a significant contributor to 'movement' from the intentions of policy designs toward incongruent outcomes. Similarly, Hajer (2005) draws upon a dramaturgical understanding of performance to see policies as at times scripted, and other times improvised in ways that ignore policy language.

These contributions share a common emphasis on the potential benefits of tracing meaning through the implementation chain as a way of providing a more nuanced understanding of how policy success/failure is differently understood among implementation actors. I incorporate such an understanding into the construction of the policy index, so that perspectives of actors throughout the implementation chain are weighted representatively. Specifically, by accounting for how implementation actors (re)frame social inclusion I gain insights into how different IDD policy structures work in practice, thus complementing the comparison of policy designs. Incorporating policy implementation into a composite index requires making difficult decisions on the proportional weighting of different dimensions, and active efforts to avoid erroneous researcher bias. However, describing provincial variation in this specific policy area, while respecting complex intersectional identity politics of this population, requires accounting for how policy is differently scripted and performed in these jurisdictions. To this end, I employ a research design that draws from conceptual frameworks on policy framing/reframing.

1.4 Research Design

This dissertation employs a mixed methods design which is divided into three phases corresponding sequentially to the two primary research questions: (1) 'how is the concept of social inclusion for people with IDD framed in the design and implementation of policies targeting people with IDD?', and (2) 'how do Canadian provinces differ in the effectiveness of social services that promote the social inclusion of people with IDD?'. The first two phases of research correspond to the first research question by analyzing the framing and reframing of social inclusion in the policy design and implementation stages, respectively. By empirically analyzing how social inclusion policies are (re)framed, I develop a descriptive foundation that contributes to the selection and weighting of the indicators that are used in the third phase to compare Canadian provinces by their effectiveness in implementing developmental services policies that target social inclusion. The first phase, presented in chapters 2 and 3, involves a Critical Frame Analysis of social inclusion framing in Canadian disability policy design. The second phase, presented in chapters 4 and 5, addresses the (re)framing of social inclusion policy through the implementation of developmental services. Taken together, these 4 chapters provide a strong descriptive foundation to inform the third phase of research, the construction of the Social Inclusion Services Index (SISI), which addresses the second research question and is presented in Chapter 6.

While related, the two research questions in this thesis do not fully overlap. For this reason, this thesis is designed to ultimately produce several standalone journal articles rather than one unified monograph. For example, even the Critical Frame Analysis of IDD policy design and implementation, which comprise the first two phases of research, do not fully interrelate. While policy design framing provides an important baseline for the analysis of implementation (re)framing, this thesis will demonstrate that many of the (re)framing processes that occur in the implementation process are wholly unrelated to – and at times unaware of – the substance of policy designs. Similarly, while the selection and weighting of indicators in the SISI draws from the insights of the preceding framing analyses, it is also informed by additional descriptive insights provided by interview participants. Therefore, while there is a clear logic to the sequential presentation of chapters flowing from the three phases of research, each of the five empirical chapters that proceed this one can be viewed as an independent scholarly contribution.

The SISI is based on two concepts, 'social inclusion' and 'effective policy implementation', which have not been elsewhere combined to explain outcomes for people with IDD in theoretical or empirical applications. I define social inclusion as 'full participation in all aspects of life', in keeping with the definition employed by *In Unison* (ESDC 1998). I define 'effective policy implementation' as 'the adherence of outcomes to policy goals' (Sabatier and Mazmanian 1981). However, for the authors from whom this definition is derived, policy goals were understood rather statically as the explicit intentions of the policy as designed. Within implementation literature it is well established that such an understanding of effective implementation imposes such rigid constraints that policy everywhere will be seen to fail (Ingram and Mann 1980). I wish to avoid the constraints of this top-down perspective by allowing that different understandings of policy goals can occur throughout the implementation chain, as the meaning of the policy goals is subject to interpretation by different policy actors. Therefore, while the variable 'effective policy implementation' compares outcomes to the broad national policy direction outlined in *In Unison*, the outcomes that are used to measure 'social inclusion' will be influenced by potentially divergent understandings of the concept by various actors. In this way, construction of the index in the third phase of the project gives equal weight to these perspectives, such that effective implementation can encompass a broader understanding of the social inclusion concept than that provided by provincial policy designs.

By combining these concepts, the SISI measures the effective adherence of developmental services outcomes to the policy goals of social inclusion for people with IDD. However, to measure these two concepts as dimensions of one index, it is necessary to first acquire knowledge of how to appropriately operationalize them. This requires the collection of data representing the implementation of developmental services, which, through descriptive inference (King et al. 1994, 56), will be used to identify the systematic components of the phenomena to be measured by the SISI. In this way, the exploratory research conducted in this first stage enables SISI to accurately compare all ten Canadian provinces by the effectiveness of social inclusion policy, such that emergent variation can be subsequently explained. Below, I specify the precise methods employed in each phase of the research design.

a) *Phase 1: Policy Design Framing*

The first phase of research addresses the framing of social inclusion in policy design. In Chapter 2, I begin by presenting a textual analysis of all policies at the federal and provincial level in Canada pertaining to the social inclusion of people with IDD (*n* = 165). Using a Critical Frame Analysis approach (Verloo 2005; Verloo and Lombardo 2007), I address the ways that social inclusion is framed as a problem to be solved by public policy in Canada. Framing involves the construction and interpretation of discourse, and thus begins before and persists after processes of policy design (Bacchi 1999; Bacchi and Goodwin 2016). Moreover, there are important differences between observing frames as objects or framings as processes, with the latter approach better able to encompass how actors engage and employ specific understandings of a policy problem in practice (van Hulst and Yanow 2016). The primary focus of this study are the processes of framing and reframing social inclusion; however, in adherence with Critical Frame Analysis it is necessary to begin by first examining the comparatively static frames contained within policy documents to assess how the problem is represented (Verloo 2005). Policy documents are critical artefacts to uncover the dominant framing of a policy problem within a specific policy domain (Yanow 2014; Stone 1989). By beginning the frame analysis with the textual analysis of the documents themselves, we thus gain greater descriptive leverage to address how framing occurs more broadly in processes of policy design.

In Chapter 3, I incorporate processes of policy design to the frame analysis by drawing from semi-structured interviews with Canadian IDD advocates (*n* = 25). In these interviews representatives of IDD advocacy groups and family and self-advocates detail their preferred framings of social inclusion and emphasize the shortcomings of existing policy designs. Moreover, they describe advocacy processes, including direct consultation practices in policy design at the provincial and federal level. This gives insight not only into the aspirations of advocates looking to improve developmental services design and delivery but also into the failures of existing policies in promoting social inclusion. What is more, by identifying the framings of social inclusion favoured by IDD advocates it becomes possible to generalize about bottom-up adherence strategies employed by policy implementers who can use their discretionary authority to tailor outcomes to the wishes of their clients (Tummers et al. 2015; Maynard-Moody and Musheno 2000), which is a focal objective of the next phase.

b) *Phase 2: Policy Implementation (Re)Framing*

Phase 2 of the research design shifts the framing analysis to focus on the implementation of developmental services. Data is derived from individual interviews – and in some cases, focus groups – with a purposive sample of representatives from the following groups in two Canadian provinces (Nova Scotia and Ontario) and at the federal level, where appropriate:

- the provincial ministry responsible for developmental services,
- disability advocacy groups operating at provincial or federal level,
- management at developmental service agencies,
- primary support workers, and
- people with IDD who receive social services (interviews and focus groups)

These specific groups were selected because they each have unique perspectives on the process of policy implementation, allowing them to frame the social inclusion concept at different scales (van Lieshout et al. 2011; 2012). Taken together these groups form integral parts of the 'implementation chain', which connects policy to action through a series of interdependent relationships (Hill and Hupe 2009, 7). It is important to emphasize that the research at this phase does not seek to explain the complex 'causal chain' of implementation (Pressman and Wildavsky 1973), but rather to identify the appropriate indicators to measure variation in the effects that these chains produce in different provincial settings. This emboldens the construction of a cross-provincial index that is better able to accommodate important differences between provinces, particularly the provinces that I exclude from these first two phases of data collection.

Purposive sampling is an appropriate recruitment strategy given the exploratory nature of this phase of the project and the fact that the interviews occur prior to hypothesis testing, thus reducing the potential for inadvertent bias in the selection process (Lynch 2013). This strategy introduces the possibility that respondents from specific groups will have less descriptive insight than others for concept building. While all of the groups that I interviewed have valid perspectives for the SISI construction, support workers and managers at developmental service agencies and IDD advocates comprise the most significant proportion of the respondent pool. This is because their position at the end of the implementation chain, in the closest proximity to the support recipient, allows them a unique perspective to mediate between policy and practice, and also allows them insight on the needs of multiple service users with whom they interact.

Constraints related to project timeframe and funding resources made conducting interviews in every province unfeasible. For this reason, to maximize descriptive leverage in this exploratory stage of research, I chose Nova Scotia and Ontario based on their values on key explanatory variables in the study (King et al. 1994, 137). Specifically, the two provinces demonstrate pronounced variation in the housing policy domain because Nova Scotia still has active residential institutions and Ontario has fully de-institutionalized. However, it must be stressed that not all of the values on explanatory variables were observed or known prior to case selection. For example, in the first phase of the project I conduct textual analysis to determine which policy designs most adhere to national social inclusion priorities for people with IDD. Because no existing empirical studies have compared the provinces by the adherence of their developmental services policy designs, I cannot select cases based on values of any explanatory variable prior to the exploratory phase. With this limitation, case selection has been decided based on maximizing variation in key areas of policy design and implementation to gain a fuller descriptive account to developmental services provision.

Nova Scotia was selected as a classic example of a 'have not' province with respect to financial capacity. In the Canadian fiscal federalism literature, the label of 'have not' is assigned to provinces who are traditional recipients of federal equalization transfers, which compensate for proportional economic disadvantage relative to the other provinces (Bakvis et al. 2009). Moreover, Nova Scotia is also a laggard in terms of existing social inclusion policies, due to the province's well-publicized failure to transition away from both residential institution and sheltered workshop models[3]. As part of the fieldwork for this dissertation I toured both a residential institution and a sheltered workshop that are both still operational in the province, speaking to staff, management, and supported individuals. The disability policy literature correlates greater financial capacity with greater likelihood of social inclusion programming (Levesque 2012), therefore, Nova Scotia is a representative case of a Canadian province without the fiscal capacity to effectively promote social inclusion policies, and one whose reliance on developmental services models that explicitly favour the exclusion of people with IDD places them in stark contrast to paradigmatic policies of the inclusion era.

Ontario was selected because of its comparatively advanced social inclusion policy frameworks, specifically the longstanding *Accessibility for Ontarians with Disabilities Act 2005*, which is a direct precursor to the national *Accessible Canada Act 2019*, and the Ontario's *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act 2008* which provides the most explicit policy focus on social inclusion of any provincial level document in Canada, despite lingering issues in enforcement (Joffe 2010; Dickson 2016). Since 2008, Ontario has been steadily rolling out a new model of developmental services, which has installed far-reaching mechanisms for provincial oversight (Joffe 2010). Moreover, the province has claimed to close all of its residential institutions[4] and all sheltered workshops[5], signalling an important shift away from policies of explicit exclusion. However, the current provincial government has also proposed significant austerity measures to the sector, drawing the ire of IDD advocates in the province[6]. While austerity measures are rampant

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[3] This was evident in a recent, highly publicized court case where three individual applicants who had all resided in residential institutions filed a complaint through the provincial Human Rights Commission that alleged that the Nova Scotia government had systemically discriminated against them due to their mental disabilities by delaying the provision of services and community residential supports. The case went to the Nova Scotia court of appeal, where the plaintiffs – joined by a coalition of disability advocacy groups – were victorious, with The Court ruling that "to place someone in an institutional setting where they do not need to be in order to access their basic needs, which the Province is statutorily obligated to provide, is discriminatory" (paragraph 175). Ruling retrieved online from: https://www.canlii.org/en/ns/nsca/doc/2021/2021nsca70/2021nsca70.html

[4] A group of survivors from the Huronia Regional Centre, Ontario's largest residential institution, were able to secure a $35 million legal settlement against the province https://www.canlii.org/en/on/onsc/doc/2013/2013onsc6686/2013onsc6686.html

[5] https://www.mcss.gov.on.ca/wp/en/programs/developmental-services/shifting-from-sheltered-workshops/
https://www.thestar.com/news/canada/2015/11/29/ontarios-sheltered-workshops-to-close-forever.html

[6] A concise and representative list of the major complaints of the Ontario IDD advocacy community about the Ford government can be found in this press release issued prior to the most recent Ontario election campaign:

throughout Canadian provincial developmental services sectors, Ontario's highly centralized structure, typified by tighter regulation and accountability measures through the implementation chain creates a particularly challenging implementation context amidst austerity (Courtney and Hickey 2016). Comparing outcomes in these divergent political and institutional contexts will provide insight into their effects on shaping policy outcomes. This comparison will also shed light on the amount of discretion held by frontline workers, who may be equally constrained or empowered by divergent provincial governments and governance structures (Dickson 2022).

Despite these attempts to provide divergent cases for the fieldwork, it is important to re-emphasize here that this stage is exploratory, and therefore is focused on gaining different perspectives to inform index construction. As such, the two provincial cases – in addition to data that collected from national-level advocacy groups – are not expected to account for the whole range of potential perspectives across the spectrum of provincial developmental services governance in Canada. Instead, this phase of data collection is designed with the construction of the index in mind to maximize the breadth of perspectives that will inform construction.

c) *Phase 3: Constructing the Index*

The third phase of the project is the construction of the SISI by combining key indicators in four domains. Policy indexes have been demonstrated to be valuable tools for comparing regional capacities in addressing policy issue areas (Ferrer et al. 2016; Rigla et al. 2015; Zaidi 2013). The SISI has a technical advantage over other indexes because numerous measures currently exist to formally assess social inclusion as a quality of life domain for care recipients (see Schalock et al. 2008). What is more, appropriate measures have been developed to specifically tap social inclusion for older adults with IDD, even identifying broad categories of disability supports that correspond to specific social inclusion needs (Schalock 2004). While these existing measures have been designed for psychology and social work applications, the categorization and weighting are a valuable reference point in index construction.

Most importantly, the broader implications of the SISI have been expanded by a recent push in the field of social work to create an integrative framework that connects these specific personal outcome measures to disability supports in the broader context of disability policy (Shogren et al. 2015). This push is echoed in the specific context of Canadian disability politics by Prince (2009) who emphasizes the central importance of a national level disability social inclusion index in propelling efforts for disability mainstreaming (p.91-100). As such, the SISI represents a significant advancement in this burgeoning, multidisciplinary research area, while also presenting practical applications for IDD advocacy and service provision.

1.5 Outline of Dissertation Structure

The remainder of this dissertation is divided into six chapters. In the proceeding chapter, I begin by presenting a conceptual sketch of the concept of social inclusion as it has been employed by social policy in the welfare state. I then narrow the scope to specifically focus on

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https://www.aodaalliance.org/whats-new/during-its-four-years-in-power-ford-government-made-ontario-a-more-dangerous-place-for-vulnerable-people-with-disabilities/

disability politics, before homing in on how the policy problem of social inclusion has been translated into policy designs targeting people with IDD in Canada. This provides a descriptive foundation for the chapter's empirical component: a Critical Frame Analysis of all Canadian IDD policies targeting social inclusion. By identifying and categorizing framings with the design of Canadian IDD policies, I am able to shed light into frame dominance and opposition over time, and to assess which specific framings have become 'institutionalized' (Bjornehead and Erikson 2018) by their formal use in policy documents. This textual analysis is a necessary first step in achieving the dissertation's first objective: to compare practical outcomes by their adherence to the explicit goals set forth by provincial policy designs.

The third chapter takes up the analysis of policy design framings by examining how IDD advocates influence the design of Canadian disability policies by (re)framing the concept of social inclusion. I begin by first describing the political context within which social policy occurs in Canada, with specific attention to the impact of federalism and intergovernmental relations on the opportunities available for policy advocates. I argue that the historical progression of IDD advocacy is shaped by the evolution of Canada's welfare state. The evolution of the welfare state has created new opportunities for IDD advocates to affect the policy agenda, most notably reflected in the birth of the community living/deinstitutionalization movement. What is more, I point to the complexity and ambiguity of these political institutional avenues by demonstrating the fundamental conflict between competing views of Canadian federalism within the academic literature. I contend that the dissensus between contrasting definitions of federalism belies a broader ambiguity about political institutional behaviour and intergovernmental relations in Canada's 'social union', which affects the interpretation of policy goals and the decisions made by policy actors, particularly in issue areas where federal steering powers exist. This is relevant to developmental services because the federal government has traditionally steered service provision through intergovernmental agreements (Prince 2001; 2009) and has committed to install federal standards through the *Accessible Canada Act, 2019* that will extend into several domains of provincial developmental services. I support this line of argumentation by presenting textual evidence derived from interviews I conducted with IDD advocates. With an eye to the political institutional context, I present evidence that an 'empowerment/recognition' framing of social inclusion is preferred by advocates who are weary of tokenistic consultation practices in processes of policy design. This sets up a discussion of implications for the SISI at the conclusion of the chapter.

The fourth and fifth chapters shift the focus of the dissertation to the implementation of developmental services policies. In the fourth chapter I provide an extensive literature review of policy implementation literature and introduce the policy re(framing) conceptual framework that I use to identify and classify implementation framing processes. The literature review is organized by separating policy implementation scholarship into three streams: top-down, bottom-up and hybrid perspectives. Within each stream, I discuss how Canadian policy implementation literature has identified relevant actors and instruments favoured by the approach. This sets up my argument that implementation is an act of (re)framing – which I ground in a discussion of divergence from policy intent as a reframing of policy. To this end, I propose three possible explanations for frame divergence, which form a theoretical foundation for the analysis of interview data presented at the end of Chapter 4 and throughout Chapter 5. I argue that focusing on divergence is misleading because it mischaracterizes policy intent as static and uniform, rather than something which is dynamically interpreted by actors throughout the implementation chain. To this end, I propose a novel typology in Chapter 5 to classify implementation decisions based on their adherence to existing frames that correspond directionally to the three streams of literature introduced in Chapter 4. I organize the data from interviews with developmental services implementers in accordance with this novel typology to gain insight into which framings of social inclusion influence their implementation decisions. Both chapters conclude with a discussion of key implications for the construction of the index.

In the sixth chapter, I present the SISI by first discussing the methodological approach to indicator selection and weighting. This methodological approach is justified in adherence to the framing analysis conducted in the previous chapters, such that the connection between the descriptive data is made explicit. I then systematically introduce each of the four dimensions of the SISI by justifying the specific indicators used and how they are weighted, describing cross-provincial variation, and acknowledging limitations. This is followed by a section that outlines the weighting of all four dimensions in the index, and a broader discussion of cross-provincial variation across domains. Discussion of the implications of SISI is presented in the dissertation's final chapter, which is organized to present some primary discussion points originating from the index scores. This is complemented by a discussion of the index's artificial bias towards older adults with IDD, which opposes the tendency of developmental services policies to prioritize younger service users. Next, I present a thorough discussion of the early impact of COVID-19, both on the research findings and more generally on social inclusion in the provision of developmental services. The dissertation concludes with a discussion of key theoretical and empirical contributions, and potential future applications of the SISI by both scholars and practitioners.

CHAPTER 2: FRAMINGS OF SOCIAL INCLUSION IN CANADIAN INTELLECTUAL AND DEVELOPMENTAL DISABILITY POLICY DESIGN

"The crisis of disability programs is in part the result of an impossible concept – the concept of categories as a sure means of separating the needy from the non-needy... If one starts from the opposite assumption – that people exist only as social beings, inherently dependent and inextricably bound to familial, communal and economic structures – the very idea of self-sufficiency on which the categories are predicated becomes absurd."

- Deborah A. Stone 1984,
The Disabled State, p.191

2.1 Introduction: The Institutionalization of Social Inclusion Policy Framing

Having introduced the purpose and objectives of the project in the first chapter, this chapter undertakes an exploration of the concept of social inclusion as it used in Canadian disability policy design, culminating in a framing analysis of all provincial and federal level policies applying to people with intellectual and developmental disabilities (IDD). First, I present a conceptual sketch of social inclusion by examining how this multidimensional and contested concept has been a defining objective of social policy since the early development of the welfare state. Next, I explore how the concept of social inclusion has been understood in disability politics, and by extension how it has been defined as a problem to be solved by public policy. This is followed by a discussion of how the problematization of social inclusion has been distilled into policy objectives targeted at people with IDD in Canada. I demonstrate that the processes that distill the broad concept of social inclusion into specific policy objectives are shaped by interpretations of the concept and the prioritization of specific deliverables by various actors at multiple levels or scales. With concepts such as social inclusion, which are inherently amorphous and broad, the possibility of multiple problematizations leads to high ambiguity that disrupts the instrumental analysis of policy design as a product of singular and specific problematizations (Rein 2006). To mitigate this ambiguity in this chapter, I group policy designs in to separate framing categories, reflecting specific problematizations of the social inclusion concept as it pertains to policies targeting Canadians with IDD.

Drawing upon this theoretical and historical context, I then provide a cross-provincial comparison of social inclusion policy framing which first distinguishes distinct framings of social inclusion through a textual analysis of all provincial and federal level disability policies, and then examines whether specific framings of the concept have become institutionalized as they apply to people with IDD. The discussion of policy framing is informed by a conceptual framework proposed by Bjornehead and Erikson (2018) called the frame institutionalization ladder, which identifies four stages of frame institutionalization, defined as "the process in which a frame gradually gains influence and regulative functions" (p.113). Frames may ascend or descend the ladder of institutionalization depending on their influence at a certain point in time. This conceptual framework provides descriptive leverage to analyze a process that has long been central to the study of policy framing: the replacement of previously dominant frames by emergent opposing frames, particularly during situations of policy controversy (Schon and Rein 1994). In the past, policy framing analysis has tended to be more of a 'winner-takes-all' proposition, where the shifts in dominant framing are determined primarily by their formal institutionalization in legislation. The frame institutionalization ladder framework allows a more nuanced approach to frame dominance and decline in policy design over time by reference to the four distinct stages:

<u>Frame institutionalization ladder</u>

i) ***Reaching the political agenda*** (usually propelled by advocacy efforts)
ii) ***Support from a coalition of actors or key actors*** (e.g. politicians or civil servants)
iii) ***Official acknowledgement*** (e.g. formally through government reports/directives or informally when recognized by all actors within political debate)
iv) ***Formal institutionalization*** (expressed in formal institutions, often legislation)

(Bjornehead and Erikson 2018, p. 113)

In this dissertation, the framings of social inclusion contained in IDD policy designs are foundational to the comparison of how the concept is framed and reframed throughout the policy process. In order to understand how policy relevant actors reframe policy designs, specifically in the implementation stage where they may differently interpret, or intentionally diverge from policy intent, it is necessary to first take stock of how a policy was framed in the design stage. This is all the more important with the social inclusion concept, which is so amorphous in its definition as to engender numerous possible interpretations and operationalizations by different stakeholders.

2.2 Social Inclusion as a Contested Concept in Public Policy Analysis

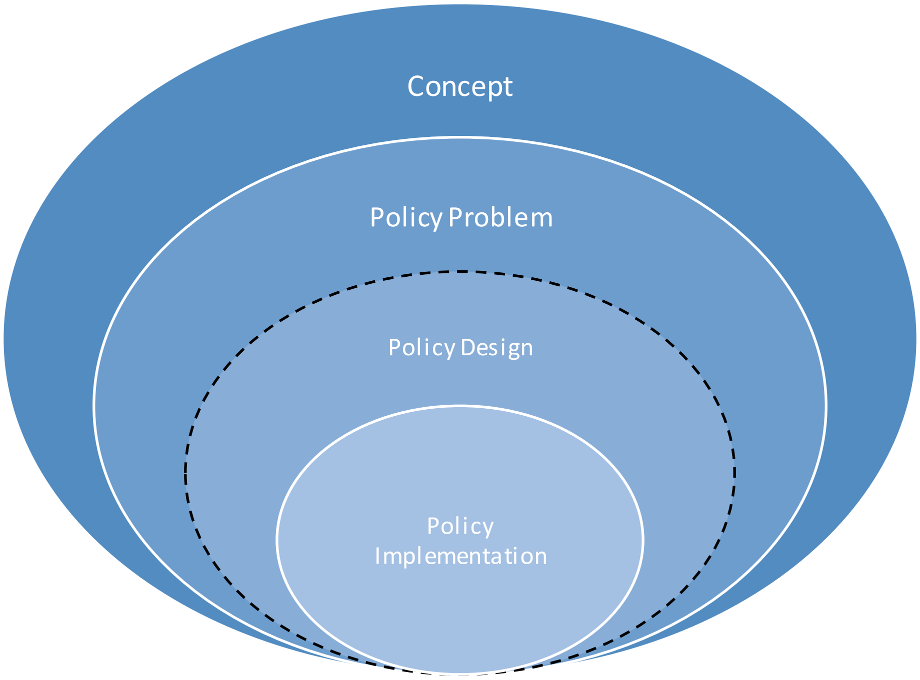
At first glance, social inclusion appears to be a normatively attractive concept, specifically in the realm of IDD policy, where it has widespread support without much contestation. In broad strokes, most would agree that the prospect of 'full participation in all aspects of life' (ESDC 1998) should not be actively denied to anyone. Consensus on the normative attractiveness of social inclusion contributes to the political appeal of the concept and has thus made it a reliable target in policy design. Indeed, social inclusion satisfies the criteria of what Pollitt and Hupe (2011) call a 'magic concept' - a pervasive power word that is frequently, uncritically employed by both scholars and practitioners, such as 'governance', 'networks', and 'accountability'. They attribute four main characteristics to magic concepts:

i) broadness - both in terms of the scope and multiplicity of possible definitions
ii) normative attractiveness - both by positive connotation and not lending to binaries
iii) implication of consensus - rarely defined, and insulated from incommensurable logics
iv) global marketability - frequently used by scholars and practitioners

(summarized from Pollitt and Hupe 2011, 643)

At the conceptual level, social inclusion meets all these criteria. It is frequently used without being defined, has broad implications for different theoretical and practical approaches, and is normatively attractive because the opposite – social exclusion – is commonly presented as undesirable. But how does this 'magical' quality travel as the conceptual scope is limited by the policy process? That is, do these characteristics still apply as the concept is operationalized into policy problem definitions, and further into policy designs (see Figure 2.2)? In this chapter, I argue that the concept loses magical qualities such as definitional breadth, normative attractiveness and the implication of consensus as it is operationalized in policy designs. This effect can also be seen with the magic concept 'accountability', which similarly loses its magic via distillation into good and bad accountability mechanisms in various policy designs and governance structures (see Saint-Martin 2004). As the conceptual scope is limited through problem definition, policy design and implementation, the 'magic' is lost.

Figure 2.2. Decreasing conceptual scope of social inclusion through policy process



At the conceptual level, this thesis does not set out to empirically establish the fit of social inclusion as a magic concept, although it clearly meets many of the criteria[7]. Instead, this thesis focuses on the distillation of the concept into policy design and implementation framings. Nonetheless, the notion of the 'magic concept' is a useful way of accounting for the ambiguity of the social inclusion concept, which has important implications for the multiplicity of potential policy framings. As the next section will demonstrate, when applied to the context of disability politics, social inclusion is attached to numerous possible definitions of varying scope. Although the term is often employed without qualification or additional definition, this multiplicity of

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[7] Although 'magic concepts' are relatively new in the policy literature, several scholarly contributions demonstrate the ease with which social inclusion in IDD policy fits the criteria. First, Bragaglia (2021) establishes 'social innovation' as a magic concept, and Torfing et al. (2022) address 'co-creation' as a magic concept, both employing concepts which share important ideational commonalities with social inclusion, despite their very different application in EU policy discourse, and Norwegian social policy design, respectively. Second, Carey and Malbon (2018) successfully employ the magic concept framework to chart the movement of a concept through the implementation of the Australian National Disability Insurance Scheme, thus demonstrating important procedural overlap with this thesis.

definitions at the conceptual level generates contestation when they are reified into disability policy ideas. Therefore, by contrasting empirically how this concept is understood and operationalized in policy designs at the federal level and within Canadian provinces, we gain insight both into the ways the concept is ideationally framed, and the policy areas to which it is applied. By analyzing the historical evolution of available policy frames in terms both of their quantity and thematic substance, it is possible to engage a discussion of the dominant social attitudes that underlie histories of social *exclusion*. What is more, by highlighting areas of discrepancy between theory and practice regarding social inclusion for people with IDD specifically, it is possible to highlight areas of focus for identity social movements aiming to work against exclusion more generally.

A common starting point for the understanding of social inclusion as a policy objective is T.H. Marshall's notion of social citizenship (1950), which reflects a vision of the welfare state as a key catalyst in the promotion of social equality. Indeed, social policy analyses have applied Marshall's social citizenship to frame inclusion in policy areas such as immigration (Banting 2005), education (Wallner 2010); citizenship (Jenson and Saint-Martin 2003; Prince 2012), governance (Barnes 1999), and disability (Heyer 2015; Prince 2009). In this view, social inclusion, conceptualized as community participation, is seen as the next step in the evolution of citizenship rights, which, crucially, is dependent upon decreasing income disparity so that economically disadvantaged individuals may achieve a social minimum that enables their inclusion and participation (see Marshall 1965. 210-215). To this end, when social inclusion gained popularity as a policy objective in Europe during the 1980s, it was increasingly promoted to counteract the enduring effects of poverty, where social exclusion was made synonymous with labour market exclusion (Levitas 2006, 125). Conceptualizing social inclusion as such thus privileges employment-based solutions, and thereby constrains the universe of available policy options.

This fundamental ideational connection between poverty and exclusion resonates in modern social inclusion policies, most notably the European Union's bilateral efforts through the Open Method of Coordination (OMC), which defines social inclusion as "the process by which societies combat poverty and social exclusion" (Atkinson and Marlier 2010, 1). For some authors, the efforts of the OMC demonstrate the high priority that social inclusion is afforded in the modern social policy context, as the fifteen member states quickly created National Action Plans based on common policy goals with the aim of elucidating best practices in this policy area (Begg and Berghman 2002). However, the EU case also demonstrates a fundamental problem with aggregating social inclusion policies because the shift from common policy goals to individual policy instruments requires contending with contextual factors unique to both individualized policy areas and specific target populations within each jurisdiction. As a result, Mabbett (2007) argues that the policy strategies adopted at the national level diverge significantly from the citizenship-oriented focus of the OMC and have instead been tailored towards achieving improvements in a select, and rather limited group of common indicators, such as risk of poverty, unemployment, education and life expectancy.

Canadian social policy shares this ideational foundation regarding the role of policy in promoting inclusion with a specifically labour market focus (Porter 1965; Banting 1987; Brodie 1999). It also shares the problems of operationalizing social inclusion in policy design. At the ideational level there has been a growing commitment to the notions of inclusion and equality as fundamental rights since the enactment of the Charter of Rights and Freedoms in 1982, which created opportunities for identity social movements to pursue social inclusion policies (Smith 2005). However, scholars have been critical of the ‘false universalism’ of this type of rights-based framing because it ignores key differences between identity groups, which are often the basis of discrimination and exclusion (Dobrowolsky 2008). Moreover, this framing coincided with the increasing influence of economic logic on policy design, resulting in a neoliberal shift towards the marketization of social programs in the 1990s, which served to shape public attitudes about which groups were ‘deserving’ of state intervention (Rice and Prince 2013).

Several authors have found that this marketization favours policy designs that positively affect economic indicators such as tax revenue and employment rate, thus constraining the policy frames available to identity social movements such as Indigenous peoples (Jenson and Papillon 2000), Quebec sovereigntists (Changfoot and Cullen 2011) and LGBT groups (Smith 2005), who seek to address a wider range of barriers to social inclusion. This logic has also been attributed to welfare state retrenchment signaled by decreased federal funding for social programs, thus signaling both an increase in provincial autonomy and a gradual decline in the strength of Canada’s social union in upholding a concept of universal social citizenship to mediate regional tensions (Banting 2012; Noël 2003). In Canada, as in the EU, there is thus an inherent tension between the broad understanding of social inclusion as a macro-level policy priority, and its comparatively constrained definition in policy applications. As such, I expect the cross-provincial framing analysis to reflect this tension in policies directed toward Canadians with IDD with a high variability in scope between policy instruments. This divergence between policy problematization and the universe of available solutions matters both to policy analysts – because it speaks to both the inherent design biases of IDD policy structures – and to anyone invested in understanding the potential of Canadian social and political institutions to overcome systemic biases to promote the inclusion of marginalized groups.

2.3 Social Inclusion as a Disability Policy Idea

Before addressing how social inclusion is distilled as a policy idea and framed in different disability policy designs, this subsection begins by engaging with the definitional breadth that makes it an exceptional or ‘magic’ concept, by examining the extent of its contestation. Not only do different policy actors advocate for different understandings or dimensions of social inclusion (e.g. employment, housing, social recognition, etc.), but even when the concept is tightly specified there are disputes over how it is interpreted (e.g. debates over what constitutes inclusive housing). To this end, I examine two aspects of the social inclusion concept that amplify its contestation when it is applied to people with disabilities generally, and with IDD specifically: i) its overlap with the concept of personhood and ii) the dynamics of performance/performativity that result from the embodiment and enactment of inclusion.

a) Disability and the Politics of Personhood

First, perhaps more than any other ‘big idea’ that grounds policy, social inclusion must be understood as a fundamental component of personhood. Even big ideas such as poverty reduction or religious freedom – which at the conceptual level provide normatively attractive foundations for policy – are more conducive to politicization and polarization, and thus more unlikely to generate similar widescale consensus than social inclusion, particularly as essential aspects of personhood (Natili 2019; Yuval-Davis et al. 2019; Witte and Green 2012). By contrast, as Ikäheimo (2008) asserts, the idea of social inclusion fundamentally requires an interpersonal recognition of personhood, and this recognition is a vital dimension of personhood – even as it is constituted individually. That is, by aspiring towards an inclusive society we must accept the project of recognizing and accommodating difference, which is a project of accepting personhood, both for others and ourselves. As such, promoting social inclusion through public policy equates to promoting a vital *interpersonal* aspect of personhood that has been systematically denied by what Ikäheimo calls an absence of 'recognitive attitudes' (2008, p.78). This resonates deeply with the history of disability politics, where the fight for the recognition of disability personhood has been a central focus.

An obvious example of this push for disability personhood is the advocacy efforts centred around person-first language. These efforts began as early as the 1970s but were significantly propelled by the surge in advocacy surrounding the 1981 International Year of the Disabled, where person-first language – best exemplified by the phrasing *people/persons with disabilities* – became the primary terminology preferred by disability advocates and scholars writing in the burgeoning field of disability studies (see Titchkosky 2001). These efforts were rationalized by the desire to link the concepts of personhood and disability in the public discourse, in recognition of the fact that many facets of personhood had been categorically denied to people with disabilities. It is worth noting that the effectiveness of this discursive distinction was quickly criticized by disability scholars, including the main proponents of the social model of disability. For example, in the pre-eminent text on the social construction of disability, Oliver (1990) argues that person-first language portrays disability as an appendage rather than an essential component of who *disabled people* are (p. xiii). This line of argumentation is continued by Titchkosky (2011) who argues that person-first language ascribes value to the person, while devaluing their disability, which by its separation from the individual is constructed as a difference that is both a danger and impediment to personhood (p. 53-4). Thus, by separating disability from personhood, we deny it a place as an aspect or dimension of personhood, and thereby problematize inclusion for disabled persons. Despite these compelling critiques from the field of disability studies, person-first language has come to dominate disability parlance in policy and practice in Canada, as is evident in the federal and provincial policy review discussed later in this chapter.

The fundamental connection between social inclusion and personhood, foregrounded by the debates surrounding person-first language, demonstrates one domain of difference between disability politics and other identity politics for which social inclusion is a desired policy outcome. For example, Yuval-Davis et al. (2019) argue that for racialized minorities social inclusion revolves around the politics of belonging, where membership in powerful collectivities is denied as a political hegemonic project of exclusion (p.7-9). Thus, in the politics of belonging, discrimination is prohibited *de jure*, as racialized minorities may be protected by anti-discrimination laws; however, they are excluded *de facto* through barriers to entry into powerful social groups. In contrast to the politics of belonging, the politics of personhood precludes group membership by calling into question whether people with disabilities are entitled to the same treatment, or more specifically in debates such as those over legal decision-making capacity, the same basic rights as other humans.

While the fight for personhood has long been a central focus within disability politics, in contrast to the broader disability community, people with IDD encounter a unique, and in many ways more pervasive set of barriers to personhood. Particularly confounding to efforts toward social inclusion are the barriers of stigma and structural discrimination, which impede the implementation of social inclusion policies for people with IDD across the world, perpetuating their heightened vulnerability to poverty and the denial of human rights (Ditchman et al. 2016; WHO 2011). We may draw a compelling example of these barriers from longstanding debates in moral philosophy regarding the interrelationship between personhood and the capacity for decision-making. For moral philosophers such as John Rawls, cognitive impairments pose a significant challenge to individual agency, and thus personhood, by limiting an individual's capacity for rational judgement. Nussbaum (2010) critiques Rawls' theory of justice on the grounds that it ignores the claims of people with IDD by requiring that all equal partners in a social contract are 'free, equal and independent' and possess approximately equal amounts of physical and mental capacity (p.77). That is, imposing a minimum threshold based on cognitive capacity for social functioning creates an insurmountable barrier for people falling below these thresholds, whose avenues for appeal are equally curtailed by the presumption of their incompetence. Nonetheless, this Rawlsian notion of personhood is reflected in numerous Canadian social and political institutions, which valorize independence and continue to deny IDD personhood, as has been evident in two recent focusing events.

First, the debate around Canada's medical assistance in dying legislation Bill C-7 has drawn attention to the pervasiveness of medicalized notions of disability, in contrast to the ubiquity of the social model within disability policy and politics. What is particularly upsetting to people with disabilities and other disability advocates is the bill's provision to classify "people with disabilities and disabling conditions as the *only* Canadians to be offered assistance in dying when they are not actually nearing death"[8]. This both propels the ableist assumption that a disabled life is not worth living, while also furthering the ableist mythology that paints disability as a personal tragedy (Barnes 1990; Oliver and Barnes 2012). Despite an unprecedented display of unity among Canada's disability advocacy groups – discussed in greater detail in later chapters of this dissertation – the targeted sections of Bill C-7 were not revised, and the bill received parliamentary assent on March 17, 2021[9].

A second focusing event for policy advocacy around disability personhood occurred in the immediate aftermath of the COVID-19 pandemic when provincial health ministries quickly drafted triage protocols in preparation for potential shortages of hospital beds and ventilators as cases quickly grew. Specifically, in Ontario and Quebec the draft protocols allocated ventilator access based on the use of frailty scales, leading disability scholars and advocates to quickly denounce the protocols as ableist and discriminatory (Lemmens and Mykitiuk 2020). In both provinces, the public backlash[10] successfully led to revisions of the draft protocols; however, the very fact that such major mobilization to protect the right to medical treatment for a population that was disproportionately affected by the pandemic (see Brotman et al. 2021) points to the precarity of IDD personhood. As is discussed further in chapter 3, the history of IDD advocacy contains a multitude of examples of this ongoing fight for personhood, fuelled by social and political institutions that seem designed to dehumanize people with IDD.

b) Performativity and the Exceptional Challenge of Disability Politics

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[8] Quoted from a joint statement of 147 Canadian disability advocacy groups voicing shared opposition to bill C-7 available at: http://www.vps-npv.ca/stopc7

[9] The final version of the bill is retrievable at: https://www.parl.ca/DocumentViewer/en/43-2/bill/C-7/royal-assent

[10] A summary of the position taken by Quebec advocacy groups can be found at https://triage.quebec/

The barriers of stigma and discrimination are obviously not unique to people with IDD, or people with disabilities more broadly, but these exclusionary attitudinal barriers are enacted against and experienced by people with disabilities in unique ways. This leads to a second important aspect of what makes social inclusion a contested concept: the divergent and at times contradictory ways that inclusion/exclusion is performed by/against different marginalized identity groups. A common starting point for identity politics is the notion that exclusion is enacted in the ways that social and political institutions behave, specifically in the exclusionary (racist, sexist, ageist, sanist, ableist, etc.) performative expectations they impart on their subjects (Béland 2017; Vanhala 2009; Fischer 2003). In the case of people with IDD, the backdrop against which inclusion/exclusion occurs are the performative expectations of institutionalized ableism, which are amplified further for people with IDD, whose neurodiversity confounds numerous social norms.

Public policy has long recognized the social disadvantages imposed on people with disabilities. The quote from Deborah Stone which appears in the epigraph to this chapter neatly sums up the exceptional challenge that disability poses to welfare state structures that are predicated on the notion that social policy exists to lift people out of poverty and dependence to a state of self-sufficiency. For people with IDD, many of whom rely on accommodations and supports to gain equal opportunity of access to social functions such as employment and education, the objective of self-sufficiency is untenable. By contrast, by simply adjusting performative expectations in ways that accommodate IDD diversity, the false idealism that underlies existing accessibility policies would give way to material manifestations of neurodiversity (Erevelles 2002). In this way, performativity has as much to do with the politics of belonging as it does the politics of personhood. Indeed, as Orsini (2012) argues, for Canada to truly accommodate IDD (his work focuses on autism, but it applies to IDD more broadly) would require a reconfiguration of the citizenship regime that accommodates neurodiverse performativity. These accommodations can entail the provision of additional supports in key areas of social inclusion, such as classroom assistants to facilitate educational integration or on-site job coaches to support acclimation to a work environment. Obviously, this is a herculean task for the machinery of public policy, specifically when we consider the limitations in terms of resources available to departments in charge of developmental services at the provincial level. Nonetheless, the point remains that accommodating the exceptional challenge of IDD performativity becomes dramatically more tenable when we begin to take aim at the ways existing institutions perpetuate social exclusion.

Disability politics has adopted the concept of performativity from gender politics, and specifically the work of Judith Butler. For Butler (1990), gender identity exists solely as it is performatively produced, specifically through language, such that individual actions are not expressions of a pre-existing gender identity, but rather that these actions are only legible by how gender has already been discursively constructed (see also Salih 2003, p.56-9). Disability scholars employing Butler's notion of performativity find value in combining it with theories of embodiment to examine how disabled bodies, through their different performative capabilities, can challenge ableist norms. As Goodley (2013) succinctly puts it: "(t)he dominant ableist self is ready and willing to bring disabled people back into the norm (re/habilitate, educate) or banish them (cure, segregate) from its ghostly centre" (p. 640). However, at the same time, disability performativity also has the potential to disrupt normative expectations by providing a strong foundation for critiques of ableism, specifically as it is enacted by public policy.

In the opening chapter, I discussed how interpretive policy scholarship treats public policy as a language artefact that signifies a specific causal story through text (Yanow 2014; Stone 1989). Performative acts are also human artefacts in the sense that they have the potential to elucidate relevant constructions of meaning (Yanow 2014, 138). The exceptional challenge of IDD performativity enables powerful critiques of the mechanisms by which existing institutions attempt to accommodate people with IDD. Ahmed (2012) examines these mechanisms as forms of 'institutional commitment', which she defines – drawing from Butler – as a subset of the 'non-performative' ways that institutions behave. Using the example of racial equality policies within the institutional environment of the university (such as diversity statements that 'commit' to racial equality in hiring practices), she points to how non-performatives are designed precisely to not achieve the effect that they name (p.116-21). Drawing directly from Ahmed, Mitchell (2015) critiques the phenomenon of 'inclusionism' in disability policy as a non-performative form of institutional commitment, where mechanisms of integration – that favour disabled people who are most able to meet the performative expectations of an ableist society – produce a weak form of inclusion that more forcefully excludes and further renders invisible all other disabled people. He argues that this is particularly true of weak accommodation policies which ignore the diversity of disability embodiment and tend to privilege types of disability that are easiest to accommodate (p.36). Any study of social inclusion policy must be cognisant of 'inclusionism' by examining how performative expectations determine who is included, and how it is enacted.

2.4 Social Inclusion as a Policy Objective for People with IDD

Within the disability literature, social inclusion has been most commonly associated with the idea of participation through social functioning. The most prominent example of this association is Wolfensberger's (1983) 'social role valorization' approach, which posits that 'normalization' will occur when people with IDD are seen holding valued social roles, such as the worker or student, that challenge exclusionary constructions. Wolfensberger contends that social roles both award a person with a 'place' in society and allow them to be situated and defined by others (2000). This perspective is reflected often in the Canadian disability policy literature, which emphasizes employment as the primary venue for social inclusion (Prince 2014; Toth and Dewa 2014; Hall and Wilton 2011; Thun 2007). These authors propel the notion that greater access to employment for people with disabilities provides both personal benefits, derived from financial reward and emotional fulfilment, and external benefits from increased public visibility. This latter benefit is especially important to challenging the disadvantaged roles of people with disabilities as excluded or 'absent citizens' (Prince 2009).

Despite its ubiquity, 'social role valorization' has been critiqued for ignoring how older adulthood and other intersectional categories, such as gender or race, problematize the idea of normalization (Walker and Walker 1998). Further critique has pointed to the connection of normalization discourse to professional interventions, rather than the preferences of people with IDD themselves (Chappell 1992). For example, older adults with IDD are thought to prefer alternative avenues to social inclusion, such as recreational programming or community engagement, which are given less priority within the literature and within disability policy instruments (Salvatori et al. 2003). These divergent preferences are accommodated by broader definitions of social inclusion outcomes, which include interpersonal communication and meaningful interaction (Amado et al. 2013; Schalock et al. 2008). Yet, the potential of disability policy to explicitly provide opportunities for these particular outcomes with this specific population has been sparsely addressed in the Canadian literature, creating a significant gap in terms of scholarly knowledge and strategies for practitioners, thus compounding the policy gap.

One promising report published by the Roeher Institute proposed a more broadly-devised definition of social inclusion based on the dimensions of 'Access' and 'Support' – the latter of which incorporates interpersonal relationships as a key component (Crawford 2003). This same study put forth an index of social inclusion for people with all disabilities in the specific area of employment. While the author suggests that this same strategy could be used to measure the domains of access and support for other areas of social inclusion, the reliance of the index on large-n survey data derived from national post-censal disability surveys limits the potential for indicators across all dimensions of social inclusion. Moreover, the nature of these post-censal surveys has limited applicability for older adults with IDD, who are so sparsely sampled by national level surveys, that even provincial demographic statistics do not reach reportability thresholds (Statistics Canada 2009). In addition to these limitations in even purposive sampling, the national disability surveys are designed to emphasize access to employment and education as key variables of inclusion, which are of greater relevance to younger people with IDD. Finally, owing to the general nature of these instruments, they provide minimal insight into the support dimension of social inclusion.

For this reason, the Canadian literature on inclusion for people with IDD has in large part ignored the survey instruments, placing greater value in the experiences of personal support workers in navigating the existing policy landscape to help facilitate social inclusion outcomes for service users (Pedlar et al. 2000; Sparks 2000; Kelly 2016). This has enabled the development of new indicators to tap social inclusion at the individual level. For example, Wilton et al. (2018) explore consumption as a key social inclusion domain by providing a thorough analysis of the activity shopping as an indicator of social inclusion. In particular, they emphasize the ways that the normative ideas of performative appropriateness or belonging in consumption spaces – such as shopping malls or grocery stores – can constrain the social inclusion of people with IDD. In this way, they stress that it is important to go beyond the question of *if* people with IDD are included in these spaces to gain a greater sense of *how* inclusion occurs.

This preference towards more subjective measures of social inclusion has become increasingly common in the literature. In a highly influential treatment of the topic, Simplican et al. (2015) conduct a sweeping review of the existing literature before advancing a definition of social inclusion for people with IDD that is based around two domains: interpersonal relationships and community participation. In both domains, they emphasize the importance of integrating subjective feelings, such as that of belonging, alongside the more the objective measures of social inclusion that are associated with measurements of quality of life (such as Schalock et al. 2008). This approach is adopted by Overmars-Marx et al. (2017) who extend the scope of subjective experiences beyond people with IDD themselves, to include their support staff. By interviewing group home staff, they find that the "professional role identity" of group home staff relative to both the developmental services organization and the supported individual is a significant determinant of social inclusion outcomes. However, without the tools to conceptualize the influence of both organizational configurations and the discretion afforded to frontline workers in deviating from or conforming to operant policy designs, their findings have limited implications for best practices. This points to the importance of policy implementation in understanding social inclusion outcomes for people with IDD.

By bringing relationality and interpersonal relationships in, the concept of social inclusion gains important analytical breadth, allowing it to extend into complicated dimensions that speak to the unique experiences of people with IDD. This is reflected in an emergent stream of scholarship, which attempts to incorporate power as a key dimension of social inclusion. Drawing from the fields of critical disability studies, or more specifically critical autism studies (see Orsini and Davidson 2013), authors in this emergent stream see the persistence of power asymmetry and oppressive social practices as an ongoing barrier to inclusion policy for people with IDD. Simplican (2019) argues that challenging behaviours such as aggression and self-injury, which are often used to justify the exclusion of people with IDD from social domains, are often a reaction to asymmetries or power imbalances, particularly in the delivery of developmental services. To this end, she cites a study by Griffith et al. (2013) where the authors conduct a thematic synthesis of 15 existing studies on challenging behaviours in people with IDD and find that the most prominent cause is a perceived power imbalance, where individuals feel out of control of their immediate environment and their broader life trajectory (p. 476-7).

Accounting for power and relationality is a key component of Bigby and Wiesel's (2011) work on 'encounter' as a valuable dimension of social inclusion. The authors argue that in order to move beyond the ambiguity of 'community participation' as a frequent target of inclusion policy, efforts should focus on the types of encounters experienced by people with IDD in their daily interactions. The benefit of this focus on encounter is that it shifts the onus for inclusion beyond the excluded individual and their closest social supports to focus also on increasing the inclusivity of social structures, community spaces and non-disabled strangers (Ibid, p.266). Once again this requires taking stock of how persistent power imbalances, shared social structures and community spaces may perpetuate social exclusion by presenting barriers to power-neutral encounters.

For example, it has long been established in Canadian jurisprudence that if a community space is not accessible, then an affected individual cannot be considered to have equal opportunity of access. This precedent was established when the Supreme Court of Canada upheld a decision by a Saskatchewan Court of Appeal in the case of Canadian Odeon Theatres Ltd. v. Huck (1985, 6 C.H.R.R. D/2682) stating that "(a)cts which are neutral on their face, which treat individuals in the same way, are nonetheless prohibited if they have the effect of continuing discriminatory practices."[11] Huck, a wheelchair user, originally began the court battle after attempting to attend a movie theatre where he was unable to safely transfer to a theatre seat nor easily view the movie from a small designated area at the front of the theatre. While the movie theatre company claimed that their sole responsibility was to meet the criteria of equal opportunity by providing a film and a space to watch it, the Supreme Court of Canada established that it is discriminatory to provide a service that is not accessible to people with disabilities, setting an enduring precedent for accessibility legislation in Canada (Lord 2010, 117). This is a useful foundation for understanding the concept of encounter as a key dimension of social inclusion for people with IDD because power imbalances in social relationships can be understood as barriers to inclusion in the same way inaccessible spaces are. In a practical sense,

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[11] Saskatchewan Court of Appeals summary retrieved from: https://www.canlii.org/en/sk/skca/doc/1985/1985canlii183/1985canlii183.html

these imbalances can be addressed by non-tokenistic approaches to promoting power-neutral encounters in processes of IDD policy design, including effective consultation and target-setting.

2.5 Method: Critical Frame Analysis

To identify and distinguish between operant social inclusion policy framings as they apply to people with IDD, I draw from the critical frame analysis approach (Verloo 2005; Verloo and Lombardo 2007). This approach, stemming from interpretivist policy scholarship, perceives policy as inherently political, as policy problems and solutions become analytically legible through the way they are discursively framed. In this way, the framing of policy problems originates in normative understandings that extend the traditional idea that problem definitions create policy solutions or shape the agenda (Rochefort and Cobb 1993), to focus on how representations of the problem structure the policy discourse, thus shaping the ways a policy is practiced or experienced beyond the scope of policy design (Bacchi 1999). By taking stock of these discursive dynamics, critical frame analysis is well situated to address the political instrumentality of competing frames. Schon and Rein (1994) argue that taking stock of political dynamics is important because frames are inherently competitive, with dominant frames offering insight into which actors have the most authority over intractable policy controversies (p.28-9). In the present study, critical frame analysis is particularly valuable because it is designed to compare policy frames both cross-provincially and across multiple governance levels by accounting for the interactive nature of policy design (Verloo 2005, 19). As such, the methodology was chosen for its ability to elucidate the dominance of particular policy framings, which enables their comparison across time, province and level of government.

The concept of social inclusion is well suited for critical frame analysis, as it has been applied to numerous groups of actors, in multiple policy contexts (Percy-Smith 2000; Cushing 2003). For people with IDD, social inclusion has been measured through tightly specified, multi-dimensional indicators, with applications in policy-relevant fields such as social work (Simplican et al. 2015; Schalock et al. 2008). However, it is important to note that critical frame analysis does not draw from pre-formulated codes when identifying frames, but rather identifies emergent frames in the analysis stage, which are grounded in the data (Verloo and Lombardo 2007). While this approach explicitly relies on the subjective interpretations of researchers in identifying framing categories, it provides the benefit of allowing researchers to observe more of the relationship between frames in comparative contexts. In keeping with this methodological strategy, framing categories were open-coded to highlight specific differences in provincial policy designs promoting social inclusion for people with IDD

The broad scope of disability policy allows for a large sample of relevant policies and programs across all ten Canadian provinces. A primary search of Canadian disability policy was achieved by referring to a comprehensive and current disability policy review (McColl et al. 2017). Using this review as a starting point, I collected copies of all the legislative acts and program documents listed therein and supplemented in cases where more current legislation existed or where omissions had occurred. This produced an initial sample of 398 policy documents from the federal and provincial levels. I then excluded from the sample policies that only applied to disabilities other than IDD, such as accommodation policies for visual impairments or physical disabilities, which reduced the sample to 275 policy documents. The second exclusion criterion for disability policy was whether it applied, in broad strokes, to social inclusion as a policy objective, including synonyms such as community participation or social integration, and also policies that only focus on the removal of specific barriers to inclusion. To this end, I selected some policies with very superficial connections to the concept, with the knowledge that non-pertinent policies would be excluded during the frame analysis. Relevant examples include federal student grant policies or provincial adoption acts, which both make reference to IDD and pertain to social inclusion. This reduced the sample to 165 policy document that pertained, in broad strokes, to both IDD and social inclusion.

Following these exclusion criteria, I approached the documents by first identifying whether they explicitly mentioned social inclusion. If yes, I noted the ways in which this concept was framed. Finally, where relevant, I assessed how social inclusion is defined by identifying and categorizing distinct policy frames. Interestingly, very few of the documents in the sample provided an explicit definition of social inclusion. For example, in broad scoping acts of legislation, such as the *Accessible Canada Act, 2019* (ACA), key definitions are often provided at the outset of the document so that terms, such as 'disability' and 'barriers' are clearly understood prior to their application thereafter. Despite being identified as the cornerstone of the Canadian federal government's 'Disability Inclusion Action Plan' (Speech from the throne 2020), the ACA does not define social inclusion, nor does the term 'inclusion' appear once in the text. Similarly, Ontario's *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* – broadly referred to as 'the social inclusion act' – provides extensive definitions of both 'services and supports' and 'persons with developmental disabilities' while also omitting a definition of social inclusion, and any use of the term subsequent to the title of the Act.

This lack of explicit social inclusion definitions supports the idea that the concept is 'magic', as the breadth of the concept limits the need, or even the potential, for definition in policy designs (Pollitt and Hupe 2011). The lack of definitions also supports the common argument in policy framing research that ambiguity in legislative instruments can be politically valuable, specifically when building consensus for intractable policy problems among large networks of policy actors (Schon and Rein 1994; Dekker 2017). Despite the general absence of explicit definitions, additional insight into the thematic character of framings was gained by drawing from examples of social inclusion contained within the documents. Where provided, I recorded the types of examples specified to demonstrate social inclusion. I paid particular attention to the ways in which these policy documents outlined how social inclusion could be achieved. For example, in the current generation of accessibility policies, which spans from the *Accessibility for Ontarians with Disabilities Act 2005* to the ACA 2019 and focuses on the removal of exclusionary barriers, the content pertaining to the removal of barriers was coded within the 'Community Participation/Removing Barriers' framing category. This open-coding approach led to the construction of six framing categories, which are introduced and discussed below.

By applying the exclusion criteria to the initial sample of policy documents, I ended up with 63 documents containing social inclusion policy frames for people with IDD. The frames were open-coded, with 6 major thematic categories emerging through the analysis (see Table 2.1). The framing categories were coded intuitively, with policy dimensions loosely corresponding to existing multidimensional conceptualizations of social inclusion from the disability policy literature (Shogren et al. 2015; Schalock et al. 2008). The first theme corresponds to policy frames focused on the promotion of 'independence, self-determination, choice and/or individual responsibility'. In this framing, the onus for social inclusion is placed on the individual, whose capacity for overcoming exclusion is limited by a lack of opportunities, thus providing the rationale for policy intervention. These policies framed inclusion broadly as the promotion of independence and choice, and thus had rather limited practical application. The second frame coded 'labour market participation' also emphasizes the provision of opportunities for individuals, but here the focus is directed to active labour market participation. A distinguishing feature of this frame is the emphasis it places on the social value attached to paid employment. For example, this frame was used in numerous disability income support policies to emphasize that effective vocational training and employment supports would reduce uptake on income support. This framing was employed by income support program documents in four provinces: Newfoundland, Ontario, Alberta and British Columbia. In stark contrast to the first frame, the second framing has precise policy applications, but is applicable to a relatively smaller sub-section of people with IDD for whom employment is both a desirable and realistic avenue to social inclusion.

Table 2.1 Themes emerging in frame analysis

Social Inclusion Policy Frames	IDD Policies
1. Independence/ Self-determination/ Choice/ Individual Responsibility	6
2. Labour Market Participation	11
3. Community Participation/ Removing Barriers	35
4. Anti-Discrimination/Human Rights	21
5. Attitudinal Barriers (Stigma)	5
6. Social Inclusion/Integration	20

The third frame emerging in the analysis was coded 'Community Participation/Removing Barriers'. This frame maintains some focus on individual responsibility, as active participation in society connotes autonomy and agency, however, this frame also acknowledges that society has a role in removing the exclusionary barriers that obstruct participation. In this framing, barriers are understood more as environmental obstacles that can be overcome with accommodations so that people can be included on equal terms. As such, there remains a significant onus on the role of the individual to actively facilitate their participation in the community. Policies in this framing category tended to apply to people with disabilities more broadly, rather than specifically targeting people with IDD. This framing is consistent with the ideas of universal design and reasonable accommodation, popularized by their inclusion in national level documents such as the *Americans with Disabilities Act 1990* in the United States. These ideas underpin a broader understanding of inclusion, applicable to all disabled people, which can be used to challenge and remove barriers to community involvement. As with the first frame, this framing is not well-suited to specific policy applications. However, unlike the first frame, this framing acknowledges that there are significant barriers to social inclusion that must be removed to create opportunities for inclusion. Therefore, while the first three framings tend to 'responsibilize' social inclusion by emphasizing the role of people with IDD in actively working towards their own inclusion, there are key differences in how this personal responsibility is understood.

This is a stark contrast to the fourth and fifth frames, which are focused more squarely on society's role in perpetuating exclusion. The fourth frame focuses on exclusion through discrimination and uses the language of human rights entitlements to prohibit exclusion based on individual characteristics. Outside of provincial human rights acts, this frame was most commonly employed in equal employment legislation, as a policy mechanism to prevent employers from discriminatory hiring practices. In this way its scope is comparatively smaller than the fifth frame, which takes aim at the broader social attitudinal attitudes that underlie discrimination. Policy in this 'attitudinal barriers (stigma)' frame adopts a more holistic approach to social inclusion based around promoting visibility to disrupt uninformed, yet broadly-held attitudes that act to stigmatize marginalized populations. The distinction between these two categories is very nuanced and is certainly a product of the framing categories being grounded in the data. Nonetheless, the distinction is important because it demonstrates a shift that has occurred over time from a focus on prohibiting discriminatory practices to changing stigmatizing ideas.

The final frame that emerged in the coding includes policy documents that either make specific reference to social inclusion or provide a working definition. This framing was the broadest in scope and was the closest aligned to what Schon and Rein call a 'rhetorical frame' than the other framing categories, which are definitively 'action frames'. Rhetorical frames are associated with a policy debate and provide a sort of normative rationale for action frames (Schon and Rein 1994, 32). In this way, the 'Social Inclusion/Integration' category most embodies the 'magical' elements of the social inclusion concept, as it asserts that inclusion is a worthy policy goal without specifying specific ways to promote it. Owing to its broad scope, this framing usually occurred alongside other frames within a single policy document. As is evident by the greater number of frames than policies, documents that employed multiple policy frames simultaneously were coded across multiple categories, such that 63 documents contained a total of 97 policy frames. Below I outline the key findings before assessing their relationship in a discussion of the operationalization of the social inclusion concept in policy design.

2.6 Framing Social Inclusion in Canadian IDD Policy Design

The most common framing for policies pertaining to people with IDD was the 'Community Participation/Removing Barriers' frame. Part of the preponderance of this frame can be explained by a wave of provincial accessibility legislation designed with the primary intent of providing access to public spaces for people with physical disabilities. In cases where the disability definition in accessibility legislation was sufficiently broad to include people with IDD, the policy was coded in this framing category. As such, it is necessary not to overemphasize the dominance of this frame in terms of its implications for the progress of developmental disability policy more generally. Qualitatively, many of the instances of this framing had only marginal relevance for people with IDD.

Nonetheless, the 'Community Participation/Removing Barriers' frame was more commonly employed than the 'Social Inclusion/Integration' frame in policies pertaining to people with IDD. It is worth noting this frame itself was likely propelled by the community participation framing contained within the important *In Unison* vision paper, put forth by Canada's first ministers in 1998. This vision paper has been heralded as a key moment where the focus of Canadian disability policy shifted more directly toward the removal of social and structural barriers to social inclusion, informing subsequent provincial strategies (Prince 2016). This is reflected in specific policy language, where *In Unison*'s commitment to "full participation of people with disabilities in all aspects of Canadian society" (ESDC 1998, 7) is echoed, almost verbatim, by several policy documents emerging in the immediate aftermath of the vision paper[12].

From a historical standpoint, the most significant characteristic of the 'Community Participation/Removing Barriers' frame is its adherence with the social model of disability, thus signaling for the first time in Canadian disability policy a formal recognition of disability as something socially constructed rather than individually bound. This shift was first evidenced by the publication of *Advancing the Inclusion of People with Disabilities* (HRSDC 2002), the first in a series of quasi-annual reports produced by Employment and Social Development Canada (ESDC) to track the progress of the department's disability inclusion focus following *In Unison*. While this shift in the framing of disability was noteworthy at the time, the acceptance of disability as a social rather than individual problem in Canadian public policy was quickly critiqued for the lack of 'reciprocity' in policy solutions that were still squarely focused on increasing the includability of disabled persons, rather than the inclusiveness of society (Titchkosky 2006).

This critique remains valid today, as the accessibility focus of Canadian disability policy, propelled most recently by the ACA 2019, has continued to generously engage the problematization of disability as a social phenomenon, while favouring policy solutions that are more individually bound. This was most evident in the frame analysis by the manner with which policy documents discussed attitudinal barriers to inclusion. Whereas the disability policy literature identifies these as the most significant barriers to inclusion for people with IDD, the policy documents less commonly engaged with this frame, with only 5 documents falling within the 'Attitudinal Barriers (Stigma)' framing category. Most surprisingly, the documents that did explicitly acknowledge attitudinal barriers were broad accessibility policies, which gave attitudinal barriers comparatively far less attention than physical and environmental barriers[13]. For example, since its enactment Ontario's *Accessibility for Ontarians with Disabilities Act 2005* has seen the development of clearly specified standards for physical and environmental accessibility, leading to the removal of barriers to access in spaces such as public buildings and transport. Meanwhile, attitudinal barriers, and the accommodations necessary to overcome them received comparatively little specification in the formal integrated standards, which make no mention of attitudinal barriers and only indirectly address them in a short section on 'customer

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[12] This frame is most closely echoed in Quebec's *An Act to Combat Poverty and Social Exclusion, RSQ, c L-7 2002,* Alberta's *Premier's Council on the Status of Persons with Disabilities Act, RSA 2000,* and Newfoundland's *Income and Employment Support Act, SNL 2002;* however, several other documents emerge at this time with the community participation framing.

[13] These were Manitoba's *The Accessibility for Manitobans Act, C.C.S.M. c. A1.7 (2013),* Ontario's *Accessibility for Ontarians with Disabilities Act, 2005* and the previous *Ontarians with Disabilities Act, 2001,* Nova Scotia's *Accessibility Act, 2017*, and the national-level *Accessible Canada Act 2019*

service standards'[14]. This may reflect discomfort within the legislative sphere of targeting these barriers with policy interventions but may also be a result of attitudinal barriers being implicitly addressed by the broader 'Social Inclusion/Integration' framing. This topic is picked up further in the final section of this chapter.

The framing analysis shows that 'Social Inclusion/Integration' frame appears more frequently in recent policy interventions, specifically in the context of official program literature. Interestingly, 10 out of the 20 documents pertaining to this frame were program documents, which is noteworthy because program documents only comprised 39.7% of the final sample. Moreover, whereas legislative acts often simply included the word social inclusion or social integration, the program documents went into much greater detail about how these outcomes should be achieved within existing social service governance structures. In large part, this is intuitive, given that program documents present more opportunity for discussion of specific aspects of a policy target, but it warrants attention that social inclusion and social integration were not defined in the definitions section of any of the 10 legislative acts. This includes Ontario's *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* and Quebec's *An Act to Secure Handicapped Persons in the Exercise of their Rights with a View to Achieving Social, school and Workplace Integration, RSQ, c E-20.1,* which both make explicit mention of this policy frame in their titles. As such, it is noteworthy that in all 63 policy documents, there were only implicit definitions of the social inclusion concept, thus lending to support to Pollitt and Hupe's (2011) argument that the concept magically confounds efforts at explicit or uniform definitions.

By contrast to the increasing popularity of the 'Community Participation/Removing Barriers' and 'Social Inclusion/Integration' frames, the 'Anti-Discrimination/Human Rights' frame appears to be declining in usage. This shift has elsewhere been noted by Prince (2009) who notes that over time Canadian disability advocacy groups have tended to prefer 'positive action' legislation – such as accessibility legislation in the mold of the ACA – that takes action against disabling barriers before they arise, rather than anti-discrimination policy that creates significant resource costs in the litigation of individual barriers post hoc (p.217). This explains why disability advocacy groups have pushed for the establishment of robust accessibility standards, and indeed why a national level disability act became a focus of advocacy efforts decades after they were implemented in Australia, the United Kingdom and the United States (see Prince 2010). The shift towards positive action framings over time makes evident the connection between political instrumentality and policy design and elucidates the value of frame analysis as a tool to understand frame (de)institutionalization. This topic is further explored in the discussion of results from the framing analysis of Canadian disability policy designs in the next section.

2.7 Trends and Areas of Divergence in Provincial and Federal Framings

Through critical analysis of the emergent frames in Canadian IDD policy design, one noteworthy trend and several areas of divergence became apparent. This section first focuses on one recent trend that appeared in the policy framing analysis: a shift towards broader social inclusion language, occasionally incorporating multiple framings within the same policy design.

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[14] An updated and complete list of integrated standards is documented in *Ontario Regulation 191/11 Integrated Accessibility Standards* retrieved from: https://www.ontario.ca/laws/regulation/r11191

This trend is noteworthy because it could portend shifts in Canadian IDD policy design moving forward, however, it does not have significant implications for the construction of the index because at this stage the implications are mostly stylistic. With limited scope to effect current social inclusion policy in practice it thus warrants comparatively less attention than the areas of divergence in policy design, which are discussed in the three subsections that follow, corresponding to: a) personal vs societal responsibility, b) provincial differences, and c) policy areas.

The tendency in recent policy documents to employ multiple framings of social inclusion is most likely a reflection of the broad scope of federal and provincial accessibility policies. Indeed, the single federal and three of the provincial (NS, QC and MB) accessibility policies comprise four of the only six policies in the entire sample that employ three or more social inclusion framings concurrently (see Table 2.2). For example, within the sample, the policy document that employed the most framings at once is the *Accessible Canada Act 2019* (ACA), which employed all but one of the six framings of social inclusion that were detected in the analysis[15]. Given their breadth of scope, and that accessibility policies use very similar wording across federal and provincial cases, it is unsurprising that they employ multiple framings. Moreover, given that accessibility policies are emblematic of a new wave of policies unique to the inclusion era in Canadian disability policy, the presence of multiple frames may portend a shift towards *increasing* conceptual ambiguity. Nonetheless, drawing from policy framing theory, the presence of multiple framings *is* surprising when we consider the emphasis that policy framing literature has placed on policy controversy, and the intractability of competing frames (Rein and Schon 1994). More specifically, the presence of multiple frames in accessibility policy suggests that policy framings may resist descending the frame institutionalization ladder where the scope of policy is sufficiently broad.

Table 2.2 Multiple Framings in Accessibility Policy by Year

Policy Name	Year	Framings
An Act to Secure Handicapped Persons in the Exercise of their Rights with a View to Achieving Social, School and Workplace Integration, RSQ	2004	4
Accessibility for Ontarians with Disabilities Act	2005	2
The Accessibility for Manitobans Act	2013	3
An Act Respecting Accessibility in Nova Scotia	2017	3
Accessible Canada Act	2019	5

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[15] Moreover, even though the ACA technically excludes the 'Labour Market Participation' framing, it does contain specific references to the only federal policy that employs this framing, respectively: the *Employment Equity Act 1995*

Another viable explanation for the confluence of multiple policy framings in accessibility policy is the rather limited practical scope of these sets of policies from the standpoint of implementation. In policies with precise implications for service delivery (such as those pertaining to direct support, of which 15 out of 20 contained only a single framing) there is a greater opportunity for divergent framing by policy implementers derailing policy intent, and thus a greater impetus for clarity of policy framing. By contrast, accessibility policies are comparatively less demanding on policy implementers, particularly at the frontlines, as they employ a common strategy of gradually rolling out standards for public organizations and non-profit disability agencies, the latter of which are already leaders in accessibility out of practical necessity. For example, the ACA 2019 has not yet delivered a list of accessibility standards to guide the application of its provisions. Indeed, even in Ontario, where the *Accessibility for Ontarians with Disabilities Act* has been in effect since 2005, the standards that exist now pertain mostly to broad structural barriers (such as building codes and employment practices for large businesses) rather than more individualized supports that could significantly diverge from policy intent through divergence in implementation.

Most importantly for people with IDD, it is worth noting that the standards approach to accessibility policy is meant to be mutually constitutive and present an evolving context, such that ideas of universal design when applied to physical spaces are thought to set the stage for the eventual appearance of more aggressive accessibility standards addressing pervasive attitudinal barriers (Onley 2019). As such, the accessibility focus within Canadian disability policy may eventually give way to a new policy design framing that is more conducive to targeting the social inclusion of people with IDD using specific tools addressed at attitudinal barriers.

a) *Personal vs. Societal Responsibility*

The first significant area of difference in policy designs pertains to who should be responsible for promoting inclusion. Existing scholarship on disability policy in Canada has stressed the individualizing influence of neoliberal approaches to social policy, which emphasize the importance of active citizenship, and reducing dependence on government interventions (Kelly 2016; Prince 2009). While independence and self-determination have been important areas of emphasis for IDD advocates historically, in this context, disability policy is thought to place the onus for inclusion squarely on the individual (Titchkosky 2011). As such, it is surprising that two of the three least prevalent framing categories were the ones that assigned the most responsibility to individuals with IDD in achieving inclusion: the 'Independence/ Self-determination/ Choice/ Individual Responsibility' and 'Labour Market Participation' framings.

Indeed, for people with IDD, the onus for social inclusion was far less frequently placed on the individual, in keeping with the social model understanding of disability as something socially constructed, external to individual impairment (Barnes and Mercer 2004). This framing is also consistent with discriminatory attitudes, which portray IDD as a 'personal tragedy', where exclusion is a result of something that *happens to* an individual (Oliver and Barnes 2012). In this way, people with IDD could be the beneficiaries of positive social constructions, which contrast notions of the 'deserving poor' who are the most disadvantaged by neoliberal narratives of individual responsibility (Schneider and Ingram 1997). The higher prevalence of social responsibility framings may allow for more diverse policy strategies to promote social inclusion for people with IDD because the greater the consensus that society plays a role in excluding this population, the greater the potential exists for mechanisms to promote social inclusion.

The relatively smaller amount of individual responsibility framings is surprising because wider narratives surrounding disability policy in Canada have been shaped by the guiding logic/morality of austerity, which tends to prioritize individual responsibility for *achieving* inclusion over society's responsibility for *accommodating* inclusion. Mitrea (2017) calls this broader narrative 'moral austerity', which is a pervasive phenomenon that projects the neoliberal impulse towards the 'responsibilization' of social citizenship, thus connecting individuals to governments through a shared need for self-sacrifice. While it is surprising that moral austerity does not dominate Canadian disability policy designs, this narrative may be more likely to appear further down the policy implementation chain.

Indeed, the moral austerity narrative – specifically as it pertains to individual responsibility – has been used to rationalize recent cutbacks to developmental services in Canada's two most populated provinces, Quebec and Ontario[16], suggesting that this narrative is perhaps more pervasive in implementation than in policy design. Moreover, the social inclusion focus of policies in the sample may limit the likelihood of moral austerity appearing in the policy framing. It is more likely that complementary policies, including those that affect budgeting of developmental services and the options available to service users will be more likely to reflect individualization. In Chapter 5 on reframing in policy implementation, I present further analysis on how the dynamic between individual and social responsibility for social inclusion is reframed by developmental services actors and users.

b) Provincial Differences

When analyzing the data, the differences between provincial policy frames were often more telling than the similarities. For example, every province had their own human rights act which employed an anti-discrimination framing in the discussion of social inclusion for people with disabilities. However, what was surprising was the divergence in policy framing with respect to a newer wave of policy documents, emerging in the past decade, which offer a broader legislative commitment to social inclusion.

In these policy documents there is significant provincial divergence in terms of policy frames, despite seemingly similar wording elsewhere in the documents. For example, Nova Scotia's *Services for Persons with Disabilities (SPD) Program 2012* and Ontario's *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act 2008* both stipulate that social inclusion goals should be worked into annual support plans for people with IDD, while Quebec's *An Act to Secure Handicapped Persons in the Exercise of their Rights with a View to Achieving Social, school and Workplace Integration, RSQ, c E-20.1* and Manitoba's *The Accessibility for Manitobans Act, C.C.S.M. c. A1.7 2013* frame these same planning policies as social integration and community participation, respectively. In practice, these policies behave similarly in terms of how they govern the conduct of support workers; however, the differences in how they frame social inclusion may discursively shape the type of outcomes that implementation actors see fit to pursue (see Dickson 2022). In part, this provides further evidence that the framing categories can overlap, with different frames operating within

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[16] Quebec: https://www.cbc.ca/news/canada/montreal/outcry-over-service-cuts-for-severely-disabled-unreasonable-says-health-authority-senior-manager-1.4418696
Ontario: https://windsorstar.com/news/local-news/devastated-families-fight-funding-cuts-for-people-with-disabilities

very similar policy instruments. But these divergent frames also suggest that there are different understandings of the overarching policy goals at the provincial level, which may be representative of different bureaucratic cultures (Kernaghan 2000), or indeed different social attitudes when it comes to IDD. In this way, fully drawing out the implications of these divergent policy designs will benefit from a deeper engagement with differences in policy implementation at the provincial level provided in later chapters.

Provincial divergence could also reflect the imposition of provincial norms on broad disability policy frameworks over time. Indeed, IDD policy has undergone a steady evolution as it has incorporated dominant policy ideas over time. This originates with the Anti-Discrimination/Human Rights framing, which coincides with the first explicit mentions of people with IDD in a social inclusion context in various federal and provincial level human rights acts. From this shared origin, disability policy has evolved in concert with emergent realities of increased provincial autonomy and the increased influence of market logic on social services design (Prince 2002). The frame analysis demonstrates rather uniform temporal shifts in the dominant policy frames. Once again, this may result from the evolution of disability policy as it has undergone shifts over time, owing in part to the opening of important policy windows[17], for example following the Charter of Rights and Freedoms and the *In Unison* report, which have offered greater opportunities for social movement influence (Chivers 2008). However, once again, the divergent framing categories that have emerged between provinces are more reflective of the broader implications of provincial political discourse than representative of how a policy is framed throughout the process by policy actors with a far narrower focus.

c) *Policy Areas*

The frame analysis demonstrates that IDD policy covers several policy areas, though employment remains among the most dominant areas for social inclusion policies. Nonetheless, I also observed strong concentrations of policies relating to direct support, which encompassed a broad umbrella of services – including recreational activities, transportation, health care and housing – that are all considered key domains of social inclusion policy for this population (Simplican et al. 2015). However, it is important to emphasize that this breadth of scope is not accompanied by a corresponding deep engagement with the social inclusion concept in policy design, where it is rarely defined and even more rarely connected to specific policy instruments. While employment policies provide numerous types of specific instruments, such as funding for on-site vocational supports or job-skills training, instruments in policy areas such as recreational activities and housing are notably murkier in their design.

For example, recreational activities were often mentioned within the community participation framing category, however very few of the legislative acts and program documents went into much detail as to what form these activities take. To the extent that recreational activities were mentioned at all, it was in the context of access to day program and leisure services, however specific mechanisms for increasing participation were mostly absent across the provincial policies. By contrast, employment inclusion policies are remarkably similar across provinces, and are dominated by the 'Labour Market Participation' framing category. These policies often use the term 'employment supports', either explicitly in the legislative act or in the

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[17] The evolution of IDD advocacy as it relates to shifts in the broader Canadian social policy landscape is a central focus of Chapter 3.

program documentation, reflecting the influence of intergovernmental labour market agreements which govern the allocation of federal transfer funding[18].

Table 2.3 Social Inclusion Framings by Policy Area

Policy Area	Frequency
Accessibility	4
Income	6
Human Rights	16
Employment	13
Residential	2
Direct Support	20
Education	2

Aside from provincial employment policies, and to a lesser extent education policies, most of the policy instruments targeted at other policy areas only superficially relate to people with IDD as a target population. For example, several of the transportation policies employ a sufficiently broad definition of disability that they can be applied to people with IDD, but it is clear that they are primarily designed for people with mobility disabilities. To this end, none of the 37 transportation policies I reviewed contained a social inclusion frame that applied to people with IDD, and this policy area was only identified in broader legislation aimed at removing barriers to community participation. As such, only the policy areas of employment and education provide opportunity for deeper substantive analysis of framing shifts over time. In this way, the broadly defined concept of social inclusion appears tightly constrained by its operationalization in employment and education policy instruments for people with IDD, and thus bears little resemblance to the magic concept identified at the outset.

2.8 Conclusion: Implications for the Index

When attempting to measure and compare the effectiveness of social inclusion policies, the framings employed in policy design do not provide much explanatory leverage when separate from data on policy implementation. While the findings provide preliminary evidence that the concept of social inclusion loses much of its breadth of meaning as it is operationalized in policy design, this is not altogether surprising given the broad scope of the concept. The majority of Canadian provinces lack a coherent multi-dimensional policy framework for promoting social inclusion. Moreover, where these frameworks exist – such as in Ontario with the 'Social Inclusion Act' 2008 – they are narrowly focused with weak accountability mechanisms to promote effective implementation (Dickson 2022; Bishop 2022; Joffe 2010).

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[18] This specific wording is uniformly used across the federal level disability employment policies included in the analysis.

More fascinating are the feedback effects that social inclusion policy designs have on broader understandings of the concept. However, taking stock of these effects requires engagement with how policy relevant actors frame social inclusion for people with IDD. Clearly, at the conceptual level, there is room for a broad range of understandings of social inclusion informed by scholarly contributions from identity politics and critical policy studies. However, prior to policy design, when the social inclusion concept is condensed to a policy problem for a specific population, it is reduced to a small number of policy frames, which are applied substantively to an even smaller number of policy areas. Just as policy problem definition is thought to constrain the universe of policy solutions (Rochefort and Cobb 1993; Peters 2005), it is also thought that policy designs themselves can tell us about broader social attitudes towards target populations (Schneider and Ingram 1997). From this perspective, we gain insight not only into where society is becoming more inclusive, but also into where exclusion is still latently accepted.

This was most evident in the analysis through the lack of policy instruments targeted at attitudinal barriers towards people with IDD. Insofar as stigmatizing attitudes both underlie and reinforce exclusion more generally, people with IDD are under-served by existing policy designs. For groups contending with negative social constructions, policy interventions are vitally important to unlock access to social citizenship. Consider that for people with IDD, their historical exclusion has reinforced pervasive stereotypes about their capabilities. These stigmatizing social attitudes act as constant barriers to inclusion, and yet they are not significantly addressed by existing policy designs. Where attitudinal barriers are mentioned, it is in broad and opaque terms that do not lend to the creation of specific instruments – or provide explicit incentives to implementation actors – to address them. The framing analysis demonstrates that comparing accessibility policies provides an excellent example of the shortcomings of a design-only approach. If we compare the ACA with the *Accessibility for Ontarians with Disabilities Act 2005* (AODA) using policy design only, the former appears far superior to the latter. The ACA employs a much more inclusive definition of disability, commits to adhering the principles of the United Nations Convention on the Rights of Persons with Disabilities, and commits to the involvement of people with disabilities in processes of policy design. However, in terms of current impact, the AODA has far more impact on effecting the social inclusion of people with IDD than the ACA because it has elaborated a robust set of accessibility standards that enable its application, while the ACA has not.

In situations like the above comparison, framing analysis of policy design does not tell the whole story. Another cautionary example is the recent *Canada Disability Benefit Act 2021*, which was added to the sample of policies when it came into effect in June 2021. This act commits to the development of a new federal level income benefit for all Canadians with disabilities, modelled after the Guaranteed Income Supplement benefit targeted to older adults. Once again, in terms of policy design framing, the Canadian Disability Benefit is a major advancement in addressing the poverty of Canadians with IDD; however, at present the benefit amount has not been stipulated nor has a start date been set. Again, this policy design may have minimal impact on the social inclusion of Canadians with IDD in a material sense.

Even in areas such as employment policy, where barriers to inclusion are more often targeted by explicit interventions, marginal gains in the paid employment of people with disabilities have come largely via targeting structural barriers, most often through the anti-discrimination framing. Research has shown that this strategy has relatively less of an impact on the experiences of disabled workers, who still face oppressive and exclusionary attitudes in the practices of paid employment (Hall and Wilton 2011). As such, exclusion is reinforced not only by the limited breadth of existing policy frames, but also by the limited depth of their reach.

Many of the trends that emerged in the analysis will benefit from additional observations at the implementation stage, specifically where the existing policies are vague and non-descript. For example, recent policies (including accessibility policies) have begun to shift rhetorically away from the community participation paradigm towards more direct engagement with attitudinal barriers and policies designed to empower social workers at the frontline. This reflects a tendency towards active inclusion policies that has been observed elsewhere and corresponds to the increasing popularity of more bottom-up approaches to governance for social policy issues (Kunzel 2012). By adding insight into how frontline workers use their discretion and, perhaps more importantly, how provincial ministries in charge of developmental services use budgetary discretion to administer these services, it becomes possible to assess whether the active inclusion character of emergent policy designs has the effect of broadening the scope of social inclusion policies. In this way, triangulating policy design framing data with the reframing data from implementation actors will contribute descriptive leverage to benefit the index in comparing effectiveness of social inclusion policies cross-provincially.

Similarly, just as incorporating the bottom-up perspective will yield insight into where implementors are empowered by policy designs to use their discretion, we will also gain greater insight into where they are stifled by the limited reach of non-performative policy commitments (Ahmed 2012). Specifically, we learn whether and where the phenomenon of ‘inclusionism’ (Mitchell 2015) is present in IDD policy. Therefore, while this dissertation is primarily concerned with what IDD social inclusion policy *does*, achieving this objective requires first taking stock of what it *says*. To this end, the cross-provincial trends and differences discussed in this first stage of analysis provide a necessary descriptive foundation to inform the assessment of design shortfalls and implementation gaps in the promotion of social inclusion for people with IDD.

CHAPTER 3: IDD ADVOCACY AND THE PROMOTION OF ALTERNATIVE FRAMINGS OF SOCIAL INCLUSION

"A fundamental issue of public policy is at stake when any specialized group, such as psychiatrists, is authorized under various conditions to dominate others by making decisions of enormous importance for their physical and mental well-being and for their freedom of participation in the familial, political, and economic institutions of society. We have called attention to the fact that the traditional assumptions used to justify these islands of presumably benevolent coercion are no longer to be taken for granted."

- Robert Rubenstein and Harold D. Lasswell 1966,
The Sharing of Power in a Psychiatric Hospital, p.279

3.1 Introduction: Framing and Reframing in the Context of IDD Advocacy

This chapter poses the question 'how is advocacy framed and reframed in policy design?' Traditionally, we think of advocacy targeted at the framing of policy concepts occurring at the front end of the policy process, in the stages of problem definition, agenda setting and policy design (Schon and Rein 1995; Rochefort and Cobb 1994). However, for identity social movements, such as the disability movement broadly, and the IDD movement more specifically, thinking of advocacy in this way only tells half the story. This is because advocacy efforts to promote the inclusion of people with IDD are confronted by a persistent paradox. On one hand, advocating for policy change is more effective when advocates have access to the policy process, where attitudinal barriers that create and sustain exclusion at both social and political levels can be confronted. However, access to the policy process is also impeded by these same barriers, so that people with IDD and their family members are rarely afforded opportunities to contribute meaningfully to the design and implementation of the policies that directly affect them. This has necessitated an alternative vision of IDD advocacy, where rather than gaining access to the institutions that generate exclusion, the focus is instead on creating and promoting positive representations of IDD as a social/political identity, with the aim of empowerment at the individual level and the prioritization of self-advocate voices (Petri et al. 2020; Stainton 2005). In important ways, this latter vision of IDD advocacy is oppositional to the former because it flourishes outside of existing political institutions, by taking aim at the oppressive ideas that are 'baked into the cake' of Canada's social fabric. As such, there exists a tension between these two visions of IDD advocacy, which are not mutually exclusive, but not altogether compatible either.

This chapter begins to address this tension in IDD advocacy in Canada by examining the shifting composition and goals of the social movement vis-à-vis the political opportunity structure, defined as the specific institutional context that shapes the available avenues to achieve desirable policy outcomes (Tarrow, 1994). Specifically in contentious political contexts, where multiple groups compete to shape the policy agenda, political opportunity structures are the formal avenues to affect change within a fundamentally static institutional environment. While the concept of political opportunity structure allows broader application to such topics as social movement formation and collective identity construction, it is specifically useful in mapping how conflicts between advocacy groups and actors are mediated and constrained by the opportunities for action afforded by political institutions (Vanhala, 2014; Smith, 2008). To this end, it is used here to elucidate an important historical shift in Canadian IDD advocacy, from the first appearance of advocacy groups following the collective action of family advocates, to the present day wherein self-advocate voices are increasingly prominent in the public discourse around IDD.

Rather than explain this shift, this chapter examines the evolution of organized advocacy groups along with family advocacy and self-advocacy within the political opportunity structure. This leads to insights into how to overcome the tension between IDD advocacy aimed at i) society (through identity formation/individual empowerment), and ii) the state (through political institutional avenues to policy change). Against this historical backdrop, this chapter extends the policy framing analysis from Chapter 2 to analyze how policies are framed and reframed by IDD advocates in processes of policy design. The framing of IDD policy by advocates in Canada occurs against a backdrop of complex political discourse, specifically as it pertains to the interacting contexts of social policy and identity politics.

This chapter begins by describing the social policy context by analyzing competing understandings of the welfare state in the framework of Canadian federalism. I argue that the characteristics of the Canadian welfare state reflect the nature of intergovernmental relations, and thus significantly affect the advocacy avenues available within the political opportunity structures. As evidence, I discuss how historical shifts in the nature of federal-provincial/territorial funding and jurisdictional arrangements constitute major changes in the social policy context within which IDD policy framing occurs. This is followed by a historical review of the development of IDD advocacy in Canada, with specific attention to the types of policy framing that characterized the three distinct stages that precede the current inclusion era. This is followed by an in-depth presentation of the current framing approaches to policy design favoured by formal advocacy groups and self- and family advocates, drawing evidence from the interview data. The chapter concludes by summarizing the key takeaways from these groups and discussing their implications for cross-provincial comparison.

3.2 Federalism, Intergovernmental Relations, and Provincial Variation in Social Services

The central purpose of this dissertation is to identify and analyze cross-provincial variation in the design and implementation of developmental services policy. Of these two important aspects of developmental services policy, this chapter focuses specifically on variation in provincial policy design, culminating in a comparative analysis of social inclusion policy in Canada's ten provinces that helps to inform the selection and weighting indicators of the Social Inclusion Services Index (see Chapter 6). Prior to explaining divergence in provincial designs, however, it is necessary to account for the forces of convergence and divergence that operate within Canadian federalism. More specifically, developmental services policy is a part of the Canadian social safety net and must be understood within the context of Canadian federalism and intergovernmental relations. While social services are primarily governed and regulated by the provinces (McArthur 2007), the social safety net is a fundamental entitlement of broader Canadian citizenship, and thus connects the outcomes faced by individual citizens to the actions taken by governments.

This section aims to assess the role of intergovernmental relations in the concurrent evolution of both fiscal federalism and the welfare state in Canada. The literature reveals that while the principles of fiscal federalism and the welfare state have frequently been in conflict within the Canadian context, the nature of this conflict is shaped by dominant challenges to intergovernmental administrative coordination within specific historical periods. While these challenges to institutional structures have had dynamic implications for many social policy issues over time, these implications are made legible by identifying macro-level shifts in the notions of i) social citizenship, ii) the role of federal funding of social programs, and iii) the nature of intergovernmental relations in Canada. Moreover, by accounting for these shifts and, how they interrelate it is possible to situate the historical evolution of a specific social policy area – in this case IDD policy design – to divergent understandings of Canadian federalism.

I invoke the concept of the *social union*, understood broadly as a guiding formulation of Canadian intergovernmental relations where the federal government identifies key priorities to guide provincial governments in the design and implementation of policies under their purview (Saint-Martin 2004). This formulation is contentious and ever evolving; however, the shifts in power between the two levels of government are vital to understanding the history of social policy in Canada (Vaillancourt 2003, 157; Fortin 2009). To this end, it is important to distinguish the concept of Canada's social union from its application in various eras of Canadian federalism, most notably the creation of the Social Union Framework Agreement, which came in response to growing intergovernmental tensions about the appropriateness of federal leadership following reductions in key provincial transfers during Chrétien's first term as Prime Minister (Noël 2009). Taking a broader view of Canada's evolving social union gives important context to the more specific evolution of IDD policies in Canada, which is firmly embedded in the contested space between federal priority-setting and provincial administration. Broader still, the social union concept reflects a desire for an inclusive administrative state, where the provinces are united by a shared sense of purpose, equality, and fairness in the enterprise of social policy. Taken this way, the social union concept exists as a state-level analog to the concept of social inclusion at the societal level.

a) The Social Union: Welfare State Citizenship Definition

The first definition, which I have labelled the welfare state citizenship definition, focuses on the role of the welfare state as an instrument to protect the rights of citizens. A commonly quoted definition (Rice and Prince 2013; O'hara and Cox 1998; Lazar 2006), which typifies this stream in the literature, defines the social union as "the web of rights and obligations between Canadian citizens and governments that give effect and meaning to our shared sense of social purpose and common citizenship" (Biggs 1996, 1). This definition sees the social union to represent the deep connection between welfare state programs and a united sense of Canadian national identity. Rice and Prince describe this connection as "a shared political view of social purpose and citizenship" (2013, 126), which has been given increased priority following the perceived erosion of national identity in response to pressures of globalization. This belief that program entitlements are 'social rights' informed the construction of the Canadian welfare state and has been identified in many modern policies and programs, despite more nuanced and divergent current understandings of social citizenship (Jenson and Saint-Martin 2004). Indeed, the endurance of homogeneous conceptualizations of welfare state citizenship is a common research puzzle for scholars investigating systematic disadvantage in the Canadian context.

The notion of Canadian social citizenship has also been problematized for its exclusion of the Québec national identity (Dufour 2002). For example, Noël (2000) argues that while the idea of the social union presents an opportunity for Québec to federally institutionalize its distinct policy preferences, the broad consensual nature of the concept also brings implicit concessions pertaining to provincial autonomy in policy provision. This concern is echoed by Gagnon (2000) who notes that Québec has been generally weary of the formalized cooperation that a social union entails, fearing that it would present institutional barriers to provincial policy innovation and responsiveness. Clearly, overly universalistic notions of welfare state citizenship are fundamentally insensitive to the connection between Québec national identity and provincial autonomy in social program delivery. Indeed, Québec's provincial welfare state is so distinct from other provinces, both in terms of size and generosity, that it is more useful to study individually than as part of the broader Canadian welfare state (Daigneault et al. 2021). In these ways, historical attempts to conceive of Québec as part of the social union – both ideationally and institutionally – have been problematic.

Within this stream of literature, there is an obvious kinship between debates over social citizenship assumptions and broader debates over Canadian national identity that have been at the foreground of federal-provincial relations since the 1960's (Simeon 1972). Therefore, many define this concept of the social union in a manner that is so broad as to attempt to mediate the persistent tension between social citizenship and regional variation in the Canadian context (Banting 2012, 161). The universal vision of Canadian entitlements in this version of the social union is also designed to promote the cross-provincial mobility of Canadian citizens who, it argues, should not be deterred from pursuing economic opportunities in other provinces based on discrepancies in social programs (Bakvis et al. 2009). However, as is clear from this review of the concept, the welfare state citizenship definition of the social union is so broad and all-encompassing, that it mainly represents a sort of symbolic attachment between Canadian citizens and welfare state programs under provincial jurisdiction. While this definition only rose to prominence in the 1990s, the phenomena that it describes dates to the birth of the Canadian welfare state following World War II. In this way, it provides important insight into not only the evolution of intergovernmental relations, but also that of the relationship between Canadians and the service structures which frame their identity.

b) The Social Union: Fiscal Federalism Definition

A second prominent definition of the social union draws from the literature on fiscal federalism. This stream of literature defines the social union as complementary to the concept of Canada's economic union. Specifically, the fiscal federalism authors see the social union as structurally upheld by the use of federal spending power. This is based on the core assumption that fiscal federalism exists to achieve the dual goals of capitalizing on provincial advantages in efficient design and effective delivery of social services, while promoting the overarching interests of the national market through redistribution and risk-sharing (Lazar 2000b, 119). However, as Simeon and Nugent attest, the end of welfare state advancement, in addition to the increasing 'weight' of provincial governments in intergovernmental negotiations, and, most importantly, an ongoing decline of the federal share of social spending, has limited the extent to which the provinces are willing to stomach federal interventions into provincial jurisdiction (2012, 63). Despite a persistent trend towards increasing decentralization dating from the establishment of the welfare state in a context of federal dominance in the 1940's, increased provincial authority in social policy areas has been accompanied by a strong distrust of federal intervention (Brown 2012). Specifically, there has been an ongoing suspicion among provincial governments that revenue sharing between governments has created a vertical fiscal imbalance that favours the federal government (Lazar 2000a; 2006).

An equally important feature of the fiscal federalism literature that pertains to the social union is the argument that the role of federal spending power has often been overrepresented in the Canadian context. These authors emphasize that Canadian provinces have unusually high levels of fiscal autonomy in comparison to regional governments in other federal systems (Doern et al 2013; Bakvis et al. 2009; Graefe 2006). This contrasts with the more traditional understanding of Ottawa's role in shared jurisdiction programs, which focused on the federal government's use of spending power to 'harmonize' provincial social policies through the application of national standards (Forget 1986). While this traditional understanding of fiscal federalism is important to the evolution of the Canadian economic and social union, it is tightly attached to the creation of welfare state programs, which involved the substantial engagement of federal spending power to both fund and regulate programs in areas of provincial jurisdiction (Leslie 1993; Savoie 1981). For example, the introduction of the Canadian Assistance Plan in 1966 provided the basis for cost-sharing programs targeted at disability services across the country (Jongbloed 2003). This was followed in the 1970s by provincial reforms to move purview of developmental services from ministries of health to ministries of community and social services to ensure the involvement of people with IDD in cost-shared programs (Stainton 1998). Therefore within the realm of social policy, cost-sharing regimes became an important mechanism of intergovernmental relations. For this reason, a new take on fiscal federalism was necessitated when the federal government began rolling back cost-sharing schemes in the 1990s.

Despite the fiscal crisis that followed the thin spread of federal dollars into provincial social policy areas, the federal fiscal retrenchment was not proportionately matched by a significant withdrawal of federal coordination. This acknowledgement of what was labeled the 'zero-sum' nature of federal fiscal 'steering' was typical of a period of 'competitive federalism', where provincial and federal governments grappled for control over issue authority in social policy areas (Simeon 1994). This zero-sum quality was exemplified in 2004, when prime minister Paul Martin changed the formula for equalization payments such that provincial allotments would come out of a fixed pool, meaning increased transfers to one province would spell less for others (Béland et al. 2017, 36). This was met by a swift reversal to the previous formula following rhetoric surrounding the proposed shift to ‘open federalism’ during Stephen Harper’s three terms as Prime Minister. However, this rhetoric has not corresponded to any substantive shifts towards the ideas of repairing the fiscal imbalance or empowering provinces with more autonomy over social programs, which were hallmarks of the ‘open federalism’ discourse (Hueglin 2021). Indeed, as Banting (2006) has suggested, the rhetoric of open federalism was mostly employed as an electoral strategy, aimed at securing votes in Québec.

During the Harper years and since, Canada’s fiscal system has demonstrated a growing ‘vertical imbalance’, where the federal government has occasionally exerted unilateral agenda-setting authority in social policy areas, while continuing to download responsibilities to provincial governments, who in turn are increasingly embracing austerity in social spending practices (Ouimet 2014; Hueglin 2021). In this way, the fiscal federalism definition of the social union encompasses both the historical variation in proportional fiscal commitments by the federal government, and the ongoing debate over which level of government *should* have the most oversight with welfare state programming. With respect to this latter dispute, the fiscal federalism definition shares some common conceptual ground with the third, and final stream of the social union literature, which is related to the nature of intergovernmental planning.

c) The Social Union: Intergovernmental Planning Definition

The final way that social union is defined pertains to the relationship – in practice – between federal and provincial governments in social policy areas. This more practical approach is represented in a definition provided by Saint-Martin (2004), who claims:

> “Social union is the latest term for the old problem of what the relationship should be between the two orders of government so that they can work effectively together in the areas of exclusive provincial jurisdiction – health, education, and welfare” (p.30)

What is central to the definition in this stream of literature is that the social union is shaped by intergovernmental relations, which have a significant influence on whether national or regional priorities are given precedence. As with fiscal federalism, the nature of intergovernmental planning is highly dependent on historical context. For example, intergovernmental conflict was long contained by effective coordination between federal and provincial administrations in the period from 1945-1970, prior to the emergence of the executive federalism (Stevenson 2004). However, as the dominant model shifted from one of government as a consistent ‘social safety net’, to one that gave greater emphasis to market forces, and limited government’s role as a ‘social trampoline’ that bounced impoverished Canadians back into the workforce, the dominant model of federal-provincial coordination has shifted as well (Rice and Prince 2013, 152). This has led to greater diversity in the type of intergovernmental coordination depending on administrative practices that have emerged in response to specific issue areas. A classic example is McRoberts’s (1985) distinction between multilateral, bilateral, and unilateral forms of governance pertaining to specific policy issue contexts. What separates the forms is the strength of the ‘political will’ emerging from the centre, in relation to strength and number of potential veto players (Friendly and White 2012).

Ultimately, this definition is predicated on establishing the hierarchy present between the two levels of government in a particular issue area (Inwood 2000). In this way, the intergovernmental planning stream of social union literature gives greater emphasis to the effect of historical context on institutional arrangements than the other two streams. This definition is particularly useful when addressing the growth of welfare state policies within a particular policy area over time. Intergovernmental relations in Canada are significantly shaped by the paradox that the federal government can dominate the social policy agenda by using spending power to intrude on areas of provincial jurisdiction, while simultaneously avoiding the political repercussions for these interventions (Inwood et al. 2011, p.137). The history of Canadian IDD policy has been deeply influenced by shifts in governmental oversight, as the devolution of state authority away from the federal level has changed both the institutional avenues available to IDD advocates, and the substance and scope of their approaches to framing IDD policy design.

3.3 The History of IDD Advocacy in Canada

This section provides an overview of IDD advocacy by connecting its historical evolution to important shifts in Canadian intergovernmental relations. Accounting for these shifts is foundational to the project of the cross-provincial comparison. Even though the provincial governments have exclusive purview over most social policy areas relevant to the promotion of social inclusion (i.e. housing, education and developmental services), and are the most important governmental actor in areas where federal programs have some impact (i.e. employment and income support), the potential role of the federal government in establishing service standards and shaping the disability policy agenda through an expansive disability citizenship regime makes it a key focus of Canadian IDD advocacy (Prince 2009, p.192-3). Moreover, the introduction of the federal *Accessible Canada Act, 2019* (ACA) portends the introduction of robust federal standards for the removal of barriers to inclusion for people with disabilities, extending far beyond the commitments made by existing provincial level documents. While provincial governments have historically had significant autonomy over the design and implementation of IDD policy – owing in part to the lack of formal policy commitments at either level explicitly addressing IDD specifically – the ACA opens up new avenues of federal influence, and is thus a primary focus of IDD advocacy.

Any exploration of the history of Canadian IDD advocacy must begin and end by addressing institutionalization and its ongoing impact on survivors. While a central objective of this dissertation is to explore the multi-dimensionality of social inclusion as a policy outcome for people with IDD; historically, housing has been the most important dimension of IDD advocacy on inclusion. The reasons for this are multiple. First, the creation of residential institutions was the first act of IDD advocacy to take place in the early days of Canada's confederation. This early policy focus had the effect of not only institutionalizing people, but also *institutionalizing* ableism by authorizing and embedding discriminatory ideas into the Canadian policy landscape, creating path dependencies in IDD policy that persist to this day. Second, Canada's fundamental acceptance of the exclusion of people labelled with IDD – through forced segregation in residential institutions – was replicated in the ideational foundations of the basket of social policies that emerged in the early development of the Canadian welfare state. This section argues that the replication of exclusionary policy ideas at this critical juncture in the growth of the Canadian social union allowed ableism to pervade systemically the political and policy structures of Canadian federalism.

Finally, housing is the most important dimension of inclusion historically for Canadian IDD advocates because the reaction to the horrific experiences of those who resided in residential institutions acted to catalyze the IDD social movement – specifically the independent living and community living movements that gave rise to advocacy groups representing the interests of family advocates and self-advocates, respectively. By tracing the history of Canadian IDD advocacy it becomes clear that the traumatic experiences of institutional survivors gave urgency to the creation of professionalized advocacy groups, whose efforts to draw attention to the hidden atrocities of institutional care created an enduring foundation for the IDD social movement. Expanding on the discussion of policy design framing in the inclusion era from chapter 2, this section provides a concise background of Canadian IDD advocacy in the three historical stages that preceded the current era: a) institutionalization: the early history, b) normalization: post-welfare state, and c) anti-discrimination: independent living and the charter. While each of these stages warrants deeper engagement than is provided in the following subsections, I focus on highlighting key examples in each era which reflect the shifts in dominant policy framing/reframing as they pertain to IDD advocacy.

a) *Institutionalization: The early history of IDD advocacy*

The birth of the residential institution in Canada during the early years of the confederacy was rationalized at the time as an act of benevolent government intervention. Canada's first institution, the Huronia Regional Centre (originally called the Orillia Asylum for Idiots when opened in 1876) was designed as a place where medical care could be provided to people with IDD. As with all Canada's residential institutions, the Huronia Regional Centre was operated solely by the provincial government. From the outset, residential institutions pathologized IDD, thus rationalizing the need to isolate and contain 'patients' away from the public (Spagnuolo 2020; Hutton et al. 2017). The buildings were placed in remote areas and designed with grand and imposing facades that gave the impression that "the asylum was a positive space, a symbol of medical and psychiatric advancement, and generally, a symbol of the growing authority of medicine in Canada at the time" (Viscardis 2020, 60). The framing of IDD as a medical problem led to the construction of the residential institution as a policy solution.

This ideational foundation is not unique to IDD policy. The ideas that underpin the birth of the residential institution are deeply rooted in the birth of the lunatic asylum in Europe, where people with IDD and people with mental illness – joined under the blanket term of those afflicted with 'madness' – were forcibly excluded beginning in the middle-ages. Foucault's work is deeply interested in how political authorities perceived madness, so understood, as a threat to the project of maintaining the welfare of the general population[19] (Foucault 1973). To serve the best

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[19] Ideas he would later clarify in his work on biopolitics and governmentality, where the discourses of rational action, and the objectification of human subjects would be clarified as part of a project to narrow the scope of human conduct, such that the 'art of government' or the 'conduct of conduct' extends beyond these common

interests of citizens during what he calls ‘the age of reason’, Foucault argues that government, in its numerous forms, made providing for the welfare of the population its primary responsibility through a logic that it reinforced by the authority of scientific techniques (Foucault 1991, 101). In this way, the asylum emerged as a natural solution. Madness, seen as a pathology, must be isolated and treated: “(i)nterest in cure and exclusion coincide: madmen were confined in the holy locus of a miracle” (Foucault 1973, p.10). His use of religious language here is intentional, as Foucault sees the birth of the asylum as part of a larger project of population control, where the ‘pastoral state’ has come to replace the church as the dominant authority. The mission of the pastoral state extends beyond political control, and is premised upon examining, analyzing, and normalizing the behaviour of individuals (Walters 2012, 22; Foucault 1973).

The discourse of the asylum was present in the birth of the Canadian residential institution. Indeed, the first residential institutions were created out of a need to decrease the burden on the overcrowded network of insane asylums in Ontario, by providing a place to separate and house the ‘incurable’ patients from the large asylums as inexpensively as possible (Viscardis 2020, 56). Residential institutions reflecting this spirit of separation and exclusion soon proliferated in all of Canada’s provinces.

The ideas that underlie the birth of the institution are doubly important in tracing the history of Canadian IDD advocacy. First, institutions were a policy solution that encapsulated the first framing of IDD as a policy problem. The framing of IDD as an incurable medical problem gave a sheen of benevolence to the efforts to segregate and exclude people labelled with IDD from the rest of society (Dear and Wolch 1987). This benevolent façade was later abandoned by the eugenics movement of the early 20th century, which positioned IDD as a pressing social risk leading to dramatic increases in institutionalization and the forced sterilization of people with IDD (McLaren 1990). Second, just as the creation of institutions can be seen as the first product of IDD advocacy in the burgeoning confederation, the ableist rationale that led to the birth of the institution has become a major target of advocacy efforts that continue to the present day.

There are innumerable examples of early advocacy efforts to draw attention to the horrendous practices of residential institutions (see Malacrida 2015; Burghardt 2018; Hutton et al. 2017). One famous example is the case of the Duplessis Orphans, a cohort of orphaned children in Quebec during a period that began roughly with the first term of Maurice Duplessis’ premiership in 1936 and ended soon after his 1959 death during his second prolonged stint in office. Many of this large group of orphans were forcibly admitted to residential institutions despite having no IDD (Dufour and Garneau 2002). This occurred because the federal government at the time provided much higher individual subsidies for children with psychiatric conditions than neurotypical orphans, creating a significant economic incentive for institutionalization[20] (Poirier and Lauzon 1999). While institutionalized, the Duplessis orphans

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articulations of power and meaning to infiltrate the more intimate processes that are manifested in individuals’ government of themselves (Foucault 1991, 95).

[20] This incentivization was compounded by the pressures of a demographically large cohort of orphans. This was the result of pervasive social stigma concerning raising children out of wedlock, which reflected the dominant influence that the Roman Catholic church had over social values in Quebec at the time (Dufour and Garneau 2002).

were subjected to the same abhorrent conditions and traumas as people labelled with IDD, such as physical and sexual abuse by staff. While the Duplessis orphans who survived residential institutions were often able to reintegrate into society in adulthood – in contrast to residents with IDD who were far more likely to remain institutionalized – their ability for adaptation in later life was adversely affected by institutional trauma, as is evident by comparison to non-institutionalized orphans in the same cohort (Perry et al. 2005; 2006).

While the Duplessis orphans were mostly neurotypical, their case has advanced IDD advocacy by drawing attention to the atrocities of the institutional environment. During the first century of the Canadian confederation these atrocities persisted with very little public attention, and thus the reintegration of institutional survivors into society shined early flickers of light on the violent ableism of early Canadian IDD policy. It bears emphasizing that ableism in this early era was explicit in policy design, perhaps most notably in eugenics policies such as Alberta's *Sexual Sterilization Act, 1928*. Based on false assumptions about the heritability of IDD, this act elaborated processes of forced surgical sterilization for inmates of residential institutions to eliminate what section 5 of the act calls the "attendant risk of multiplication of the evil by transmission of the disability to progeny"[21]. When implemented at Alberta's Michener Centre, the policy was interpreted such that any inmate with an IQ lower than 70 could be subjected to forced sterilization (Malacrida 2015, p. 29). Eugenics policies underscore the biomedical framing of IDD as disease/pathology, and the corresponding intention to separate and eliminate IDD from society. The prevalence of this framing during Canada's first century both legitimized ableism and embedded ableist ideas within Canada's social and political institutions. As the following sections demonstrate, the fight to oppose this dominant framing continued throughout Canada's history and persists to this day.

b) *Normalization: Framing Disability in the Welfare State*

The second distinct era of Canadian IDD advocacy began with the development of Canadian welfare state policies. As discussed in the preceding section of this chapter on the evolution of Canada's social union, the birth of the welfare state contributed to a more inclusive understanding of social citizenship, bolstered by an emerging basket of policy instruments designed to bring socially disadvantaged groups out of poverty. This more inclusive vision of Canadian citizenship only selectively applied to the small portion of people labelled with IDD who were most capable of conforming to the performative expectations of Canadian society, specifically as they pertained to labour market participation (Reaume 2017; Prince 2002). The gains of disability advocacy in this era were framed by the idea of 'normalization', which posited that social integration would occur by treating people with disabilities the same as their non-disabled counterparts, rather than segregating and excluding them (Nirje 1969). This can be seen as an ideational precursor to the ideas of accessibility and universal design because normalization rests on the notion that with basic accommodations disabled people can participate in society on equal footing.

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[21] The full act can be retrieved here: https://canlii.ca/t/53zws

The concept of normalization was the guiding principle behind Wolfensberger's theory of social role valorization (also addressed in chapter 2), which was a central focus of IDD advocacy during this historical period. Social role valorization held that the primary cause of disability exclusion is that people with disabilities are devalued by non-disabled people. Therefore, by increasing access to valued social roles (worker, spouse, parent, etc.), people with disabilities would be more valued by their non-disabled peers, thus limiting the exclusionary power of stigma and discrimination (Wolfensberger 1983; 2000). In the Canadian context, normalization was used as a rationale for the first generation of advocacy towards hallmark disability issues such as accessible transit and community-based housing under the auspices of universality in policy design (Brown 1977, p.456-7).

During this era, the normalization policy framing by IDD advocates was confounded by the persistence of ableist attitudes, specifically toward people with IDD who were long made invisible by their segregation in residential institutions. Instead, people with IDD were treated as 'worthy poor' by early welfare state programs, which qualified them as worthy beneficiaries of state intervention to ensure their welfare due to their perceived incompetence to participate in various social functions (Rioux and Prince 2002). For example, to confront the reluctance of private sector employers to hire people labelled with IDD, the sheltered workshop system of segregated employment was significantly expanded during this period as a mechanism of rehabilitation for workers with IDD who could not enter the workforce (Brown 1977). Sheltered workshops were designed to provide a simulated working environment, where people deemed unemployable by a certified professional would perform repetitive tasks (such as assembly line work) for a very meager hourly wage[22] without legal benefit from provincial labour codes because they were not 'genuine employees' (Reaume 2004, p. 469). The sheltered workshop system continued to grow, and still exists in some provinces despite concentrated advocacy efforts to promote real work for real pay[23].

c) *Anti-Discrimination Framing: Independent Living, Self-Advocacy, and the Charter*

The lessons of normalization seep into the next era of IDD advocacy – one that was propelled by the birth of the independent living movement and culminates in the pivotal victory of including 'mental and physical disabilities' as protected identity categories in Section 15 of the Canadian Charter of Rights and Freedoms. Indeed, the catalyzation of the early grassroots Canadian IDD advocacy movement occurred soon after the establishment of the Coalition of Provincial Organizations of the Handicapped (COPOH) in 1976. From its inception, the COPOH (now known as the Council of Canadians with Disabilities) sought to organize and unite disparate regional and impairment-specific organizations under one umbrella to maximize their presence in national level policy debates, with a specific focus on agenda setting and policy design (Hutchison et al. 2007). Specifically, COPOH united around a new policy framing of 'independent living', which was developed to challenge the inherent ableism of the dominant medical model of rehabilitation that had so long legitimized policies of segregation and

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[22] Reaume (2004) writes that the average worker in a sheltered workshop in Ontario during the 1970's would earn between 3 and 11 cents per hour (p.470).

[23] In Chapter 5 I speak to participants and staff at two sheltered workshops still operating in Nova Scotia.

exclusion[24]. The movement sought to leverage the power of people with disabilities as experienced consumers of services, and thus curtail their dependence on service professionals who they saw as ineffective gatekeepers to service access (Lord 2010, p.17). With its broad focus on promoting the independence of people with disabilities and espousing market principles of consumer control, the independent living framing sought to emphasize the capabilities of people with disabilities as valuable contributors to Canadian society.

Despite the successes of the independent living movement in both challenging the medical model of disability and reframing disabled citizenship in the Canadian welfare state, certain aspects of the ideational frame were not amenable to IDD advocacy specifically. For example, the emphasis that the independent living movement placed on autonomous decision-making is irreconcilable with the needs of some with IDD who require support in decision-making and verbal communication (Kelly 2016, 39-40). For this reason, IDD advocates during this era sought to claim their own space within the disability advocacy landscape by employing an alternative framing derived from the burgeoning international self-advocacy movement. While the formal organization of self-advocacy movements began in Sweden during the late 1960s (Rioux and Samson 2006), the first Canadian organization for IDD self-advocates People First of Canada began in 1973. This national level self-advocacy organization rejected the 'consumer' label within the independent living framing, opting instead for a 'community living' framing that directly challenged the model of residential institutionalization, while foregrounding the personhood – rather than independence – of people with IDD (Park et al. 2003).

While this community living frame would ultimately come to dominate the policy discourse, during the 1970s and 1980s the People First movement was organized more around local issues with a dispersed network of field offices. At the national and provincial levels during this time, IDD advocacy was most forcefully advanced by the Canadian Association for the Mentally Retarded (CAMR) (now called Inclusion Canada), which began as an organization of family members of people with IDD. During the 1970s, CAMR advanced the IDD policy agenda by stepping away from the traditional pity or charity-based funding model, to actively advocate for a deinstitutionalization/community living policy frame (Vanhala 2014). Drawing upon a pre-existing network of family advocates across the country, CAMR was also able to effectively mobilize in partnership with COPOH to consult with the 1980 House of Commons Special Committee on the Disabled and Handicapped, and the resulting *Obstacles* report which heralded a radically new vision for Canadian disability politics. One of the report's key recommendations was that if the forthcoming constitutional reform included a rights provision, equal protections under the law should be provided to people with disabilities (Boyce 2004, p.51). This specific house committee also hired a COPOH member as an official consultant in preparation of the report, representing an early formal consultative mechanism in Canadian disability policy design (Prince 2009, 166).

Following the formal recommendations of the *Obstacles* report, the unified network of national level advocacy groups was successful in extending Charter protections to people with

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[24] Lord (2010) attributes the birth of this policy framing to the 1980 Conference of the International Rehabilitation Congress in Winnipeg, attended by over 50 Canadian disability leaders (p.15).

disabilities (discussed further in section 3.6). This set the stage for a decade of progressive legal activism as the numerous successful charter challenges that were launched by disability rights groups had powerful effects on establishing legal precedents, such as protecting the right to vote for people with IDD (Chivers 2008, p.319). The constitutional enshrinement of anti-discrimination protections (with specific language acknowledging people with IDD) reflects the successful policy framing efforts by national level advocates during this era. The emergence of the community living framing as part of the deinstitutionalization movement established the dominant discourse for advocacy efforts over the next 40 years and set the stage for the proceeding inclusion era in Canadian disability policy.

3.4 Method: Exploratory Interviews with IDD Advocates

This chapter presents interview data derived from a sample of 25 participants. The sample consists of 9 individual interviews with representatives of IDD advocacy groups and 9 interviews (6 individual and 3 focus group interviews) with family and self-advocates. In adhering to the research ethics protocol, the exact names of the participants and their organizations is confidential[25]. Nonetheless, all advocacy group representatives included in the study hold senior positions in advocacy groups at both the provincial (7) and national level (2). Provincial level IDD advocates were recruited within Ontario and Nova Scotia.

These two provinces were appealing choices because they vary significantly in terms of both financial capacity and existing disability legislation. With regard to financial capacity, Ontario has not received federal equalization payments for the past two budgets, while Nova Scotia meets the criteria of a ‘have not’ province with its perennial reliance on equalization transfers (Bakvis et al. 2009). Existing Canadian disability policy literature correlates greater financial capacity with greater likelihood of social inclusion programming (Levesque 2012). Case selection was also based on Nova Scotia’s reputation as a laggard in the Canadian context, owing to the ongoing presence of sheltered workshops and residential institutions[26], both of which have been formally eradicated in Ontario. Ensuring significant variation on these two important variables maximizes the explanatory leverage of the interview data, with the aim of identifying key indicators to measure the effectiveness of social inclusion policies cross-provincially.

Interviews were conducted both in-person and over video conferencing software. While the interview format was semi-structured, an interview guide was broadly followed to ensure consistency of questioning in key domains. Questions were open-ended so that participants could draw from their experiences to guide the discussion towards topics that they deemed important. However, the interview guide also contained four core questions related to the current study that were posed to all participants in the following sequential order, throughout the interview:

i) What does social inclusion mean to you?

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[25] Demographic information is also withheld to protect the anonymity of all research participants.

[26] During my fieldwork in Nova Scotia I visited both a sheltered workshop and a residential institution, and interviewed staff in both locations.

ii) What effect will the Accessible Canada Act have on existing services?

iii) Describe the relative importance of the following dimensions of social inclusion (housing, transportation, day programming, employment, education, family support, community involvement, income, any others?)

iv) What is the biggest obstacle to promoting social inclusion?

Data was transcribed, coded, and analyzed using NVivo 12 coding software. A hybrid coding strategy was followed, where categories for specific items, such as domains for social inclusion were pre-identified, with additional subcategories supplemented as they arose. Emergent codes were categorized within relevant themes such as implementation, specific policies (such as the ACA), governance, advocacy, and policy design. The identification and categorization of frames followed the guidelines of Critical Frame Analysis (Verloo 2005), which posits that prior to analyzing framing in processes of implementation, it is necessary to identify and classify the frames present in relevant policy documents. The initial framing analysis is detailed in Chapter 2.

The policy frames identified in Chapter 2 serve as broad categories for both design and implementation frames, which may overlap framing categories. For instance, the example design frame 'accessible employment' could be coded under both category (2) 'labour market participation' and category (3) 'removing barriers', depending on the substance of the policy language. This fluidity between categories is likely to be even more common among professional IDD advocates, whose role supporting people with IDD involves promoting social inclusion across multiple dimensions. In this chapter, the analysis focuses on policy design framing by IDD advocates; however, implementation frames are addressed in proceeding two chapters, with a focus on IDD advocates in chapter 4.

Verbatim quotations are provided in the text with identifying information omitted to protect the anonymity of participants. Quotations are attributed using a naming convention outlined in Table 3.1 below.

Table 3.1 Naming Convention for Verbatim Quotations

Location	Affiliation
NS = Nova Scotia	AG = Advocacy group
ON = Ontario	F = Family Advocate
FED = Federal or national level	GOV = Government worker
	SW = Support Worker
	M = Manager

In the text the naming convention appears as location (participant number) affiliation. Some participants have multiple affiliations. For example, the participant labelled 'NS9 AG F' works/lives in Nova Scotia, has the identifying number of the 9th person in the sample, and is both a representative of an advocacy group and a family advocate.

3.5 IDD Advocacy Groups

While IDD advocacy groups play numerous important roles in the policy process – including 'back end' implementation processes such as service allocation and delivery, and evaluation – they are also deeply implicated in processes of agenda setting, problem definition and policy design in Canada[27]. In this chapter, I employ framing analysis to explain the focus of current advocacy efforts on policy design; however, it is useful here to invoke again Bjornehead and Erikson's (2018) concept of the frame institutionalization ladder (see Chapter 2), because advocacy groups play a crucial role facilitating ascent of competing frames until they are enacted and formally institutionalized in policy. As is evident in the prior discussion of the evolution of IDD advocacy, the major shifts that have occurred in Canadian IDD policy have come as the result of the ascendance of new policy frames, propelled primarily by the efforts of organized advocacy groups. In both the current and the proceeding sections of this chapter, I present a discussion of IDD advocacy in the present inclusion era, informed by discussions with advocates. This section presents data from high-ranking representatives of IDD advocacy groups at both the provincial and federal level. By contrast the next section, presents data from self-advocates and family advocates. The distinction between these two subsets within IDD advocacy is neither binary nor mutually exclusive. Indeed, within IDD advocacy, there has been tremendous overlap between organizational and individual level advocacy, with the largest national level advocacy groups emerging out of the organized efforts of family advocates (Inclusion Canada) and self-advocates (People First of Canada).

a) Relationship to Government and Consultation Practices

One of the central themes of discussion that came up in the interviews with advocacy group representatives was the nature of the relationship with governments at the federal and provincial levels. While Canadian governments have long made superficial commitments to partnership and collaboration with advocacy groups in processes of policy design as an essential ingredient of inclusion policy, historically advocacy groups have been sidelined. This was the case at the turn of the millennium, when in a seminal article describing the persistent 'hit and miss' nature of Canadian disability policy, Prince (2004) wrote: "(m)atters of access and inclusion for children, youth and adults with disabilities are not routinely a part of legislative and policy and program development. The lack of input by disability and family organizations in setting goals and desired outcomes compounds this problem" (p.76)[28]. In the nearly 20 years since Prince's article decried the marginalization of IDD advocacy groups by their exclusion

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[27] Given their various roles, one might wonder why I refer to these organizations as advocacy groups and not community groups, since they both advocate for policy change and provide services. First, not all advocacy groups in Canada provide services. Many such as People First of Canada and Autistics for Autistics focus solely on advocacy. Second, the groups that are also involved in service delivery such as the provincial chapters of Inclusion Canada, began as advocacy organizations before expanding into developmental services. The service delivery sides of these organizations are identical to other developmental service organizations, and only very loosely connected to the goals sought by the advocacy sides. For these reasons, and in keeping with the context of this chapter, I refer to all advocacy groups uniformly.

[28] See also Brown (1977) whose report whose report on the nature of Canadian disability policy was the inspiration for Prince's (2014) redux.

from policy design (see also Bach 2002), Canada has taken important symbolic steps to increase their involvement, most significantly the 2011 ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and the enactment of the Accessible Canada Act 2019. Both policies commit explicitly to the consultation and direct involvement of disability advocacy groups in processes of inclusion policy design[29]. As a result, the effectiveness of implementing these processes was a natural starting point for interview discussions of IDD advocacy in the inclusion era of Canadian disability policy.

In the interviews with representatives of IDD advocacy groups, participants were quick to acknowledge the increase in formal consultation processes at both the federal and provincial levels. At the federal level, advocates pointed to the country-wide consultations in advance of the Accessible Canada Act, while multiple advocates in Nova Scotia discussed the consultations in advance of the province's Disability Support Program (DSP) as exemplary of the current relationship to government. The below quote from a provincial advocacy group representative reflects advocates' frustration with the tokenistic nature of advocacy group involvement.

> *"So, I took part in that consultation… very frustrating because it was like, you know it was just token. It's kind of a token thing. You kind of know they already have planned what they want to do and it's just an afterthought. But what would be great if they involved us from the very beginning, rather than hiring an outside consultant, have us in there working on these things using our knowledge, have a broad team of people. That is the vision I think, to have that collaboration with government. And I think that it is changing it's just going to take a long time because it's so ingrained. For sure it is a common issue. It's always a very top down… you always feel when you're with (the Department of Community Services), you feel like a lesser being for sure.* (NS19 AG)
>
> *"Engaging and partnering with, rather than this is the relationship. And engaging families and individuals to find out what is really needed. People need to have a voice. And so do community-based organizations who really understand the population. And that doesn't happen. They work in isolation, they think they have ideas, they come to us for a consultation - which is just 'check, we did it'. They don't make is accessible, they do it quickly, they just whatever. And then things move forward"* (NS1 AG)

The theme of tokenism in consultative practices was echoed by other advocates at both the provincial and federal levels, however the reasons for why and the corresponding solutions varied. The first explanation is apparent in the above quote, where the participant expresses skepticism about the willingness of department staff to engage with IDD advocacy groups as equal partners in the early stages of policy design. This explanation mirrors the common

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[29] The Accessible Canada Act echoes the language of Article 4 (3) of the UN CRPD which states: "In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations".

explanation for innovation hesitancy in the 'new public/political governance' literature: that the capacity for experimentation and collaboration with non-governmental actors is severely limited by resource and time constraints on department staff (Evans and Cheng 2021; Lindquist and Rasmussen 2012). In a policymaking environment that emphasizes short time horizons, and tightly specified deliverables, the input of advocacy groups may by marginalized in favour of those of outside consultants with a broader view of departmental priorities and resources.

b) The Marginalization of Developmental Services in Community Services Portfolios

This is closely tied to a second explanation for tokenistic consultation practices – the minimization of disability policy generally, and IDD policy specifically within government departments with wide mandates, notably provincial ministries of community services and federal line departments such as Employment and Social Development Canada. For example, provincial ministries in charge of community services have a diverse portfolio including social assistance, child and youth services, Indigenous outreach, and supports for victims of domestic violence. Moreover, IDD is just one type of disability within the broader disability services portfolios of provincial departments, which include broadly targeted instruments such as disability income supports. While some provinces (such as Ontario) have IDD-specific governance bodies that coordinate service provision across regions, other provinces (such as Nova Scotia) have only disability specific organizations with much broader oversight over disability supports. Even within more targeted service categories, certain policy framings may be more amenable to solutions favouring other forms of disability, such as accessibility policy being more conducive to environmental accommodations for people with physical disabilities than social support accommodations for people with IDD to overcome attitudinal barriers (Baker 2011). These administrative barriers complicate the potential for collaboration between government and IDD advocacy organizations.

> *"But we do know that you need some trust with the civil servants. And the civil servants for Christ's sake, the deputies and the ADMs, none of them understand the first thing about disability when they start their position, so we have to bring them up to speed on their portfolios. And you basically have to give them enough time that they feel comfortable enough to drive a knife into you, and then you start that relationship of a more adversarial... In a way its like you have to get them up to speed, see how you can play them, and then move into that sort of 'ok, now you are a bureaucrat, we are going to play this game now.'"* (NS9 AG F)

> *"So, that is a bit of a frustration. But I am trying to build bridges, and helping them understand that we will, I mean people told me not to use the language "advocacy", and I decided not to do that because that is really the work, because government wouldn't hear me or listen to me, or pay attention or even take appointments. So, I don't say I want to have an appointment to talk to you about advocacy, but that really is what it is."* (NS1 AG)

Provincial level advocates like the ones quoted above have developed innovative and unique methods to advance IDD issues on to the agenda. In both examples, the relationship between advocacy groups and governments is presented as inherently confrontational, such that collaboration requires working around traditional mechanisms of consultation and advocacy pressure.

This tension between advocacy groups and governments is reflective of 'advocacy chill', where advocacy groups have been marginalized both by their exclusion from formal procedures of policy design and by reductions in government funding (DeSantis 2010; Laforest 2013). For sectors such as developmental services, where advocacy and service provision are often simultaneously undertaken by non-profit organizations, these chilling effects may extend into the service landscape (Evans and Sapeha 2015). For example, in a study of long-term care policy in Ontario, Halpern et al. (2022) find that over time non-profit providers have been increasingly marginalized in a policy climate that is increasingly advantageous to private provision. Developmental services represent a much smaller amount of social services spending than long-term care, therefore the marginalization of IDD advocates through tokenistic consultation practices is consistent with the literature on advocacy chill.

c) *Innovative Strategies and Adhocracy in Provincial IDD Policy*

While innovative approaches to advocate to government were present across the sample, they were particularly common among provincial level advocates in Atlantic Canada, where austere social services regimes and a correspondingly top-down bureaucratic culture necessitate imaginative solutions for non-profits hoping to shape the agenda and influence policy design (Myers and MacDonald 2014). More specifically, these methods conform to the basket of strategies that Levesque (2020a; 2020b) has labelled 'interpreneurship' that prevail among the most successful leaders of disability non-profits in Atlantic Canada. Drawing on specialized skillsets from outside the non-profit sector, including business, social and networking skills, interpreneurs employ a unique leadership style that allows them to effectively leverage the resources of their extensive advocacy, implementation, and research networks to affect policy change in unconventional ways (Levesque 2020b, p.189).

> *"But I'm not someone that's going to wait around for the government to come up with better policies, I'm just going to want to try to do what I can. And I think the more the community can get involved the more voice they're going to have as well and that's going to impact what government does as well. So, again, I think making it less about... I think true inclusion is a community issue and I think now that we have all these allies in communities, people hiring, and people are working, in some ways I could care less what the policies are."* (NS19 AG)

The dynamism of outside the box thinking (often involving creative strategies to secure private sector funding) is highly valuable within provincial policymaking contexts that marginalize developmental services, while simultaneously allowing significant flexibility within the portfolio. What results is an 'adhocracy', a form of decentralized bureaucratic organization that enables significant variation from intended strategies (in this case developmental services policies based on scarce government funding) by empowering actors from the bottom-up (such as low-level public servants with specialization in developmental services and IDD policy advocates) to partner, innovate, and create emergent strategies (Mintzberg and McHugh 1985). While the adhocracy structure fosters innovation and transformation within the policy environment by offering advocacy groups flexibility in microprocesses of agenda setting and policy design (Lindquist and Buttazzoni 2021), it also discourages IDD advocacy groups from shaping the agenda from the top-down. Once again, this creates practical barriers to effective consultation in policy design.

d) *Barriers to Co-Construction at the Federal Level*

At the federal level, participants also highlighted bureaucratic culture to explain tokenism in consultation practices. However, at this level, there was no discussion of adhocracy, and instead a focus on the persistence of top-down arrangements. This leads to a third explanation for tokenism – the hesitancy of government to follow through on formal commitments to foster co-construction in the IDD policy arena. Co-construction is defined as the involvement of civil society or private actors in the design of public policy (Vaillancourt 2009, p. 277). A common complaint among federal level IDD advocacy group representatives is that current consultative practices fall short of co-construction, thus perpetuating tokenism.

> *"We continue to see the same old consultative exercises. I think the movement is pushing more and more for co-creation…the advocacy community needs to get really smart and begin to explore more of these co-constructive spaces and put them on the table and make this kind of politics of co-construction and politics of consultation itself a policy issue*" (FED 23 AG7)

In the above quote, the participant both expresses frustration with the lack of de facto mechanisms for co-construction in policy design, but also suggests that advocacy efforts should be oriented towards designing effective institutional mechanisms for consultation. That advocates feel left out of co-construction processes is particularly puzzling given that the two most prominent commitments to formal consultation practices – the UN CRPD and the Accessible Canada Act – were both made by the federal government. One potential explanation for this is that federal level advocacy groups are less involved in co-production (participation in implementation of policies and programs) than their provincial counterparts. In Canada, co-production is a more common role for non-profit organizations than co-construction with governments far more amenable to partnership in implementation than in policy design (Vaillancourt 2013).

In this way, federal level advocacy groups are less tied to downstream processes of policy governance, potentially giving them less leverage to work against top-down pressures on policy design. Their advocacy efforts more closely resemble rhetorical framing than action framing, by impacting discourse and debate more than policy in practice (Schon and Rein 1994, p.32). While the installation of consultation mechanisms in significant policies – such as in the development of national accessibility standards in accordance with the Accessible Canada Act – provide opportunities for co-construction, it is unclear whether or how federal level groups will overcome their arm's length relationship to government in framing processes of policy design.

e) *Funding, Coordination, and Competition Between Groups*

In addition to the relationship dynamics between advocacy groups and government, interview participants were equally concerned with the relationships between advocacy groups within a given jurisdiction. This echoes a comment sentiment within the advocacy group literature effectiveness (Pross 1992; Smith 2000; Phillips 2004) and Canadian disability policy literature (Bach 2002; Prince 2009) that fragmentation of the agenda, and intergroup competition can limit advocacy effectiveness. This was a frequent topic of conversation among interview participants, among whom there was a consistent awareness of the importance of cross-sectoral collaboration, but also a recognition of the occasionally combative dynamics that result from competing for scarce public funding.

> *"There is a fair amount of collaboration inter-organizationally. There is not a lot of provincial collaboration... Nova Scotia is actually a model in that respect. Like, we are really lucky in that we do not have a lot of history in terms of bad blood between the (IDD advocacy groups) and the autism organizations, or the Down Syndrome society. And you are going to see that with the community-based (organizations elsewhere). Like when I was working with (federal program) across the country, we would drop into (diagnosis-specific) organizations that were like 'we are not working with the (IDD advocacy groups)'"* (NS9 AG F)

The institutional environment shapes the dynamics of advocacy collaboration, as the groups with the most access to government funding and with the most resources for the generation of policy-relevant knowledge gain precious influence over the design agenda. This is particularly true at the provincial level, where advocacy groups are more implicated in policy implementation than their federal counterparts (see chapter 4). As a result, collaboration among advocacy groups is more common at the federal level, where cooperation across the IDD and broader disability advocacy spectrum has influenced national policy directions (Prince 2009). However, in these cases of collaboration across the disability sector under the umbrella of a 'meta-organization' – where numerous impairment-specific organizations join together to forge strategic directions (Bonfils 2010) – the influence of all constituent impairment-based groups may be diluted to serve the general interests of the whole (p.49). This is supported by the persistence of federal level IDD advocacy group representatives that new consultative practices are required to advance a substantive reform agenda.

The inter-sectoral collaboration that occurs at the provincial level is occasionally more informal than at the national level, with collaboration focused on specific programs with cross-sectoral influence. However, there are numerous noteworthy examples of the meta-organization model at work throughout Canada's provinces. One such example is the creation of the Saskatchewan Disability Income Support Coalition (DISC). This cross-sectoral meta-organization comprised of disability advocacy groups (including IDD-specific groups) and self- and family advocates successfully advocated for specific design features of the province's disability income support program, including advising on policy language and implementation processes (Thompson and Morton 2017). A similar cross-sectoral initiative exists within New Brunswick, which was referred to by numerous participants as an aspirational example of collaboration in the IDD advocacy.

> *"There is, you know, a tension sometimes when there are limited funding dollars and multiple groups are trying to access that same funding pot. I can give you the example… as a positive example, like in New Brunswick there's something called NBDEN, the New Brunswick Disability Executives' Network. And they have, I would say, have been much more effective in influencing government policy as a united group of you know, 10 – I think – disability organizations speaking to certain issues, than any one of those organizations would potentially have had the capacity or the sway to have achieved on their own"* (FED 21 AG5 F4 SW7)

By fostering collaboration among disability organizations at the executive level, the NBDEN is able to maximize influence within the Atlantic Canadian policy context that is favourable to innovation and flexibility at the leadership level (Myers and MacDonald 2014). Where advocacy group strategies are fragmented, and inter-organizational dynamics are characterized by competition over funding, the provincial government has historically dominated the disability policy agenda (Levesque 2012, p.88). The NBDEN thus serves as an instructive example for other provincial advocacy groups seeking to expand influence over the IDD policy agenda, and the degree of inter-organizational collaboration represents a key indicator for success in framing policy design.

f) Policy Design Framing in the Inclusion Era

Canadian IDD advocacy groups at both the federal and provincial levels are committed to improving consultation processes as part of furthering the inclusion agenda. This fits within a broader category of policy framing, focused on the political empowerment and recognition of people with IDD. This empowerment/recognition framing was so prevalent in both the interview data presented in this chapter, and in the recent policy framing discourse presented in the previous chapter, that it is evidently a key feature of the current variety of advocacy in the inclusion era of Canadian disability policy. The prevalence of the empowerment and recognition frame results from its potential to deliver meaningful reforms at both the state and society levels.

> *"But, again, people with developmental disabilities are not at those planning tables. It's parents and families who are part of all these housing task forces, right? So, people with developmental disabilities are not present to have their voice. There's a massive disparity between access to housing and remembering people with developmental disabilities are a massive part of the poverty world, living in poverty, and relegated to living in housing and I think that we're still dealing with finding that access in the community, that community inclusion, you know? I think we're still keeping people hidden and, you know, left in housing that's not appropriate for them."* (ON22 AG SW)

> *"Is the housing program, the day program… whether we're talking policy or program delivery, is it resulting in valued patterns of recognition for people with developmental disabilities in their communities? Which requires that we look at the ways in which people come to be seen and known by others. Which, for me, is the test of it all. Have we shifted the ways people have come to be seen?"* (FED23 AG)

The above quotations from both a provincial and federal level advocacy group representative, respectively, demonstrate the marginalization of people with IDD in consultative practices. In these quotations it is apparent that the most pervasive barrier to inclusion for people with IDD continues to be the lack of recognition. They remain hidden. The inclusion era of Canadian IDD policy has been deeply concerned with increasing visibility, both by acknowledging the persistence of ableism as it is manifested in stigmatizing social attitudes, and by involving people with disabilities in processes of policy design. There is consensus among the advocates interviewed here that in order to deliver on the promise of inclusion, it is necessary to first acknowledge that ableist attitudes affect the mechanisms of policymaking. To foster the effective co-construction of inclusion policy, people with IDD must be recognized and empowered in policy design. It follows that understanding this frame requires greater understanding of how IDD self-advocates themselves frame the policies that affect them.

3.6 Policy Reframing by Individual Family Advocates and Self-Advocates

Political institutional avenues to affect policy change have historically been inaccessible to self-advocates, despite recent trends toward inclusion in processes of policy consultation and deliberation. By contrast, family advocates have had more success influencing public policy, as evidenced by their integral role in establishing the advocacy groups that have been at the foreground of crucial disability policy victories. For example, during the drafting of the Canadian Charter of Rights and Freedoms 1982, family advocates played an integral role in gaining the explicit recognition of ‘mental and physical disability’ among the identity categories protected from discrimination in section 15 (1). The catalyst for this hard-fought victory were the lobbying efforts of several disability advocacy groups before the Hays-Joyal Committee, whose recommendation to include disability categories caused a dramatic about-face from Justice Minister Jean Chrétien, who had previously recommended excluding disability (Boyce et al., 2001). One aspect that makes this victory so significant, particularly for people with IDD, is the discretion it gave the courts to interpret what constitutes equal treatment and freedom from discrimination under the law. For example, several Supreme Court of Canada rulings extend the Charter equality provision into the preservation of self-determination and autonomy, which must come to bear on any decision to declare legal incapacity (see Kerzner, 2006, p.348-350). This is one of several ways that the Charter has been used to advance legal personhood for people with IDD.

While the significance of these policy advances should not be understated, it is puzzling that such victories of disability personhood occurred largely without the direct involvement of *disabled persons*, specifically self-advocates themselves. Indeed, the IDD advocacy group at the centre of Charter negotiations was the CAMR, whose formal submission was provided by David Vickers, parent to a child with an intellectual disability (Boyce et al., 2001, p. 52). While family advocates also have a vested interest in the advancement of legal protections and are insulated from some of the social/attitudinal barriers that limit engagement with political institutions among people with disabilities, their positionality also precludes them from *identifying* as disabled. This is an important caveat when we consider IDD advocacy as a social movement that engages with identity politics by targeting ableist structures, and thus employs a ‘dual strategy’ that aims to affect change in both society and the state (Smith, 2005, p. 36). The effectiveness of this dual strategy involves reflecting upon the shared goals and collective interests of the members of an identity group. This requires more than the mere involvement of self-advocates, but their leadership in creating/shaping the agenda: nothing about *them* without *them*.

a) *Successful Design Reframing by Family and Self-Advocates*

Despite persistent institutional barriers, self-advocates have had important victories in shaping the IDD policy agenda at both the provincial and federal levels. An important example is the role that self-advocates played in advocating for the involvement of CAMR as legal intervenors in the *E. (Mrs.) v. Eve* case, where a mother sought a non-therapeutic forced sterilization of her daughter with an IDD. In addition to pushing for the organization's involvement, self-advocates active in the CAMR Consumer Advisory Committee also significantly shaped the framing of the legal arguments before the Supreme Court of Canada which led to a victorious decision that the mother did not have legal authority to consent to the non-therapeutic sterilization (Vanhalla 2014). This had the important effect of elevating the stature of self-advocates within CAMR[30]; and some of these self-advocates also went on to create a national organization for IDD self advocates: People First of Canada (Park et al. 2003). The formation of People First of Canada as an independently funded and governed organization represents a pivotal point in the history of Canadian IDD self-advocacy. Moreover, the fact that they historically emerged out of – and currently work in partnership with – Inclusion Canada demonstrates a strong foundation for building consensus and collaboration in future advocacy efforts. This relationship also demonstrates that neurotypical allies can be involved in collective advocacy, but that they must do so alongside social identity movements, rather than by leading, subsuming, or infiltrating them.

> *"You know, back in the 70s with the Eve case, when Peter Park and other people were confronting and changing a law, they went up to the Supreme Court in regards to sterilization to infer people couldn't be sterilized against their will. That was a huge, huge victory at the Supreme Court, right? So, we do have successes and we have to look at those and remember those, but again, I feel like we're still searching for this magical wrench that we need, and I think that wrench is something that's going to be unpacking those deeply entrenched, hidden, invisible, unfortunately dominant attitudes of devaluing people with developmental disabilities."* (ON22 AG SW)

The above quotation demonstrates that self-advocates have played a role in major policy advances, but these victories have often come alongside organized advocacy groups that were started by family advocates. This leads to an important question: has the success of family advocacy itself served as a barrier for self-advocates to access relevant political institutions? While a definitive answer to this question is elusive, and well beyond the scope of the current contribution, we can identify a starting point for this focus of inquiry. To begin with, Canada's political institutions are inherently ableist, reflecting broader dominant social discourses which

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[30] This group of self advocates also led a campaign to change the organization's name to the Canadian Association of Community Living. A much more detailed account of both the E. (Mrs.) v. Eve case, and the 'change the name' campaign is provided in Vanhalla (2014) and Park et al. (2003).

exclude people with IDD by positioning them as incompetent, incapable and/or dependent (Bach, 2017; Prince, 2009). The persistence of social and attitudinal barriers is what necessitates the dual strategy enacted by IDD social movements. Political institutions are by their nature far more resistant to change than social attitudes, exhibiting characteristics of stability and incrementalism (Lindblom 1979); however, the inflow of new ideas into the political discourse is a major catalyst for the change of institutional norms (Schmidt 2008; Peters et al. 2005). It follows that the ableism embedded in political institutions is far more resilient than ableism in society at large. Because political institutions act to continuously reinforce their ideational foundations, affecting significant change requires disrupting these ideas – in this case, ableist barriers to participation – because these are the engine of an institution's reproductive mechanisms (Thelen, 1999, p. 397). Therefore, assessing the role of family advocates in supporting self-advocates' access to political institutions requires taking stock of the former's success in challenging ableist ideational foundations embedded within these institutions.

b) Persistent Barriers and the Important Victories of Family Advocates

While family advocates have been comparatively more successful than self-advocates in gaining access to political institutions, they have also advanced the dual strategy by using their influence to target social barriers that exclude self-advocates. The history of Charter advocacy is an important example because it extended and protected legal definitions of personhood for people with IDD. Similarly, advocacy related to the design and adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) 2006 was propelled by the efforts of the Canadian Association for Community Living (now Inclusion Canada) and focused on advancing personhood through explicit protections in Article 12 on the preservation of legal capacity and the formal recognition of supported decision-making (Vanhala, 2014; Bach, 2017). By promoting the personhood and decision-making capacity of people with IDD, these family-led advocacy efforts have delegitimized dominant narratives justifying the procedural exclusion of self-advocates, thus taking aim at the ideational foundations of Canada's ableist political institutions.

> *"Have you ever looked at the DSP policy for Nova Scotia? It is ridiculous. And their website is not accessible. I always talk about communication. "Oh, we are working on that" what? You are not. And you are not embracing people who have the issues with it to ask them. They say they do, but they are really not."* (NS1 AG)

Self-advocates remain under-represented in policy advocacy, design, and implementation, despite their increased inclusion in policy consultation and advisory boards in recent years. For example, in advance of the Accessible Canada Act 2019, self-advocates with IDD joined community consultation processes; however, the final language of the act is vague when it comes to identifying and accommodating social/attitudinal barriers that disproportionately affect people with IDD. Similarly, self-advocates were included in joint-committee testimony in the debate to extend Canada's medical assistance in dying legislation Bill C-7. Here self-advocates participated in an overwhelming show of unity, as reflected in a joint statement from disability advocacy groups[31] denouncing the bill's provision to classify "people with disabilities and disabling conditions as the *only* Canadians to be offered assistance in dying when they are not actually nearing death"[32]. Significantly, the advocacy around Bill C-7 makes frequent reference to how the enactment of the bill violates the rights protections enshrined in both the Charter and the CRPD. Once again, the voices of self-advocates were unable to overwhelmingly shift the debate around Bill C-7, and the Senate passed the bill in March 2021.

> *"It'll take some years to get to the supreme court, but I think the court will have to ultimately weigh in on what does inclusion require? Because… this law fundamentally undermines the social contract on inclusion. That there is this group this one Charter protected group who we can say it's justified that even though they're not dying their lives… the lives of people like them, the lives of people with those characteristics we can justify terminating their lives… So, the court's going to have to weigh in on whether there's a robust enough principle of inclusion to challenge that, to challenge what is effectively an exclusion from the prohibition on assisted suicide."* (FED 23 AG7)

As is evident in these recent examples, while self-advocates are increasingly involved in policy consultation, their voices and unique positionality are not being respected in agenda setting, design or implementation. In effect, this follows a historical pattern of self-advocate inclusion as 'tokenism', where – in the words of prominent self-advocate Peter Park – "(w)e are here as real tokens, not as individuals who are respected. They don't want to respect us. That's too much like work" (quoted in Hutton et al., 2010). Pressuring policymakers to do this work by respecting self-advocates as key stakeholders in policymaking processes is a necessary pre-condition for significantly addressing the marginalization of Canadians with IDD.

It is equally important that family advocates maintain a role in the policy advocacy landscape. While the increase in consultation mechanisms is slowly carving new spaces for self-advocates in the policy design process, family advocates may find their positions marginalized. There is a fear among family advocates that these shifts will result in the marginalization of family advocacy networks, leading to the loss of critical linkages of knowledge transfer and group strategizing.

> *"The flip side for advocacy, is Nova Scotia has a real fear of, "I worked hard, I got something, but if I talk about it, I might lose it," and the government capitalizes on that. We had a case a while back, it was a community services where a living situation we were looking for – other families locally had it. They were happy to talk about it, happy to say how they got there, but when we said, "could you do an affidavit, and all we want you to do is say, this is my child, this is their needs, this is what they have." No. Because they were terrified of losing it. And we said, "look, if something happens, we'll help you. You won't have to pay for this." No."* (NS18 F).

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[31] The 147 signatory organizations included groups representing various types of disability/impairment, as well as faith-based organizations and medical associations.

[32] Joint statement available at: http://www.vps-npv.ca/stopc7

This loss of collective strength is exemplified by the above quote from a family advocate, who describes how the Nova Scotia Department of Community Services creates a culture of competitiveness and fear among family advocates. The empowerment of family advocates has been historically a vital ingredient to ensuring that Canadian IDD policy reflects the interests of people with IDD (Stainton 2016). International research shows that the systematic decline in family-led advocacy has created important knowledge gaps in processes of policy design, and that new mechanisms are required to reintegrate family advocates into the policy process, alongside self-advocates (Burke et al. 2021; Turnbull et al. 2011).

It is important to emphasize that the interests of family-led advocacy and self-advocacy often overlap, such that even when advocacy organizations are not 'user-led', their efforts may still reflect the consensus objectives of self-advocates (Hutchison et al. 2007). This is tenable because family members provide vital support to people with IDD in overcoming numerous barriers, forging relationality and interconnectivity based on their knowledge of the preferences and desires of their loved ones. This is the basis for the concept of relational autonomy in processes of medical decision-making, where family involvement can help preserve the autonomous agency of patients who are unable to independently express their wishes (Ho 2008; (Mackenzie and Stoljar 2000). In these ways, family advocates are vital actors in the advocacy community and should be increasingly implicated in processes of policy design.

3.7 Conclusion: Implications for the Index

There was broad consensus among advocacy group representatives, family advocates and self-advocates that empowerment/recognition is the most important policy design framing to advance the inclusion agenda. Advocates stressed that empowerment should be more focused on the design process than on what a policy says. Ableist stigma is not something that can be easily legislated away, no matter how tactfully a policy is designed. In a study of perceived stigma among self-advocates with IDD, Roth et al. (2016) find that many self-advocates did not understand why they were treated in stigmatizing or discriminatory ways, and that they would often remain silent in situations where they were confronted with these attitudinal barriers. This is significant because it suggests that self-advocates – who are the most authentic and effective voices to counteract these attitudinal barriers – feel silenced against the authority that these attitudes are afforded within public discourse. Put another way, if self-advocates feel stifled and silenced by stigma and discrimination to the extent that disengagement is the 'default response' (Ibid, p.54), how can we expect those with less imminently at stake (i.e., neurotypical adults with limited awareness of IDD) to acknowledge and speak out against these same attitudes?

The empowerment/recognition frame is process-oriented, but it still has bearing on policy design. Advocates have successfully used consultative design mechanisms to affect meaningful policy reforms at both the provincial and federal levels. However, these mechanisms are currently underspecified, even in the most modern Canadian disability policies, such as the Accessible Canada Act, making the advancement or even stasis of consultative practices a tenuous proposition. Indeed, during the consultations for the Accessible Canada Act, advocates were rebuked when pushing for stronger language, specifically as it pertained to the Minister's responsibilities toward public accountability on matters of accessibility (Jacobs et al. 2021, p.29).

Advocates are also involved in the development of accessibility standards, and their eventual implementation, making their empowerment in policy design even more important.

How disability policy is delivered is contingent upon which deliverables are identified in policy design and prioritized throughout the implementation process (Mellifont and Smith-Merry 2016). Ultimately, the prioritization of deliverables is contingent upon a range of factors, including notably the cost and political feasibility/value of implementation success (Lindquist and Rasmussen 2012). However, the potential for success – even where a policy is highly politically feasible/valuable and fits within existing budgetary margins – is also contingent upon a common consensus of meaning about what a policy is designed to do (Bacchi 1999). Moreover, at a symbolic level, inclusion policy particularly demands unity between policy processes and outcomes, because a policy cannot be expected to promote the inclusion of a marginalized group in a vast range of complex social contexts without sufficiently including that group in the comparatively simplistic mechanisms of policy design.

During the interviews, participants highlighted numerous dimensions to assess the effectiveness of IDD inclusion policy. First, they pointed to the consultative mechanisms themselves, which are both identifiable within existing policy documents at the federal and provincial levels, but also comparable in terms of the extent of empowerment/recognition they afford to IDD advocates. Second, advocates pointed to the extent of collaboration among IDD advocacy groups as a key indicator of group strength in shaping the agenda. Formal collaboration among IDD advocacy groups works against the divide-and-conquer, competitive dynamics that arise in austere developmental services contexts where government funding is scarce. Third, the extent of public funding for IDD advocacy groups remains a valuable indicator of the capacity of advocacy groups to create innovative programs. Building on existing research (Levesque 2012), cross-provincial comparison must consider not only the resource allocation of IDD advocacy organizations, but also the extent of their flexibility to engage outside the confines of governmental program designs – either through discretionary use of public funds or by utilization of private funding sources. While building linkages to private funding sources may ultimately create conditions to decrease public funding for IDD agencies, in the current climate of austerity – particularly in the Atlantic provinces – reliance on these sources is vital to effective service delivery. Finally, advocates expressed frustration that despite progress across multiple domains of IDD policy, exclusionary and ableist models of service provision persist – most notably the residential institutions and sheltered workshops that are still active and publicly funded in Nova Scotia. The advancement of the inclusion paradigm is challenged by the embedded ableism that was institutionalized through exclusionary practices for the majority of Canada’s history. The traumatic legacy of the pathologization of disability cannot be remedied and replaced without delegitimizing these practices.

CHAPTER 4: POLICY IMPLEMENTATION AND DEVELOPMENTAL SERVICES IN CANADA

"This disparate collection of official and non-government agencies is attempting or ought to be attempting to deal with the rights and needs of a minority group, the size and nature of which is not accurately charted, but which encompasses all age groups and a wide variety of physical and intellectual abilities. Not the least of the problems of this policy area is that disabled people do not fit neatly into any of the categories with which people identify, or into which policy-makers divide their activities. It is worth tracing some of the means by which society and its policy-makers have attempted to deal with this."

- Joan C. Brown 1976,
A Hit-and-Miss Affair: Policies for Disabled People in Canada, p.451

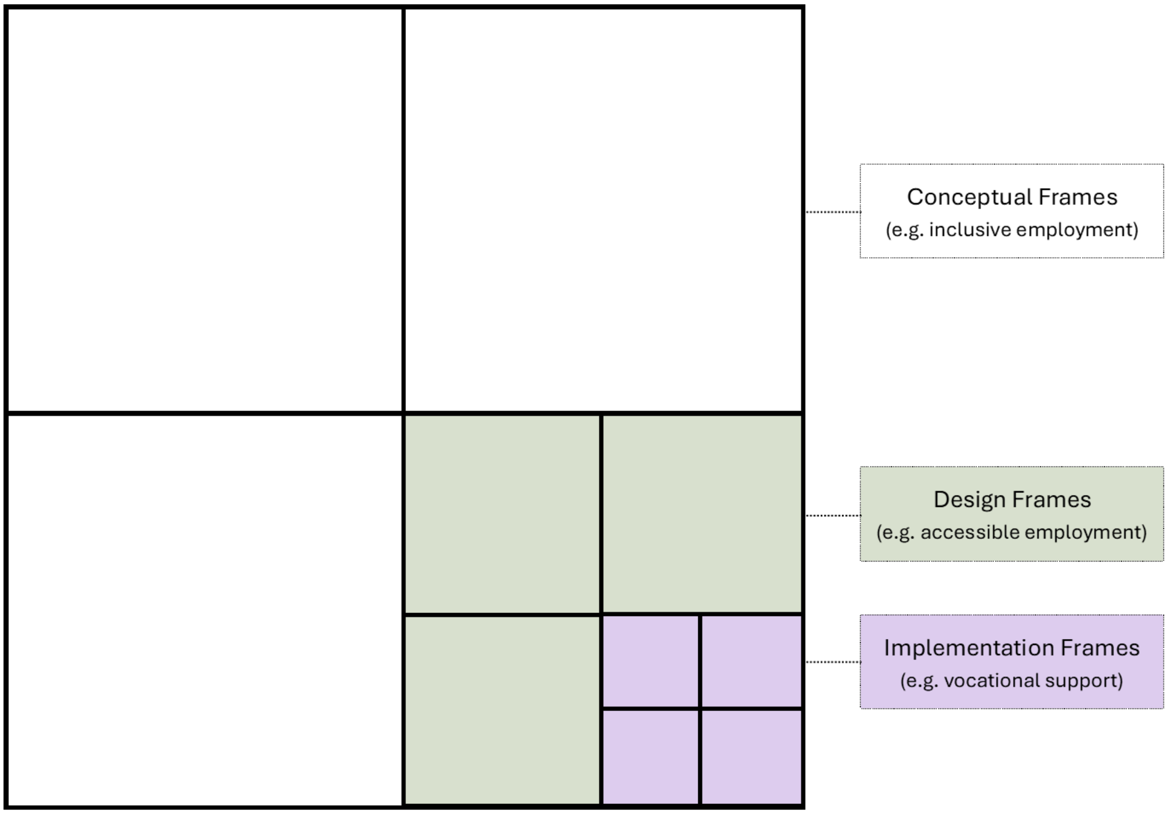
4.1 Introduction: Reframing Through Policy Implementation

Contemporary Canadian disability politics has made the pursuit of social inclusion a central focus. While the lineage of this pursuit can be traced back at least as far as the emergence of disability social movements in the 1970s, over the past 20 years social inclusion (or other variations of the same concept, such as social integration and community participation) have become ubiquitous in both public policy and political narratives about disability in Canada, resulting in what I have labelled 'the inclusion era' of Canadian disability politics. However, there is also tremendous ambiguity over what the concept means, how it is translated into policy objectives and deliverables, and which agents and actors should be implicated. The next two chapters investigate how social inclusion is understood and enacted through the implementation of disability policy.

Policy framing/reframing is the main conceptual framework used to address the research question, alongside theories of discretionary divergence in policy implementation, which offer insight into the conceptualization and operationalization of social inclusion through the policy process. While the previous chapter focused on the policy framing strategies preferred by IDD advocates in the policy design stage, this chapter will focus on how advocates reframe policy through implementation. To this end, I employ the same distinction between i) organized advocacy groups and ii) individual self- and family advocates. In Canada, some advocacy groups are implicated in the implementation of developmental services policies encapsulating multiple domains of social inclusion, including the oversight of residential support, day programming, service referral, and educational/vocational supports. They seek to develop and provide services they design without much state interference, while also receiving government funding. The policy design framing preferred by advocacy groups is often informed by experiential knowledge gained from frontline practice, specifically service delivery (DeSantis 2010, p.40), such that divergent reframing in implementation provides valuable insight into pervasive issues and obstacles in the implementation chain. By contrast, self- and family advocates are the end-users of developmental services, whose interpretations of a policy provide the definitive account of both what a policy means, and how it is translated into action. This chapter examines how IDD advocates reframe social inclusion policies in the implementation stage, setting up a deeper engagement with the decisions and actions of other IDD implementers in Chapter 6. I begin with advocates because their involvement in both policy design and implementation effectively bridges the shift from the discussion of policy design in Chapters 3 and 4, to the present focus on implementation.

The framing and reframing of social inclusion is undertaken by different actors at different points throughout the policy process. As the concept moves from a broad rhetorical construct to a feature of policy design, and ultimately an implemented policy outcome, its conceptual breadth is constrained by the actors who interpret and enact it (Rein 2006; van Hulst and Yanow 2014). Figure 4.1 illustrates how framing processes occur at three different scales throughout the policy implementation process: conceptual frames, policy design frames, and policy implementation frames. For example, one conceptual framing of social inclusion is as ‘inclusive employment’, which both fits the normative parameters of what inclusion entails and is sufficiently broad to generate multiple potential policy designs. At the conceptual level, social inclusion frames retain the ‘magic’ qualities discussed in Chapter 2 (section 2.2), insofar as they are both broad in scope, normatively attractive and conducive to consensus.

Figure 4.2. Scale frames from concept to implementation



Just as multiple frames can exist at the conceptual level, multiple and more precise design frames can exist within these conceptual parameters. For example, within inclusive employment, a corresponding design frame is 'accessible employment', which is typical of accessibility legislation directed at providing access to areas of social citizenship as a human right. Policies in the 'accessible employment' design frame attempt to address barriers preventing people with IDD from entering the labour market, such as attitudinal barriers (i.e., discriminatory hiring practices) or environmental barriers (i.e. inaccessible workspaces). This design frame then informs multiple framings of the implementation of developmental services, such as 'vocational support', encompassing specific interventions such as on-site job supports (to overcome barriers in inaccessible spaces) or vocational training (to overcome stigma/discrimination in hiring or job-training processes). As frames decrease in scale, their potential for action, and ultimately policy outcomes, becomes constrained (van Lieshout et al. 2011; 2012). Just as problem definition limits the universe of available solutions, the application of scalar constraints on policy frames reduces the universe of possible interpretations and outcomes. As a frame travels through the policy process, from problem definition to design to implementation, its meaning is interpreted and enacted at different scales, encapsulating interrelationships of accountability and discretion between policy-relevant actors.

This chapter primarily provides a theoretical foundation to analyze the interconnected sub-processes of framing and reframing a specific policy problem: the social inclusion of people with IDD in Canada. As such, it begins by providing an extensive theoretical foundation to inform the analysis of empirical evidence drawn from interviews with policy implementers. I first review policy reframing literature with specific attention to its application to contested concepts, such as social inclusion. I then shift to a comprehensive review of the Canadian policy implementation literature, organized by presenting top-down, bottom-up and hybrid perspectives and identifying key actors and instruments favoured by each approach in the literature. While the bulk of the analysis of implementation in this dissertation (particularly in Chapter 5) employs a bottom-up perspective, in this chapter I devote attention to the role of Canadian IDD advocacy groups as implementation actors who employ a hybrid perspective do to their direct engagement with policymakers and their direct representation of people labelled with IDD.

After reviewing perspectives on implementation scholarship, I argue that a major driving focus of this literature is explaining policy divergence, and that we gain explanatory leverage on both how and why divergence occurs by analyzing it as an act of policy reframing. I then introduce three potential explanations for policy divergence, also drawn from recent advances in policy (re)framing literature. This is followed by a presentation of key findings comprised of representative quotations from the interview data and organized by three key thematic takeaways. These takeaways are then discussed in relation to the conceptual framework, with specific attention to relevant explanations for policy divergence. Specific attention is paid to the recent *Accessible Canada Act, 2019* (ACA), a federal level anti-discrimination policy that aims to establish national standards to reduce barriers to inclusion for people with disabilities in several key domains. I conclude with a short assessment of the future viability of social inclusion framing in Canadian disability policy.

4.2 The Policy (Re)Framing of Contested Concepts

The analysis of policy frames first gained popularity as an effective strategy for identifying and comparing divergent – and often competing – ideas about a given policy problem. In their seminal early work on policy framing, Schon and Rein (1994) emphasize the connection between successfully defining a policy problem and exerting control over the policy process, specifically in situations of 'intractable policy controversy' where two formidable frames compete for dominance. At this time, the study of policy framing was mostly focused on agenda setting and problem definition, in keeping with the broader focus of scholars forging ahead with the 'argumentative turn' in the study of public policy (see Fischer and Forester 1993). A common feature of this important shift in the study of public policy was the understanding that the framing of policy problems constructs the universe of available solutions. Politics precedes policy, and interested actors strategically promote problem frames that are conducive to desirable policy solutions.

Drawing from this ideational politics foundation, policy framing scholarship has since evolved in two important ways. First, there has been a deeper engagement with the substantive meaning of policy frames. Rather than seeing frames as static categories propelled into conflict by strategic actors, interpretivist scholars increasingly have come to see frames as mechanisms for sense-making in an uncertain world, which generate social action both by their interplay and their dynamic appeal to multiple groups of actors, differentiated by their political identity and their role in the governance of specific policies (Laws and Rein 2003; Hajer 2003). An important product of this evolution is the notion that a policy frame can be understood differently by different actors, resulting in 'frame ambiguity' where multiple framings exist for a single policy problem (Dekker 2017). In implementation contexts where high ambiguity interacts with high conflict over preferred outcomes, an extra burden is placed on frontline implementers who must use their discretion to manage complex dynamics of competing influences from multiple directions (Ellis 2015). In this way these ideational characteristics of a policy area have important implications for the nature of implementation practice.

Policy framing analysis is well equipped for application to contested policy problems, which has contributed to a second important way that the scholarship has evolved: the focus on processes of framing/reframing, rather than frames as outcomes (see van Hulst and Yanow 2016). In particular, the interest in framing processes has extended the analysis beyond problem definition in agenda setting to also include applications to policy design and implementation. This shift has been propelled by the development of Critical Frame Analysis, a comparative methodology that accounts for meaning construction by actors throughout the policy process. Drawing from its original application to gender mainstreaming in the EU (Verloo 2005), Critical Frame Analysis has been useful in policy areas drawing upon identity politics and social marginalization, including migrant integration (Dekker 2017) and disability policy design (Mellifont and Smith-Merry 2016). In particular, this approach is useful in identifying the boundaries of framing categories in policy design, thus allowing researchers to build a descriptive foundation to address implementation processes which are more contextual, and thus less conducive to classification within bounded frame categories.

Critical Frame Analysis research has demonstrated that the conceptual framework provides the most descriptive leverage when competing frames exist to encapsulate a contested policy problem. The examples above also suggest that the approach is particularly valuable with concepts that are broad in scope and normatively appealing, particularly where they aim to counter processes of social marginalization for a specific target population. In these complex policy contexts, processes of framing and reframing are iterative and occur throughout the policy process depending on the precise context and actors involved (Jilke and Tummers 2018). The study of implementation is particularly conducive to these iterative aspects. Implementation research observes framing as specific, practical, and – especially in the context of social services – a relational process between implementer and end-user (Møller 2021; van Hulst ad Yanow 2016). Frames move and change throughout the implementation chain, and framing analysis accounts for how different processes of meaning making affect this movement (Bjornehed and Erikson 2018). The next three sections provide a review of how Canadian policy implementation literature has historically attempted to account for the different directionality of policy goals throughout implementation processes, with specific attention to implementation actors and instruments.

4.3 Top-Down Perspectives on Implementation

In their seminal work on policy implementation, Pressman and Wildavsky (1973) demonstrate the importance of policy system dynamics in linking the intent that is enshrined in policy formulation with the outcome it produces once implemented. The key to their argument is the notion of the 'vertical chain', representing the hierarchy of all actors and organizations linking a policy from inputs in formulation to outcomes following implementation. When the ends of the implementation do not match the means, they claim that the corresponding implementation deficit signals inadequate policy design, because a policy should anticipate systemic breaks in the causal chain (Pressman and Wildavsky 1973, xvii). Their perspective is informed by a strong normative attachment to the representative characteristics of government policy. That is, from the beginning the top-down perspective has assigned a high priority to the political machinery involved in the legitimate formulation of policy and has treated the machinery of implementation as simply part of the policy environment, rather than something to be distinguished (Linder and Peters 1987, 470). This normative commitment is common in the Canadian literature, where there has been significant focus on the influence of formulation and decision-making on the implementation process, more than there has been on processes of frontline implementation in practice. As the sections below demonstrate, this has resulted in a concentration of scholarly attention at the top of the vertical chain, particularly with respect to the roles of elected politicians.

Within the Canadian literature, more attention has been paid to top-down approaches mainly due to the importance that prominent authors have attributed to the effects of decision-making on implementation. For example, Savoie (1999; 2008; 2010) has focused on the increased concentration of decision-making power at the centre – held by the Prime Minister, and his/her courtiers. In this way, he argues that this 'court government' has come to replace cabinet government, and that this has important implications for implementation. For example, he demonstrates that cabinet ministers can no longer look to their cabinet colleagues to mobilize support for a particular policy initiative but must instead focus on gaining the support of the Prime Minister, Minister of Finance and the non-elected political advisors that act as courtiers (Savoie 2008, 331). Aucoin (2010) advances this argument by analyzing the historical shifts toward central control of implementation. In particular, he points to the shift towards new public management (NPM) in the 1980s, and the subsequent budgeting strategies of the 1990s that resulted in the wide-scale cutting of departmental policy research and analysis functions, given the greater priority placed on service delivery (Aucoin 2010, 79-80). Taken together, these authors share a common centralization focus, where the concentration of decision-making power at the top of the vertical chain of implementation has diverted power away from cabinet ministers, such that significant control over departmental strategy is oriented in the hands of the Prime Minister and his/her ‘court’ of advisors. A shortcoming of this literature is that it tends to focus attention solely on decision-making actors, while underemphasizing implementation actors further down the chain. To understand if, and indeed where, implementation deficits can occur within the Canadian context, it is necessary to account for these actors.

a) *Actors – Political leaders and senior bureaucrats*

From the top-down perspective, senior civil servants have assumed an increasingly important role as mediators between political and administrative interests in the context of policy implementation. This has led scholars to focus on the multiple accountabilities within the roles of deputy ministers (DMs). For example, Osbaldeston (1989) demonstrates that DMs have long performed a delicate balancing act between several complex functions, including policy analysis for political authorities higher up the chain and the management of administrative aspects of their department. Similarly, Bourgault (2013) finds that in the current context, these multiple accountabilities have been compounded by a list of emergent factors – such as increased media attention, new measures of parliamentary accountability and their declining monopoly of control over policy information in the era of globalization and the free flow of information – that have acted to overload DMs and decrease their capacity for effective implementation.

What is interesting from an implementation perspective is who wins out when these accountabilities are at odds. To this end, there has been a discernible historical shift in the Canadian literature, beginning in the 1980s, towards increasing partisan political influence over the bureaucracy. The foundation of this shift is demonstrated by Axworthy (1988), who argues that partisan political control over the bureaucracy is necessary to successfully implement the core items of an elected leader’s political agenda. His argument is based on the idea that – ideally – political leaders are elected with a policy mandate of four or five key priorities, which must be implemented in a climate of competing values and interests of different actors throughout the implementation chain. As such, Axworthy claims that a strategic implementation plan is required to ensure that this representational mandate is faithfully executed by the public service (1988, 261). Since this important article, political strategy has become an increasingly important consideration in the study of bureaucratic implementation, as prominent Canadian scholars have decried the politicization of the bureaucracy (see Savoie 1999; 2010). As a result, to take stock of important implementation actors from a top-down perspective, it has become increasingly common to evaluate the reach of politicization into bureaucratic practices.

In a review of the politicization literature, Cooper (2018) identifies two common mechanisms for political leaders to assert control over the bureaucracy: i) increasing the number and importance of political advisors in relation to the civil service and ii) using appointment power to install senior civil servants who are more likely to implement the government's agenda (p.33). Intuitively, the key actors in the first mechanism are political advisors, who have played an increasingly important role in policy formulation and implementation, in addition to providing political leaders with policy advice (Craft 2015; Esselment et al. 2014). However, the second mechanism relies on the crucial relationship between political leadership and senior civil servants. As Aucoin (2010) demonstrates, Canadian PMs have long used their power of DM appointment as a strategic tool to ensure the effective implementation of key priorities. A recurring characteristic of this relationship is the frequent rotation of DMs across departments, both to avoid their capture by specific departmental cultures and to preserve political authority within the implementation chain (Aucoin 2010, 74). Nonetheless, it is important to emphasize that the staffing of DMs is only indirectly connected with the politicization thesis, because they are still accountable to their departments and draw heavily from their expertise as long-tenured public servants.

As Bourgault and Dion (1989) aptly demonstrate, in a climate of increasing complexity, administrative competence and expertise is vitally important to ensuring effective policy implementation. In this way, they find that DMs have been historically insulated from political patronage, owing to their unique skills within the administrative machinery, which are distinct from those of the political machinery. In a more recent work, Bourgault (2013) demonstrates that the insularity of this administrative role has not significantly changed, despite the introduction of more partisan political elements to the policy landscape. This is because DMs are still selected for their expertise in the management aspects of public service, and they are allowed to operate without significant intrusion from the centre in areas that are outside of the small number of short-term issues on the public agenda. However, Bourgault argues that there have been significant changes in the influence of external actors such as national and international corporate interests and the news media, owing to the growing forces of globalization and the internet (2013, 397). Therefore, not only do these external actors constrain the implementation power of DMs and political leaders, but they may also constitute new arenas of policy decision-making and implementation themselves. The growing importance of policy actors further down, or outside of, the conventional implementation chain thus reduces the descriptive power of the top-down perspective.

Drawing from a top-down perspective, the literature thus demonstrates that policy context is important to the determination of which actors are important to implementation. When policy is designed in adherence to the central priorities of political leaders, the literature suggests a concentration of power with actors higher up the implementation chain. To this end, and where necessary, political advisors may capture some of the power traditionally associated with the bureaucracy as a means to expedite the policy priorities of the political executive. However, this does not mean that the bureaucracy has sacrificed its administrative capacity in areas outside the comparatively limited partisan political agenda. Thus, the literature broadly demonstrates that when accounting for the most relevant actors, the political and administrative spheres of top-down influence are certainly different in terms of their interests and values; however, they are not mutually exclusive in terms of their roles at the top of the implementation chain. Just as political actors must account for the nature of the administrative machinery in the pursuit of their key priorities, so too must bureaucrats be aware of the political implications of their actions. The contours of their divergence and interdependence become more apparent by reviewing the specific instruments identified by top-down perspectives as available to implementation actors in both spheres.

b) *Instruments – Policy implementation mechanisms*

As the previous section demonstrates, within federal and provincial politics partisan political control is most intensely focused on promoting the central priorities of the government in power. Sutherland (1993) argues that this leaves the bureaucracy with considerable freedom in both policy formulation and implementation, in accordance with the prevailing norms and values of the departmental culture, provided the policy issue itself does not ascend to the public agenda. She emphasizes that only a small fraction of political activity is actively considered on the public agenda at any one time, leaving the vast majority of policymaking activity under the control of the public service (p.85-6). Assessing the implementation instruments available to the public service speaks to a central debate on their role in the policy process. Aucoin (1990) gives shape to this debate when he talks about the emergence of centralization, coordination, and control as mechanisms to assert executive dominance over the bureaucracy. He claims that this perspective is a product of the public choice theory tradition and is primarily focused on promoting a top-down perspective that sees the political executive and the bureaucracy, respectively, in a principal-agent relationship. Aucoin is critical of this top-down perspective for ignoring the administrative sphere of authority, and treating politicians as managers, insofar as it propels the notions that ‘politics pervades management’ and ‘decision-making pervades administration’ (1990, 127). Indeed, Aucoin is justified in his critiques because there appears to be an overemphasis within the Canadian literature on the processes of decision-making and policy formulation, with less of an emphasis on the more practical aspects of implementation. As such, conceptualizing and specifying the precise instruments used in implementation has been a valuable tool in connecting formulation to outcomes.

Early proponents of policy instruments scholarship very much fit within the public choice tradition that is associated with top-down approaches. In an important early work on Canadian policy instruments, Doern (1974) draws from Lowi’s (1972) typology of policy types – which is based on the notion of legitimate coercion in areas of government intervention – and advises that that the choice of instrument reflects the degree of constraint that a policy is likely to encounter through implementation. Doern focuses on instruments of regulation, specifically independent regulatory boards, as recipients of significant power in the oversight of policy implementation in fields such as broadcasting, energy, and transportation. To this end, he presents an early version of the same debate identified by Aucoin (1990) above, between advocates of depoliticizing implementation and those in favour of repoliticizing it to mitigate the potential for corruption and unfair/unrepresentative processes of policymaking under regulatory boards (Doern 1974, 23). In both accounts there is a notion of the ultimate authority of government decision-making, and the strategic and instrumental quality of policy instrument choice. What is most interesting about Doern's early work on regulation is that it engages with the emergence of non-governmental entities within the implementation chain. In a later work Sutherland and Doern (1985) argue that these early moves towards crown corporations and independent regulatory boards were strategically motivated in part by the desire to preserve political control over decision-making, or at least to deny this power from the public service in an era of greater bureaucratic power (p.35). In this way, a seeming decentralization of authority down the implementation chain could have the practical effect of consolidating decision-making at the top/centre.

It is revealing that this fundamental debate between politicization in the interests of representation on the one side, and administrative independence in the interests of procedural fairness persists through more current literature on instrument choice. In one of his earlier pieces on policy instruments, Howlett (1991) critiques Doern's version of the instrument typology for relying too heavily on the notion of legitimate coercion: a concept which he argues is difficult to operationalize, and certainly varies according to divergent political contexts across cases. His point is to demonstrate that instrument choice cannot be forced into an overly rationalistic schema because it is highly dependent on context, such as the operant 'policy style' within a nation or sector (Howlett 1991, 16). This last distinction brings important implications to the fore. If policy styles are sectorally divergent, and thus require different instruments for similar policy problems in different sectoral policy contexts, the top-down perspective is limited in its applicability. In later work, Howlett (2014) demonstrates the important ramifications of this problem for top-down perspectives. He finds that beginning in the 1990s, international enthusiasm for top-down approaches to policy and instrument design began to wane, as greater attention was paid to complex networks of actors further down the implementation chain. This is not to say that instrument design has been altogether abandoned in implementation research. Instead, Howlett argues that there has been a re-emergence of the study of policy instruments, based on the aspiration to better account for complex mixes of instruments, and actors within the policy process (2014, 194; see also Eliadis et al. 2005). This speaks to the importance of incorporating new perspectives that move beyond the comparatively limited focus of top-down approaches to implementation.

4.4 Bottom-up and hybrid implementation perspectives

In response to the shortcomings of the top-down perspective in capturing the complexity of dynamics further down the implementation chain, two new perspectives emerged within the international literature. The first, the bottom-up perspective, grew in popularity at the beginning of the 1980s, and is characterized by an emphasis on the policymaking influence of frontline implementation actors. The preeminent work in this tradition is Lipsky's (1980) book on 'street-level bureaucrats', defined as public servants working at the bottom of the implementation chain that use their discretion to significantly shape policy outcomes. However, while this concept is illustrative of the potential shortcomings of top-down, policy design approaches, it tends to promote a rather anarchistic account of street-level implementation that is incommensurable, or at least problematic for existing theories of the policy process (Sabatier 1986, 22). In an attempt to overcome this incommensurability problem, Hjern and Porter (1981) introduce the concept of 'implementation structures' as a way to observe interdependent actors and organizations at the bottom of the implementation chain as a single unit of analysis. Their central argument is that the complexity of divergent organizational preferences is mediated by the effects of coordination within the hierarchy of administration, which gives each implementation structure observable characteristics as a multi-organizational network (Hjern and Porter 1981, 220). The problem with this approach is that it does not account for the important role that interactions with state structures, and indeed the policy designs themselves, have on the advantageous positioning of selected actors and organizations within implementation structures. This shortcoming led a wave of new authors to call for a more comprehensive approach bridging together top-down and bottom-up perspectives.

The hybrid approach to policy implementation emerged to address the shortcomings of insular top-down and bottom-up perspectives. In an important early work in this tradition, Mazmanian and Sabatier (1989) emphasize the importance of accounting for the priorities embedded within designs as they are formulated at the top of the implementation chain. However, they also critique purely top-down perspectives for ignoring potential non-conforming priorities of implementing organizations, which may result in a 'reformulation' of policy goals further down the chain. In this way, the hybrid approach that they promote incorporates a more bottom-up dimension. This hybrid perspective is most common in contemporary implementation research, which seeks to identify the preferences of organizations and actors at multiple levels of the implementation chain. Hill and Hupe (2009) present this more current version of the hybrid implementation perspective when they advise that a policy must be traced through numerous political-administrative layers as it works its way down the implementation chain, such that the original policy goals are subject to potential reformulation through repeated interaction with other goals at each layer. In this way, hybrid perspectives are better able to account for the involvement of differently situated members of the policy networks throughout implementation.

In light of these advantages, hybrid approaches have been more common within Canadian political science scholarship than strictly bottom-up approaches. Moreover, where bottom-up approaches are employed, they tend to focus higher than street level, treating organizations and managers as units of analysis rather than frontline workers. This is likely a result of the growing influence of new theories of decentralized governance (Rhodes 1997; Peters and Pierre 1998), which focus on the divergent interests aggregated in communities/networks of actors and coincided with the emergence of hybrid perspective in implementation. Therefore, as this review now shifts to explore the universe of actors identified by bottom-up and hybrid approaches in the Canadian scholarship, it is necessary to emphasize that this literature appears heavily influenced by the broader shift from government to governance in political science scholarship.

a) *Actors – Decentralization of authority*

The emergence of bottom-up and hybrid approaches to implementation within Canadian scholarship was greatly helped by the turn towards introducing private sector actors into governance during the 1980s. Savoie (1994) identifies this turn as part of a broader trend of distrust towards the bureaucracy, significantly propelled during the Mulroney era. However, one of his key findings is that Canada's shift towards privatization was slowed by resistance from public servants. As evidence of this claim, he examines Mulroney's version of a make-or-buy policy, which, owing in part to resistance from senior bureaucrats and public service unions, had a minimal impact on governance before its eventual abandonment in 1990 (Savoie 1994, 157). Savoie's argument situates the Canadian shift towards privatization and the concurrent reduction in the size of government within the context of a global shift, echoed in the policies of Thatcher in the UK and Reagan in the US. However, within the Canadian context, there is a consensus within the literature that these reforms were less pervasive and more gradual. Skogstad (2003) suggests that Canadian social norms of openness and accountability may explain why private actors have not been as fully integrated into governance structures here as they have been elsewhere (p. 969). Her argument rests on the notion that private sector actors do not have institutionalized mechanisms of accountability to the Canadian public, and thus require effective oversight from the representative institutions of Canadian government in order to act in the public interest.

The shift towards decentralization in Canada was significantly propelled by the emergence of strategies of managerialism, specifically new public management (NPM), in concert with the aforementioned popularity of rhetoric supporting privatization and market-authority beginning under Mulroney. While NPM is notable for introducing new instruments of governance within the Canadian context, NPM reforms also empowered new implementation actors. Actors are important, particularly from the hybrid implementation perspective, because they give shape to the universe of possible instruments. Indeed, as Saint Martin (1998) shows, the orientation of actors within the institutions of Canadian governance can explain why NPM was less successful here than in the UK. He advances this argument by examining the policy legacy that followed the institutionalization of the Office of the Auditor General in Canada as the main site for outside consultants to advocate for new, more managerial solutions to perceived problems of administration. By contrast, he finds that in the UK there was greater access to the central state institutions, allowing consultants more effective implementation of NPM reforms. It is important to emphasize, however, that this is only one site of institutional resistance, and that there was broad enthusiasm for NPM higher up the implementation chain.

The era of NPM reforms is not only noteworthy for who gained ground in the area of implementation, but also for who lost influence. Kernaghan et al. (2000) concentrate on an attitude of apathy towards some traditional state functions during this reform era, such that NPM's focus on improving the administrative capacity of government was matched by a relative lack of concern for the policy formulation capacity at the top of the implementation chain. In particular, they argue that by the mid 1990s, the capacity for interdepartmental coordination and effective horizontal policy decision-making was seen as deficient, culminating in the establishment of the Policy Research Initiative in 1996 (Kernaghan et al. 2000, 249). What is significant about this argument is that it acknowledges that the responsiveness advantages found by increasing the authority of managers further down the implementation chain are mitigated when senior bureaucrats cede their authority to coordinate and mediate between the competing interests of different departmental, and sub-departmental or organizational cultures. As such, it is necessary to account for the preferences and roles of actors throughout the implementation chain when connecting outcomes to broader processes of implementation. It is for this reason that Coleman and Skogstad (1990) advise scholars and policymakers to take stock of the relational characteristics of policy networks by situating emergent societal policy actors within the specific state institutional context of a given policy field, particularly when they seek to explain how policy outcomes are produced (p.325). Hybrid approaches are particularly advantageous in this pursuit by addressing the interrelationship between the divergent interests and instruments of state and societal actors in the policy process.

b) *Instruments – New public management and other forms of decentralized governance*

While situating relevant actors within the policy process has important implications for implementation, specifically in relation to significant reforms such as NPM, shifting focus to the precise instruments allows scholars greater descriptive leverage to explain policy outcomes. Focusing on the instruments has also been an increasingly popular strategy of policymakers, at different levels of the implementation chain, who increasingly communicate using a common language of instruments. For example, Howlett (2009) argues that the rise of evidence-based policy interventions has created monitoring, feedback and evaluation processes that rely on the participation of actors throughout the implementation chain. In this way, he advances an understanding of policy implementation that claims the most effective strategy to avoid implementation failure is though the appropriate pairing of administrative resources with policy designs (p. 162). A good example of this approach applied empirically is Sproule-Jones (1994) study of user fees as a policy instrument in four separate case studies. By analyzing interactions between actors throughout the implementation chain, he is able to demonstrate why user fees are more effective in areas, such as in cost-recovery for domestic water supply, and unfeasible in others, such as the health care. His argument relies on creating a dialogue between more managerial concerns raised by administrators, such as the service efficiency of user fees, and more normative, philosophical concerns raised by service users and their political representatives, such as redistribution to mitigate social disadvantage. In this way, his cases demonstrate a potential conflict between the instrument preferences of differently situated actors.

Actor orientations shape not only their preferences for instruments, but also the universe of instruments available to them. In an article that elucidates important differences in capacity for policy analysis between non-governmental organizations and the public service, Evans and Wellstead (2013) argue that the interaction between these groups is heavily shaped by structural and political factors. To this end, they survey policy workers in both sectors to find that despite the fact that they both devote similar percentage of their work output to policy implementation, this involves very different tasks. Non-governmental workers associated these tasks with direct consultation with stakeholders, while civil service analysts were more likely to consider consulting and briefing managers as implementation processes (p.73). In light of these divergent policy capacities, Howlett (2000) demonstrates that in response to decentralization, new instruments of policy design have emerged at the top of the implementation chain, which aim to steer policy implementation to match government priorities. These designs are more collaborative in nature and rely on formalizing partnerships between NGOs and government through instruments such as advisory commissions and interest group funding (p. 424). In this way, Howlett is effectively arguing that this new generation of collaborative instruments act as a Trojan horse, to establish government control over non-state actors. This argument is remarkably similar to one identified earlier in this chapter, made fifteen years prior by Sutherland and Doern (1985), regarding the use of independent regulatory boards and crown corporations to reinforce political control over decision-making. This is significant because it demonstrates that both top-down and hybrid approaches to policy implementation may arrive at very similar conclusions regarding the state's use of instruments to steer policy networks. In this way, there is evidence that the state has maintained significant steering control over its policy agenda.

A significant shortcoming of the state steering focus in Canadian policy instruments literature is that it neglects to explore avenues for managerial, bureaucratic, and frontline discretion, particularly with respect to the more common implementation of policies outside of the political agenda. Indeed, the study of discretion mechanisms further down the implementation chain is conspicuously absent. Moreover, what little research does exist in this area suggests that greater scholarly attention is warranted. For example, in a study on the frontline discretion of immigration officials in determining entry into Canada, Bouchard and Carroll (2002) argue that public administration literature has traditionally treated discretion as an obstacle to be overcome in policy design. By analyzing shifts in Canadian immigration policy implementation, they find that transparent uses of discretion can produce optimal policy outcomes. The key to their argument is the idea that by introducing changes to make the demographics of the government department of Citizenship and Immigration Canada more representative of cultural diversity, and by introducing measures for transparency in the use of discretion, the negative outcome of discriminatory uses of discretion in excluding migrant entry will be reduced (Bouchard and Carroll 2002, 252). This suggests that representativeness and accountability are both possible and desirable among frontline policy implementation actors, and that these characteristics can be embedded within policy instruments. Understanding how frontline actors use their discretion requires taking stock of both how they understand policy objectives, and what motivates policy divergent outcomes.

4.5 Implementation Outcomes as Reframing Effects

A central pre-occupation of policy implementation literature has been accounting for divergence from policy intent by frontline implementers, who use their discretion to significantly shape policy outcomes (Lipsky 1980; Hill and Hupe 2009). Adherence to policy intent can also involve reframing, as the broad targets of a policy objective are applied to a specific context. For example, an accessible employment policy design frame may make no mention of how on-site vocational support is provided to a person with IDD. In practice, the policy can be reframed to reflect the specific employment context and may take the form of addressing stigmatizing attitudes by co-workers, thus sharing more in common with an anti-discrimination framing, while still promoting an accessible employment outcome. However, while this example would qualify as policy adherence, the scholarly literature on implementation as reframing has been far more interested in explaining divergence. Below, I review three main explanations of divergence in the reframing literature.

The most compelling explanation for frame divergence between policy design and implementation relates to the inherent differences to these two stages of the policy process. For example, given the personalized nature of developmental services, and the massive variation in lived experiences among people with IDD, it is intuitive that the frames preferred by implementation actors should be more specific than those embedded within broad policy documents. Schon and Rein (1994) envisioned this divergence in their seminal early work on policy framing when they distinguished between two types of 'action frames'[33] that are used in policy practice: policy and institutional action frames. Policy frames are used in problem definition and thus constrain the universe of solutions available for policy design. Institutional action frames are the complex frames used by policy actors to apply designs to specific situations. While policy frames tend to be singular and static, institutional action frames may consist of multiple related frames, deployed differently depending on situational context. Crucially, institutional action frames can be interpreted differently by individual implementers, making interpretation of the frame a significant explanatory variable for the process of reframing (p.33). In this way, divergence is multifarious and relates not only to individual preferences but also to their interpretation of the overarching framing contained within policy design and institutional norms.

A second, and closely related explanation for frame divergence pertains to the scale of policy frames across multiple levels of governance. This explanation is more tied to the governance of policy problems, particularly drawing from the hollowing of central state authority and institutional void that has accompanied decentralization (Hajer 2003b). By applying scalar politics to policy frame analysis, proponents of scale framing claim that we gain insight into mechanisms of oversight and accountability, both up and down the implementation chain (van Lieshout et al. 2011; 2012). In this way, scale applies not only to the movement of policy frames across jurisdictions (i.e. from provincial policy designs to organizational policies) but also across actors or groups, and even across time. The specific demands of scalar context impact framing, and this can be a key ingredient of policy divergence.

This notion of temporal scale ties closely to the third explanation for reframing divergence: frame evolution. Just as shifts in prevailing norms can propel previously weak frames to dominance over the policy agenda, frames can also evolve further down the implementation chain, leading at certain points in time to divergent reframing. Roggeband and Verloo (2007) assess frame evolution over a 10-year period in the policy areas of gender equality and migrant integration in the Netherlands to identify similar temporal shifts in both policy areas. Interestingly, the shifts they observe entail the subversion of policy frames because of their

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[33] They classify three total types of action frames, but the third 'metacultural' frame type pertains to broad cultural frames that actors draw upon for their belief systems, thus impacting individual framing (Schon and Rein 1994, 33)

ongoing interaction with dominant framings related to individual responsibility and modernization, such that implementation failures occur in both policy areas. This finding aligns with Wolf and Van Dooren (2018), who find that time increases frame polarization and decreases tolerance for frame ambiguity. This suggests that in policy areas of deep conceptual contestation, action frames may be influenced by what Rein and Schon (1994) call rhetorical frames, or broader political ideas that act discursively to limit divergent reframing.

The following section engages with each of these three explanations for reframing divergence (or adherence) in the implementation of developmental services. The previous chapters established frame contestation in the policy area and identified six competing social inclusion frames in policy design. These existing findings are here contrasted with new observations on the implementation process from IDD advocates, which are analyzed with attention to potential reframing divergence in terms of frame interpretation and enaction, scale frames, and temporal evolution. Evidence is drawn from interviews with the same sample of 25 IDD advocates employed in the previous chapter. This provides a foundation for the next chapter, which draws evidence from frontline developmental services management and staff, and civil servants in provincial departments in charge of developmental services, and people with IDD.

4.6 Implementation Reframing by Canadian IDD Advocates

Unlike design frames, which are comparatively static and can thus be compared by their frequency of use in policy documents, implementation framing processes are relational and dynamic. For this reason, presenting and analyzing implementation framing by the frequency of themes in the transcripts would be inappropriate and misleading. Instead, the findings presented here result from interpretation of persistent themes in the interview data, with relevant quotations provided as textual evidence. The interview data highlights the unique position that professional advocates occupy in the implementation chain, as they are often able to provide insights on both design and implementation. This positionality makes them natural practitioners of a hybrid implementation perspective, as they are both reliant on government funding from the top-down and representative of bottom-up interests, not just of people with IDD but also of developmental service organizations and actors.

The analysis reveals that the positionality of IDD advocates in the nexus of design and implementation offers important preliminary perspectives on divergence, which foreground the next chapter's deeper engagement with frontline decision-making by IDD policy implementers. IDD advocates are uniquely positioned to speak about policy divergence because they are often intermediaries between policy designers and implementers. Developmental services are a social policy area that receives scarce public attention, reflected in the dearth of IDD-specific policies at both the federal and provincial levels (see Chapter 2). Consequently, policy failures are infrequently observed and reported by media or policy scholars, leaving IDD advocates as a valuable resource to identify systemic implementation barriers. To provide preliminary insights into these barriers, this section presents findings in three thematic categories that were consistently discussed across the interviews.

a) *Implementation Gaps*

Advocates frequently identified implementation gaps between the outcomes sought by existing policy designs at the federal and provincial level and the outcomes that they observed working with people with IDD. The most common reason identified for implementation gaps in social inclusion policy was the lack of specific deliverables and accountability mechanisms in pertinent policies. This was particularly common among the Nova Scotia respondents, who pointed to recent commitments by the provincial Department of Community Services (DCS) to implement major transitions in inclusive housing and disability supports (Nova Scotia 2013). The persistent failure to implement inclusive housing policies was a prevailing theme in the interviews, in large part because Nova Scotia is one of the few remaining Canadian provinces with active residential institutions for people with IDD, despite their long-standing commitments to deinstitutionalize (Barken 2013). In most Canadian provinces, residential institutions have been permanently closed for over a decade, owing to well-documented history of abuse and neglect of residents (see Burghardt 2018). Given the atrocities associated with residential institutions, this issue was unsurprisingly a focal point of advocates in Nova Scotia, who attributed gaps in the implementation of deinstitutionalization policy to decisions to the DCS, the department with administrative purview.

> *"And looking at the deinstitutionalization process - there was a real promise back in the 90s. Like it looked like Nova Scotia was going to blaze ahead, and the... nightmare that is DCS ended up being why it just totally blew up. It not only scuttled, it totally beached, and has been stalled for probably 15 years. It hasn't moved an inch."* (NS AG3)

> *"I think around housing, in 2013 the roadmap was developed which was a collaboration between government and community. And you probably know - a wonderful document - and here we are it is almost 2020 - and not moved, not implemented - 5 years stalling, blah, blah, blah. That's the way forward - those are the kinds of studies and things. SO the amount of dollars that are being spent to develop small option homes and things like that, is not happening, and more older adults are languishing in these larger institutions."* (NS AG1)

> *"I mean, there are certainly things where we have seen momentum, we've seen willingness, you know, even like within government to at least pilot certain things...but what I will say is that we have seen within government a willingness to take on projects to modernize some of those and it's been a partnership between government and some of the community groups and the agencies themselves to look at how do we bring these old sheltered models into the 21st century."* (FED 21 AG5 F4 SW7)

These are important insights that demonstrate the valuable perspectives of advocates as intermediaries between policymakers and implementers. If the analysis was limited only to policy design frames, the transition roadmap appears as a document containing multiple framings of social inclusion and gives the impression that the province on the right track to deinstitutionalization, with realistic deadlines in place. Conversely, because the transition has been stalled by the lack of investment in small option and group home alternatives, policy implementers such as the staff working at residential institutions would have little insight into the specifics of the policy design and would therefore be incapable of adhering or diverging from these policy frames. The insights provided by advocates about implementation gaps provides necessary context for accurately identifying implementation framing behaviour. Where policies are stalled, like the Nova Scotia transition roadmap, they are less conducive to comparative framing analysis across scales.

b) *Federal role and the Accessible Canada Act, 2019*

When discussing the ACA, advocates' opinions were divided between pessimism about the extent to which federal standards could potentially impact services implemented by the provinces, and measured optimism about the benefit of national standards. Taken together, these responses demonstrate the shortcomings of a strictly top-down perspective, as advocates were keenly aware of the importance of national standards that are sufficiently responsive to frontline realities. The pessimistic view echoes a long-standing sentiment among Canadian advocates, used to justify Canada's lack of a national level disability policy, even when both the US and UK instituted national level acts in the 1990s. Given the existence of the far-reaching provincial policies and the enshrinement of disability as a protected identity category in the Canadian Charter of Rights and Freedoms, it was thought that a national level act would only weaken provincial jurisdiction (Prince 2010, 200). This helps explain why the pessimistic view was more prevalent among provincial level advocates, who also may have been concerned about their ability to effectively advocate with a more centralized level of government. Moreover, despite enthusiasm about the symbolic benefit of federal level commitments, the advocates interviewed in Nova Scotia and Ontario were much more focused on accessibility policies in place at the provincial level, owing to their far greater potential to shape the IDD policy landscape.

By contrast, the federal level advocates were more optimistic about the potential benefits of the ACA. They emphasized that many Canadian provinces and territories do not have existing accessibility legislation, and that this alone was reason to celebrate the arrival of the ACA. Moreover, they pointed to the potential of national level standards, not just as a mechanism for consistency in policy delivery, but also in shaping a coherent discourse around inclusive policy at the cross-provincial level.

> *"(T)he act itself is great, but how does that actually get implemented, right? So, I think the standards that are being developed now is going to have a big impact on whether like, to what extent that federal policy actually, you know, makes practical real-life changes for people… It depends how it, you know, gets implemented and rolled out. And I think the fact that it has happened at a federal level has also potentially increased the motivation at some provincial levels, or territorial levels to follow suit"* (FED AG5)
>
> *"When we think about federally regulated entities, you know, there's thousands of entities, so… I think the principles of inclusion are, you know, in the objectives of the act and in the way that the feds are trying to position it. I think … it will help move forward the discourse on inclusion and build into the standards."* (FED AG7)

This is intuitive because, as federal advocates they are more inclined towards frame implementation as a top-down framework than advocate working at provincial or local levels. The tension between provincial and federal level policy priorities is an important explanatory variable for policy divergence in Canadian disability policy (Dinan and Boucher 2021). While the presence of competing priorities complicates a traditional top-down approach to implementation analysis, it lends nicely to a hybrid approach that can be used to assess whether provincial and/or federal policy priorities are interpreted, understood and implemented at the frontline. To this end, once federal accessibility standards are developed, the extent of their implementation by provincial developmental services structures will provide excellent insight into where and how IDD policy (re)framing occurs.

c) *Maintaining flexibility*

As a result of decentralized governance and neoliberal offloading of responsibilities, advocacy groups have become increasingly implicated in service delivery. For some organizations, this has resulted in significant discretionary authority over the design and delivery of social services within their geographic area. This flexibility was apparent the interviews with all provincial level advocates, but was most pronounced in Nova Scotia, where advocacy groups were more deeply implicated in service delivery.

> *"I can see how different every program is across the province, and I don't want to lose the ability to adapt our program to our community. I hope it's not too rigid because I think that a lot of innovation comes from really working with the community, like I said. I look at my role as a lot more about community development than about implementing some kind of government policy"* (NS AG4)

Advocacy workers frequently emphasized that the most pervasive barriers to social inclusion are not easily addressed by public policy. These include social recognition, empowerment, decision-making autonomy and respect. The academic literature on IDD advocacy has long emphasized that social barriers are the most pervasive barriers to inclusion (Petri et al. 2020; Hutton et al 2010). Personal support workers are uniquely situated to overcome social barriers by reframing social inclusion policies in the implementation stage; however, in the quotations below advocacy workers express concerns that implementers may be amplifying the shortcomings of existing policy designs.

> *"People labelled with developmental disabilities continue to be devalued and staff support continue to feel like they need to be this safety gatekeeper for people's inclusion in the community. So, people will decide, make decisions on what's an appropriate community activity. People will decide what they have time to help get that person connected with… So that they're not really being included and, to me, true inclusion is fully honouring and deeply supporting a person in making their own decisions in how they want to be included."* (ON AG6)

> *"And that comes to my next point which is that needs to shift. There needs to be a conversation about outcomes versus outputs. So we can census the gross number of programs and we can have a sense of the number of people going through it and the*

> *number of people coming out. Hopefully coming out a day program, if they are just staying in it, it is a workshop. But if we do that, we still have to have a sense of what are the outcomes built into these programs, what are the outcomes for the individuals moving through them, are they effective? are they not?* (NS AG3)

The above quotations reveal implementation gaps from both bottom-up and top-down perspectives. The notion of ‘gatekeeping’ social inclusion identified by the first respondent demonstrates the potential for frontline workers to use their discretion to actively prevent inclusion outcomes. The tendency to infantilize and ‘protect’ people with IDD reflects social stigma around disability (Barnes and Oliver 2012) and demonstrates how dominant rhetorical frames can adversely effect implementation. By contrast the second quotation demonstrates that the concept as employed in policy designs does not lend to measurable outcomes. While policy outputs, such as day program slots can be quantified, it is much more difficult to qualitatively assess whether they contributed to the feeling of inclusion for a service user. This has important implications for scalar framing, as it suggests that once social inclusion policies are implemented the outcomes may be so personalized that they are incomparable. As such, in this issue area policy (re)framing ends at implementation because the personalization of developmental services outcomes targeting social inclusion complicates evaluation, and thus problematizes the assessment of implementation effectiveness. This problem is further explored in the interviews with frontline support workers in the next chapter.

4.7 Conclusion: Implications for the Index

Although several types of policy divergent reframing were identified by interview respondents, there was less of an emphasis on the benefits of discretionary authority, which we would expect drawing from hybrid and bottom-up approaches to policy implementation (Hill and Hupe 2009; Lipsky 1980). Instead, advocacy workers suggested that implementers had a limited potential to reframe developmental services in areas that would be most beneficial to the provision of social inclusion outcomes. Specifically, they suggested that service delivery models are not yet empowering people with IDD to exert control over developmental services provision. At the provincial level, numerous policy mechanisms exist for this type of empowerment including direct funding models (Kelly 2016; Dinan and Boucher 2021), supported decision-making (Stainton 2016; Bach 2017), and person-centred care (Hebblethwaite 2013). However, the interview data demonstrates that advocates believe that these design frames have not been complemented with viable action frames, thus leading to implementation gaps. This has been the case in Nova Scotia’s prolonged stall in the deinstitutionalization transition, as the roadmap document introduced over a decade ago has not been met with actionable policies to generate and sustain the community housing model (i.e., building group homes or semi-independent living facilities).

Another important takeaway from the interview data is that recent policy advances, specifically the ACA contribute to frame ambiguity by their lack of applicable standards to inform action frames, and accountability mechanisms to enable compliance throughout the implementation chain. Two of the advocates interviewed suggested that the government response to the COVID-19 pandemic was a major roadblock to the rollout of federal accessibility standards and suggested that once these standards were formalized the ACA would lead to advances in several domains of social inclusion. Indeed, robust standards through the ACA would also represent a significant shift in the nature of Canadian developmental services, with this sort of federal oversight necessitating a more top-down approach to the study of implementation. However, in its current form the ACA is oriented strongly towards a *rhetorical* framing of social inclusion, that is more conducive to frame ambiguity and less conducive to implementation reframing than *action* framing (Rein and Schon 1996). The language of the ACA incorporates numerous compatible social inclusion design frames, but the practical implications of the act only become apparent when we look beyond rhetorical frames to observe the lack of viable action frames in the implementation of the policy in its current form.

While rhetorical frames can motivate policy implementers to use their discretion to pursue desirable implementation outcomes, this potential is limited in policy contexts of high ambiguity, where it is difficult to generate consensus on available solutions (Coburn 2006). Moreover, provincial accessibility policies with similar design and scope to the ACA have been criticized for ambiguity in application. Notably the *Accessibility for Ontarians with Disabilities Act 2005,* has been roundly critiqued by both advocates and disability services organizations for implementation challenges relating to the ambiguous standards within the act and the lack of clarification from the overseeing advisory committee (Onley 2019). Given the lack of direct federal oversight over most developmental services and the challenges posed by multilevel engagement in frontline implementation outcomes, it is reasonable to expect the ACA to face similar implementation challenges, even after more robust standards are established.

A somewhat surprising finding was that advocates tended not to emphasize scalar politics, specifically temporal scale, when discussing divergent implementation. Rather than portraying implementation framing processes as dynamic, and subject to prevailing shifts in public attitudes towards the issue, they tended to see implementation as relatively static when compared to more common shifts in policy design. However, this finding should be approached cautiously for two reasons. First, the fissure between design and implementation framings is very likely a product of aforementioned implementation gaps resulting from weak accountability mechanisms in policies such as the ACA. Without mechanisms for implementation, policy designs can give the false impression of being reformist in their adoption of progressive framings, while effectively maintaining the status quo (Verloo 2005). Another possible explanation is the fluidity with which advocates move across scale frames, by mediating between policymakers and implementers without being firmly embedded at either scale. While advocacy groups are often implicated in aspects of implementation, the participants that I spoke to worked at levels far removed from the frontlines. The smaller scale of implementation reduces acts of reframing to microprocesses that are deeply personal and iterative (Coburn 2006). To adequately assess these microprocesses requires engaging with implementers and service users so that they can account for how policy framing is enacted and experienced (Van Hulst and Yanow 2016). This deeper engagement is pursued in the next chapter.

The most significant takeaway from the interview data is that social inclusion is a remarkably ambiguous concept, making coherent and consistent problematization very difficult.

Multiple respondents questioned whether the concept was worthy of its ubiquity in the disability policy discourse, and often suggesting alternative framings such as ‘recognition’ and ‘empowerment’ that would better address the social barriers faced by Canadians with IDD. This sentiment is perfectly encapsulated in the following quote:

> *“I’ll just say social inclusion is the most overused, misunderstood, and improperly implemented euphemism I’ve heard in developmental services. I hear the term inclusion thrown around as a tokenistic term and it’s rarely implemented properly”* (ON AG6)

Ambiguity not only impedes frame evolution (Roggeband and Verloo 2010), but it also polarizes the policy discourse, thus limiting the potential for consensus building and partnership across policy domains (Wolf and van Dooren 2017). Crucially, this type of consensus among vital stakeholders is needed for a frame to become *institutionalized*, thus finalizing an ideational or paradigmatic shift within a policy area (Bjornehed and Erikson 2018). Despite the longstanding prevalence of social inclusion atop the disability policy agenda, there is little to suggest that the frame has been institutionalized.

CHAPTER 5: REFRAMING SOCIAL INCLUSION THROUGH THE IMPLEMENTATION OF DEVELOPMENTAL SERVICES POLICY

"Within such instances of promised supports offered then taken away, (people with disabilities') status within neoliberalism situates them as veritable canaries in the coalmine of arbitrary, restrictive, and narrowly defined government-funded policy initiatives. Within such practices a neoliberal bait-and-switch with disabled lives is at stakes. The paradox of support for living in the community while simultaneously gutting the very social service systems needed to accomplish this kind of integration sits at the heart of the weakened strain of inclusionism extant in neoliberalism"

- David T. Mitchell with Sharon Snyder 2015,
The Biopolitics of Disability, p.38

5.1 Introduction: Frame Ambiguity and Implementer Decision-Making Roles

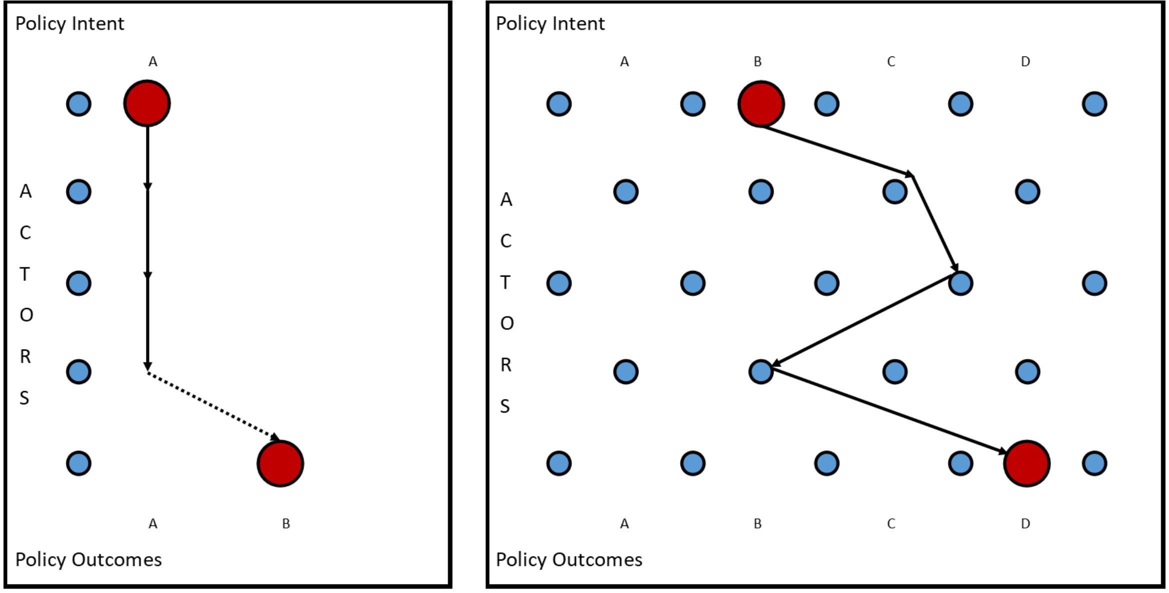
Drawing from the previous chapter's deep engagement with policy implementation research and the preliminary analysis of how IDD advocates reframe social inclusion policy, this chapter takes up the central question: how do policy implementers reframe social inclusion in Canadian IDD policy? To answer the question, and in adherence with a hybrid approach to policy implementation, I analyze (re)framing strategies by implementers from both the top-down (bureaucrats senior civils servants working in government departments administering developmental services) and bottom-up (frontline workers implementing developmental services). The interview data analyzed in this chapter, derived from implementation actors throughout the developmental services implementation chain, demonstrates that divergence in the social inclusion policy area occurs at multiple different levels and in multiple directions (rather than merely from the top-down). This evidence informs two central lines of argumentation:

i) Interpretation of policy intention can vary significantly among implementation actors across levels, thus making policy divergence difficult to both identify and classify post-hoc; and,

ii) Because (re)framing during implementation occurs at multiple levels and in different directions, implementation framing effects are neither cumulative nor directly comparable across levels. Therefore, better understanding the use of decision-making discretion requires analyzing it as an act of adherence to policy framing from one of multiple possible directions, rather than as an act of potential divergence from top-down policy intent.

From its origins, policy implementation literature has taught us that divergence is manifested in outcomes that deviate from policy intent (Pressman and Wildavsky 1973; Lipsky 1980). However, processes of divergence are not static because even very similar policy outcomes can result from the differently motivated actions of implementers. The present contribution demonstrates that policy intent is not always static either. The previous two chapters have demonstrated that with broad, multidimensional concepts like ‘social inclusion’ there may be numerous different understandings of policy intent, particularly in cases where policy language is vague and allows for interpretation by actors throughout the implementation chain. Indeed, in policy areas characterized by such ambiguous problematization and multiple potential locations of actor discretion, processes of implementation do not resemble a vertical chain at all (see Figure 5.1a) and are more appropriately visualized as a ‘plinko’ board (see Figure 5.1b) where multiple potential interpretations of policy intent across levels disrupt the path between what a policy *says* and what it *does*.

Figure 5.1. Two Models of Policy Divergence


a) Divergence from static intent **b) Multiple divergent interpretations of ambiguous intent**

This is especially relevant to the case of developmental services policy, where implementation actors across levels are afforded extremely high amounts of discretion in decision-making processes. The two models in Figure 5.1 first differ at the policy intent level, where 5.1b presents 4 possible interpretations of policy intent, in contrast to a singular, static interpretation. As a policy – represented by the red ball – moves down the implementation ladder it is subject to reinterpretation by numerous implementation actors, whose decisions and actions may diverge from the policy intent, resulting in a new policy framing. In situations of high ambiguity, the potential for this type of divergence is greater as more potential interpretations of policy intent generate more opportunities for (re)framing through implementation processes (Ellis 2015; Hupe 2011). It is also noteworthy that divergence may occur through multiple implementation decisions and actions that occur before the policy outcome. For example, a manager at a developmental services organization may reframe a supported housing policy such that funds targeting recreational programs are actually used in a vocational training program. While both recreational and vocational programs promote social inclusion, the precise nature of the policy in this example is interpreted, specified and reframed at the managerial level. This occurs prior to the program actually being delivered to the end user, as there are still further opportunities for divergence once the program is implemented by frontline staff and experienced by people labelled with IDD.

Within the field of public administration, it has been long established that perfect adherence to policy intent, or 'perfect administration' is not possible owing to the complexity of implementation processes (see Hood 1976). However, despite the recognition that complexity and context disrupt adherence, policy implementation literature has been infatuated with divergence, or policy failure, most notably with the seminal works of Pressman and Wildavsky (1973) and Lipsky (1980). Ultimately, implementation research is about analyzing a policy problem and asking 'why is this policy not working like it *should*?' Disagreement arises when we attempt to generate consensus on how a policy *should* work, and this the root of the top-down versus bottom-up debate. Determining how a policy should work is a fiercely subjective proposition, and I argue that these determinations are made at numerous points throughout the implementation chain. Accounting for these determinations is especially important in policy contexts which bestow significant discretionary authority on implementation actors (such as developmental services) and where policy designs create ambiguity over top-down intent (such as social inclusion policies). This chapter sets out a novel schema for classifying these determinations, while introducing appropriate examples from implementers of developmental services policy in Canada at multiple levels.

In addition to the seminal contributions acknowledged above, other early writers in the implementation literature acknowledged the fallacy of defining policy success or failure relative to a singular, static policy intent. In a work that foreshadows the arguments I set forth in this chapter, Barrett and Fudge (1981) argue that policy implementation is best understood as a negotiation process, where policy goals are often reformulated and enacted throughout the implementation process, such that is useless to attempt to distinguish between formulation and implementation in action. In this way, their approach accounts for ambiguity, and serves as a foundational influence on the 'implementation as reframing' approach that this dissertation employs.

Upon this foundational assertion that policy formulation/intent is not static, policy implementation scholarship has expanded the exploration of the contextual complexity of implementation processes by both examining structural explanations (such as those related to specific governance arrangements) and interpretivist explanations (such as those related to competing ideas/framings within specific policy areas). A key feature in both types of explanation is the study of the nature of discretion afforded to key implementers. As part of an edited volume that takes a multidimensional approach to the study of discretion (Evans and Hupe 2020), Brodkin (2020) argues that the discretionary space afforded to frontline agencies creates a point of entry for welfare state politics to influence policy outcomes by creating patterns of implementer engagement that are difficult to detect. She argues that these patterns of discretion may be influenced by professional norms or administrative logics, but also may reflect the moral character of individual agents and the potentially contentious aims of politically/socially disadvantaged publics[34] (see also Brodkin 2011). Viewed in this way, the discretion afforded to implementing actors and organizations can be seen not simply as a potentially unfortunate cause of policy 'failure', but as a valuable tool to elucidate how decisions are made – and framed – in highly ambiguous policy areas. This is all the more important in the context of neoliberalism, where policies of austerity reduce resource allocations such that implementers at the frontlines are increasingly forced to scramble to mitigate the damaging effects of spending cuts on the lives of the people they support (Newman 2013).

The two central arguments presented in this chapter are linked together by the realization that in this specific policy area – social inclusion policies for people labelled with IDD – accounting for ambiguity and adherence is more important than accounting for divergence. This chapter does not aim to explain divergence/adherence, but rather to situate the actions of implementers within a context of policy ambiguity in order to better understand what factors lead to effective implementation. Recall that this study defines effective implementation as 'the adherence of outcomes to policy goals' (Sabatier and Mazmanian 1981). To this end, adherence is examined in relation to actual, specific decisions and actions, rather than solely in relation to an overarching policy intent. Building on the work of Møller and Stensöta (2019) and Tummers et al. (2015), this chapter introduces a novel typology for classifying the decisions that implementation actors make in highly ambiguous policy contexts. This typology prioritizes adherence over divergence by focusing on whose/what interests implementers perceive themselves to be acting on behalf of. Table 5.1 sets out three ideal types of decision-making roles among developmental service workers.

The typology of implementer decision-making roles draws first from Tummers et al. (2015), who examine a specific sub-category of implementation decision-making, namely coping strategies employed during situations of stress during public service delivery. They identify three distinct types of strategy: i) moving towards clients (e.g. using one's personal resources to better a client's situation in a context of scarcity), ii) moving away from clients (e.g. rationing resources or strictly adhering to administrative routines), and iii) moving against clients (e.g. rigidly following protocols to the detriment of clients). While this schema for worker-client interactions provides a compelling foundation to study implementation behaviour, by focusing only on coping behaviour the study limits its analytical scope. In accord with this critique, Møller and Stensöta (2019) extend the scope of this analytical lens beyond simply examining the behaviour of workers in response to work stressors, to also focus on how problem conceptions privileged by the overarching welfare state regime affect implementers' actions. Specifically, they introduce two novel classifications of implementer roles, which both prioritize the interests of clients: the statesperson and the professional. The statesperson role views clients as entitled to a high standard of quality services provided in transactional exchange for the taxes they pay. The professional role privileges clients by acting autonomously on their behalf, still adhering to organizational/institutional norms. This latter role is particularly interesting because it challenges previous understandings of client-centred implementers as 'citizen-agents' who necessarily

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[34] Equally, it is possible that frontline actors may use their position to – both intentionally and unintentionally – further disadvantage already marginalized populations (e.g., police brutality). For example, there were times during the interviews where personal support workers used ableist stereotypes when discussing their work.

diverge from the interests of the state (see Maynard-Moody and Musheno 2000). Drawing on this theoretical foundation, it follows that in a context of true autonomy professional norms may occasionally not align with client interests, particularly when the decision-making context forces the implementer to choose between sub-optimal outcomes.

The three roles proposed in the typology of implementer decision-making roles that I introduce are distinguished by their adherence to policy frames from three directions. These roles are described in greater detail throughout this chapter, but they are briefly introduced here. First, the 'public servant' role adheres to policy intent from the top-down, with implementers employing their decision-making discretion to align with a policy frame transferred from higher up the implementation chain. While there remains a potential for multiple interpretations of policy intent owing to frame ambiguity within the multiple social inclusion policy problem definitions, the universe of interpretation may be relatively more constrained for the public servant due to accountability mechanisms that constrain their discretion. Second, the 'professional' role I describe aligns closely with the characteristics described by Møller and Stensöta (2019) in their discussion of the professional: namely adherence to norms that specifically govern their role within the implementation process. While this role may often lead to favourable outcomes for clients, professionalism is the ultimate impetus for action, such that strategies will occasionally adhere to Tummers et al. (2015) description of 'moving away from clients'. Finally, the 'proxy advocate' decision-making role closely resembles the citizen-agent description of frontline implementer behaviour, as decisions are made with the primary criteria of supporting clients in achieving their goals. Implementers adopting this decision-making role have numerous courses of action to use their professional discretion to achieve policy outcomes that match the framing preferred by their clients/service users.

Table 5.1. Typology of Implementer Decision-Making Roles

Public Servant	**Professional**	**Proxy Advocate**
Interprets their actions as adhering to top-down policy framing to provide support as it is intended	Interprets their actions as conforming to professional ethos/organizational norms, often on behalf of clients	Supporting clients/service users by listening to their needs and working around existing policy gaps
↓ Adherence	→ Adherence	↑ Adherence

By descriptively analyzing data from implementers working within the developmental services systems of two provinces and at the federal level, this chapter sets forth a discussion of each of these decision-making roles in turn. Put simply, (re)framing occurs at the three levels described. The roles classify the choice an implementer makes when they decide which frame to adhere to with respect to a specific job task. In this chapter, each role is examined with respect to specific (re)framings of developmental services policy, with specific attention to the directionality of adherence. Examining adherence in this way is revealing, because the (re)framing of a policy involves more than its substantive content, but also affects the relationships of interaction and procedural aspects of implementation that dramatically shape outcomes. As van Hulst and Yanow succinctly state: “(f)or actors involved in intractable controversies, then, reframing the policy issue might involve reconceptualizing not only vested interests but also personal identities—identities that are interwoven with beliefs that the world is or ought to be as they perceive it” (2016, p.102). These relational processes of sense-making among actors involved in the actual implementation of policies are tremendously beneficial to the project of understanding how actors at various levels exert influence on what a policy *does*. As such, these roles are mutually exclusive insofar as they relate to a specific decision made by an implementer within the context of their discretionary authority. The chapter concludes by discussing the implications of adherence to policy framing at multiple levels and a discussion of key takeaways to inform cross-provincial comparison of social inclusion policies for people labeled with IDD.

5.2 Method: Interviews with Implementers at Multiple Levels

This chapter draws from a sample of 32 interview participants comprised of bureaucrats working within provincial departments with purview over developmental services ($n = 4$), managers and support staff at developmental services agencies ($n = 15$), and developmental services users ($n = 13$). In some cases, interview respondents could speak to experience in multiple roles. For example, all 6 of the managers that were interviewed had prior experience working as frontline support workers, which allowed them to speak to both how the support worker role has evolved over time, and how managers and support staff interact in the implementation of developmental services. Interviews were semi-structured and lasted between 60 to 90 minutes. With the developmental services users sample, I conducted both individual interviews ($n = 2$) and focus group interviews ($n = 11$). The three focus groups contained between 3-4 respondents and were conducted on site in residential settings.

All interviews were audio recorded with accompanying notes for later analysis. Transcription and coding were conducted using NVivo 12 qualitative analysis software. While this phase of data collection is exploratory, and thus designed to generate descriptive rather than causal inference, coding was still conducted within controlled parameters. Parent codes were created for prevalent topic areas such as ‘implementation’, ‘austerity’, ‘role of government’, with lower-level nodes generated for more specific thematic categories under each parent code. In addition, specific (re)framings of social inclusion were coded in correspondence with the policy design frames identified in Chapter 2. This follows the methodological guidelines of Critical Frame Analysis (Verloo 2005), which stipulates that design frames within relevant policy texts must be identified and classified prior to implementation frames.

Rather ironically, a significant challenge for this research project was the inclusion of people with IDD in the pool of interview participants. Concerns over the legal competence of people with IDD create challenges surrounding the provision of informed consent to participate in research projects or fully understanding the implications of divulging information which may negatively affect their welfare. Within the context of legal ethics, numerous metrics now exist to assess the decision-making competence of people with DD (Fischer 2003). Similarly, within the context of support work practice, substitute decision-making by support workers on behalf of people with DD whom they support is common practice. For this reason, many researchers have chosen to limit their focus to support workers, who, owing to their close role as advocates have tremendous insight into the preferences and attitudes of the people they support (Pedlar et al. 2000; Sparks et al. 2000; Mahon and Mactavish 2000). However, rather than settle for support workers as proxies for the attitudes and beliefs of the individuals they support, this project seeks to effectively distinguish legitimate, yet preventable ethical concerns from paternalist or essentialist generalizations about people with IDD.

Disability researchers have developed several strategies to include people with IDD as research subjects, while conforming to the ethical guidelines of research ethics boards. This project employs several of these strategies as safeguards to protect the rights of research subjects, and received ethics approval from Concordia University Human Research Ethics Committee. First, participation in the study involved acquiring the consent of not only the person with IDD, but also of a family member or support staff who can confirm their willingness to participate. This has the advantage of belaying some concerns as to whether the subject's agreement to participate meets the threshold of informed consent, which was achieved in this project by the use of a specialized instrument called an 'assent and consent form', which combines the consent of both parties (Bach and Rock 1996). To this end, it was necessary to secure provisional consent from the person with IDD first because there can be doubt as to whether participation is truly voluntary when the support worker or family member has agreed first, potentially creating external pressure for someone dependent on care (Griffin and Balandin 2004).

The second strategy involves the acquisition of pre-approval from the ethics board of the organization that provides developmental services used by the research subject. As a reaction to mounting concerns over the involvement of people with IDD in research projects, disability organizations have increasingly developed their own internal ethics review boards to protect client interests (Iacono 2006). Going through organizational review boards provides an extra measure of assurance that the research design meets the rigorous thresholds of care and protection from abuse that organizations are entitled to meet. The third strategy involves extra measures to protect respondent confidentiality. People with IDD are a demographically small group, such that including verbatim quotes that identify the location of the respondent, even without attribution, can allow readers to possibly identify research subjects. Therefore, in addition to omitting identifying information, it was necessary to meticulously screen any verbatim quotes prior to inclusion in the text. While alternative research designs may allow for more relaxed approaches to the acquisition of informed consent – specifically as it pertains to the assent and consent procedure – the strategies employed in this research design encapsulate an approach to research ethics that prioritizes safety and anonymity for all participants.

5.3 The Public Servant: Top-Down Adherence

Policy implementation literature's primary focus on divergence may obscure the fact that implementers often act in accordance with their interpretation of policy intent. This can be a product of limited opportunities for discretion but can also reflect implementation actors' commitment to their role in delivering on policy intent. Policy divergence, or what Pressman and Wildavsky (1973) call 'incongruent implementation' was originally thought to be more likely to occur in situations where there are more links in the implementation chain, and thus more sites of potential divergence from policy intent. This approach assumes that policy intent is static, but it also problematically reduces divergence to a probabilistic calculus, thereby ignoring contextual factors that make some implementation actors more likely to diverge than others. Hupe (2011) expands on the incongruent implementation thesis by arguing that rather than viewing implementation as a vertical, hierarchal chain, a more accurate metaphor invokes the thickness of hierarchies at multiple layers within the governance of a particular policy issue. To this end, managerial competence is an important accountability mechanism to ensure that implementation corresponds to policy intent (p. 76-7). Understanding adherence that is congruent with policy intent thus requires taking stock of the implementation context and the specific administrative factors that discourage divergence.

This section explores the factors that lead developmental services implementers to act in a manner that they interpret to be congruent to the explicit intentions of social inclusion policy. The 'public servant' role type exhibits faith in the machinations of the administrative structure they work within and sees value in adherence to policy objectives. Top-down adherence may also be reinforced by effective accountability mechanisms, which limit the possibilities for discretionary divergence. In the subsection below, I examine the accountability mechanisms identified by developmental services implementers. This is followed in the next subsection by a discussion of how implementers embodying the public servant role may also view top-down adherence as a democratic principle, thus using their discretion to follow policy intent as a matter of moral – rather than professional – commitment to the administrative structure.

a) *Accountability Mechanisms and Limitations on Discretion*

As a means to encourage policy adherence, accountability mechanisms contribute to a decision-making context for frontline workers. The presence and effectiveness of accountability mechanisms are a characteristic of the particular governance structure. To this end, it is worth emphasizing that accountability mechanisms need not be top-down. Indeed, as Hupe and Hill (2007, p.289) discuss, and as I will elaborate in later sections, accountability mechanisms may exist both horizontally (in forms of professional accountability) and from the bottom-up (in forms of formalized accountability to clients). However, with respect to multilevel or multi-layered governance structures, such as the governance of Canadian developmental services, governance structures can vary significantly on the amount of accountability they impart (Hooghe and Marks 2003). For example, in previous research Dickson (2021) demonstrates that Ontario's more centralized governance structure is more likely to impart greater accountability throughout the implementation chain than Quebec's more decentralized structure. However, it is necessary to look beyond the mere presence of accountability mechanisms when assessing their effectiveness in practice.

In Ontario's developmental services system, accountability is enforced at the frontlines by the implementation of individualized support plans (ISPs) for each supported individual. These annual planning documents are mandated by the 'Quality Assurance Measures' regulation added to the Social Inclusion Act (O. Reg. 299/10), and the most significant implementation mechanisms to ensure that developmental services outcomes match the aspirations of provincial level policies. In previous work, Dickson (2016) finds that support workers in Ontario were not adhering to social inclusion planning priorities in the creation of annual goals during the ISP process. However, managers and support workers in Ontario interviewed for this thesis placed far more emphasis on adherence to planning procedures. One respondent, quoted below, indicated that the Ministry of Children, Community and Social Services (MCCSS) has set out compliance mechanisms to audit the implementation of ISPs.

> *"So there is some degree of oversight, but it seems like it's just..so they'll come in and they'll say, 'OK, you're missing ISP's, you have set amount of time to get this in place. I could just not know about this, but I've never heard about them coming in and saying like 'wiping the table' is not an acceptable goal. It could happen, I don't know.I might just not be aware of it, but the focus is more on like is it done? Is the paperwork completed? Are the online updates being done?"* – ON 26 SW9 M3

In the above quotation, the respondent discusses compliance mechanisms to ensure that residential staff are following through on ISP documentation. While the respondent clarifies that the MCCSS does not regulate the specific goal objectives that frontline workers choose, it is noteworthy that the ministry has enforcement mechanisms to ensure that timely documentation and monitoring of goals occurs.

While these mechanisms are relatively limited in scope, the presence of upward accountability can affect the decision-making calculus of frontline workers in ways that extend beyond the mechanisms themselves. For example, by emphasizing the importance of documentation and monitoring, the auditing of ISP compliance both imparts additional authority to the MCCSS and reinforces the framing of pertinent policy problems: in this case, the framing of social inclusion. This latter outcome mirrors what Van Lieshout et al. (2012) call the downscaling of policy frames, where a broad policy framing is transferred through interactive accountability mechanisms from the top-down to a lower policy level that is more conducive to specific action (p.177). This has the effect of encouraging adherence in implementation processes that are susceptible to frame ambiguity.

By contrast, Nova Scotia participants reported comparatively less accountability in the annual planning process, allowing greater frame ambiguity to persist. This has important implications for implementers who adopt the 'public servant' decision-making role, as top-down adherence is less effectively translated or downscaled to the frontlines, allowing *de facto* adherence in implementation to more loosely adhere to policy intent as it is framed *de jure* in policy documents. In Nova Scotia, annual planning falls under the purview of the Department of Community Services (DCS) and is specifically outlined in the Disability Support Program – Program Policy (DCS 2012). In addition to setting out the procedures for Nova Scotia's 'Individual Support Plans', this document assigns responsibility for assuring compliance in annual support planning to a 'Care Coordinator' employed by the DCS, overseen by a Casework Supervisor. While the program policy describes top-down accountability through these two roles, the practice of annual support planning described by participants is very loose in its adherence to the policy intent:

> *"Our IP, it depends on the client. It's usually either every six months or one year. Then we go over it so the team sits around the table. Sometimes we'll meet first without the client, and then bring the client in and meet with them, and sometimes the client will just meet with them for the whole time. So it's just a chance to go over kind of everything, head to toe about the client, medical, social. And then smart goal planning. So yeah, smart goals. So like the specific measurable, attainable, reliable, timely goals…The long term goal might be that they want to live in a group home. And so that could be 10 years down the road. There's no group homes open. You have very specific medical needs. You need you use a wheelchair. You need lifts throughout the house. That doesn't exist right now, so the short term is. Let's see if we can get (them) taking transit, using the bus by yourself, so you can be more community involved."* - NS10 M

In this quotation, the respondent makes no mention of departmental oversight in the design, implementation and evaluation of yearly individualized support goals. Moreover, they explicitly acknowledge the inability of the developmental services system to accommodate transition from a residential institution (where this manager was employed) into a group home. This is noteworthy because it directly contradicts the language of prominent Nova Scotian developmental services policies, specifically the Disability Support Program and Community and the 'Roadmap for Transforming the NS Services to Persons with Disabilities Program' (Nova Scotia 2013), which explicitly emphasize the transition to community living as the fundamental social inclusion goal for people with IDD in the province. It is revealing that short-term goals are described as 'measurable', 'attainable', 'reliable' and 'timely', yet they still follow a community participation framing of social inclusion, specifically independent use of transit. As such, this is not an example of divergence, but rather of adherence to policy intent that cognizant of the limitations of developmental services provision.

The capacity of managers to workaround the limitations of the administrative structure is a useful tool in promoting top-down adherence. This function of managerialism enables the preservation of policy intent in situations where the divergence would otherwise be highly likely (Brodkin 2011), thus embodying a key characteristic of the 'public servant' role type further down the implementation chain. The quotations below from two managers working at the same residential institution in Nova Scotia provide an excellent example of how managerial competence can be useful in potentially achieving specific policy objectives that are made difficult by the limitations inherent to the developmental services structure.

> *"And as well, we've had quite a bit of turnover and management. .. there's been quite an influx of younger managers, which is awesome too, because fresh ideas and fresh energy, so it's been good because you're seeing… a lot more of social inclusion and we call it transformation where we're trying to get clients into the community as much as possible."* (NS10 M)

> *"And then obviously we've did some training for all of our frontline staff, and that that is ongoing support. For example, I'll work with some staff and they will say, 'you know, the client gave me this idea and this is what they really want to be doing and I don't know what to do with that'. I'll say bring it to the table, we'll talk about it. So, then we have the*

> *support of our clinical team. We have our psychologists or (occupational therapists) or (physical therapists), our dietitians. Sometimes we have to get pretty creative, right? So how are we providing those opportunities? What can that look like? How do we track if they're being successful? So I think we've identified that something we really want to provide for the clients here."* (NS11 M)

In the first case, the participant is speaking specifically about trying to transition people labelled with IDD into the community, in adherence with the transition roadmap set forth by the province. In the second quotation, they are discussing the development of their own internal planning system to compensate for the shortcomings of the DCS planning structure. The first quotation comes from the same manager that previously highlighted the impracticality of the provincially regulated annual planning structures. In this quotation they are more optimistic about the potential for transitions into community housing; however, importantly, they attribute the potential for successful transitions to the arrival of a new cohort of managers, whose competencies are better suited towards promoting social inclusion. Moreover, they even appropriate exact language from the relevant policy (Roadmap for Transforming the NS Services to Persons with Disabilities Program) when they say '*we* call it transformation', referring to this new cohort of managers.

Just as the administrative structures are different in both provinces, so too are the types of top-down adherence that they foster. Where accountability mechanisms are less effective in downscaling policy frames, managerial competence is a vital asset in promoting adherence. While managerial competence is not capable of overcoming significant impediments, such as the lack of investment in group home alternatives to expedite the transition away from institutional models of housing in Nova Scotia, the empowerment of competent managers creates new opportunities to reframe the broad objectives of policy designs. Through the creation of new mechanisms of monitoring and assessment that conform to the broad framing of policy intent, developmental service managers can create new opportunities for top-down adherence.

b) *Top-Down Adherence as a Moral Obligation*

Why do implementation actors choose to broadly adhere to top-down policy intent, even in situations where they are empowered with discretion to diverge? Early implementation scholars Hjern and Hull (1983), drawing from a constitutionalist perspective, attributed adherence to a commitment by implementation actors to democratic principles. In their view, organizational context and implementation actor interests were vital variables to the study of implementation outputs, which thus broadened the study of policy adherence beyond the simplistic calculus of static policy intent contrasted with policy outputs. While this early perspective – grounded in organization theory and influenced by the work of Scharpf (1977) – was still quite limited in terms of the contextual factors it incorporated into the study of implementation, it has served as a bellwether for subsequent research addressing why actors choose to adhere. For example, Schofield (2004) adopts a policy learning approach to address the difficulties inherent to the operationalization of new policy initiatives by managers, arguing that administrative structures act both to guide learning during practices of implementation and to promote adherence by imposing boundaries to divergent behaviour (p.300). This broadens the possible rationales for top-down adherence beyond just a political sense of democratic duty to also include adherence based on commitment to administrative structural imperatives.

By taking an expansive view of the range of moral obligations that lead to top-down adherence we gain a better understanding of 'the public servant' decision-making role. Ultimately, this role reflects an actor's faith in the validity and effectiveness of the political and administrative systems that govern service delivery. For developmental services implementers, this faith can be challenged by the persistence of negative social inclusion outcomes, such as the lack of employment opportunities or the stalled transition towards community living. During the interviews there were several occasions where – either as a result of caregiver fatigue or emotional dissonance (Egan and Dalton 2019, Nam and Pak 2017, Pinquart and Sörenson 2006) – implementers justified policy adherence by demonstrating their detachment from the lived experiences of developmental services users. This detachment was most apparent in quotations like the two below, where developmental services implementers invoked ableist and ageist stereotypes and rationalized these discriminatory attitudes by suggesting their adherence to developmental services policy objectives.

> *"…a lot of us were maybe a little thrown about the talk of – like, not the building closing, but kind of like the big facilities and how they don't exist. Because some of them have been, like 'this is home', right? Like, this is definitely their home and I can attribute this to, like I went to university and I lived in residence for four years, right? And everybody said university is going to be one of the best times of your life… And it was 'cause like your friends were right there, minimal housework. I lived in a single room and you know, they did the floors and stuff… I was fed and my friends were there and once you got your work done you could go have fun, like in here… I mean, some people are retired. Some people work on the units. But there's work times and then then it's fun time. Then it's like, let's go play bingo in the gym or let's go to the movies or you know my friend lives on that unit like let's go shopping together or like. These are their friends, right?... I think I can see why that government and some people want them out in the community, but this is their community. Some of them, would really struggle to leave. I mean change is hard for all of us, but I don't know if it would be beneficial."* (NS15 SW)
>
> *"Like, old people, first of all, no one really wants to spend time with. Like, it's not very fun. Well it's true. And I always speak out of my own experience, having to toilet my dad before he went into a nursing home. And then you go into nursing home and it doesn't smell good there and old people smell. Period. And then add in the disability portion and people are afraid of disability and they don't know how to interact with someone with a disability and they don't like old people anyway. It scares them too because they see themselves in 20 or 30 years. There's just nothing, there's like… it's just an uphill battle"* (NS3 GOV)

The first quotation comes from a support worker who was employed at a residential institution in Nova Scotia. They rationalize the stalled transition towards deinstitutionalization in the province by suggesting that many people living in the institution would be incapable of adapting to life in a community setting. This justification based on infantilization employs a well-known ableist stereotype – the myth that people labelled with IDD are frozen in a state of childhood, and thus incapable of adult responsibilities (Oliver and Barnes 2012; Dickson 2018). The second quotation comes from a bureaucrat working within the DCS in Nova Scotia, who attempts to explain the lack of progress towards social inclusion outcomes by claiming that ableism and ageism are entrenched social barriers. It is jarring how easily the interviewee employs ageist and ableist stereotypes and generalizations, which connote a detachment from the population they purport to serve. Moreover, they use these stereotypes to defend the failure of social inclusion policies, suggesting that they feel departmental policies are effectively deployed, but ultimately circumvented by social barriers during implementation.

Taken together, these quotations demonstrate an insidious form of top-down adherence where decision-making assumes the character of policy legacies, which can be entrenched into the delivery of policies at the national and subnational level (see Wallner 2012). Legacies of segregation, exclusion and devaluation of the lives of people with IDD persist through policies continued reliance of residential institutions as an acceptable form of housing for people with IDD. Moreover, when these ableist policies are coupled with limits of professional discretion to negate their effects – either through strict accountability mechanisms or top-down adherence as a moral obligation – there is greater potential for implementation that moves away from the interests of clients/service users. Therefore, examining the interaction between the qualitative implications of existing design frames and the practical opportunities for professionals to employ their discretion to adhere to alternative implementation framings that challenge the potentially negative ideational foundations of design frames is a promising avenue for cross-provincial comparison.

5.4 The Professional: Horizontal Adherence

The 'professional' decision-maker role is distinct from the 'public servant' role because adherence occurs horizontally rather than vertically. That is, rather than implementing policies based on adherence to top-down policy intent, 'professional' decision makers choose to operate in adherence to the organizational norms that govern their work. Horizontal adherence is thus not predicated on a moral obligation to uphold democratic governance, but rather on an ethos of professionalism. This type of adherence may produce very similar policy outcomes to those of the 'public servant', as previous research demonstrates that a higher degree of professional training and knowledge can make implementers more likely to adhere to top-down policy objectives where effective management and accountability mechanisms exist (May and Winter 2009; Moynihan and Pandey 2005). However, in these cases where managerial competence and accountability are high, it may be unclear whether implementers are truly acting in adherence with norms of their practice or whether they simply fear reprisals for diverging from top-down intent. For this reason, the 'professional' decision-making style may be easier to detect in situations where implementers are provided with greater discretion in day-to-day decision-making (Evans 2011).

What separates the 'professional' decision-making role from a typical bottom-up perspective on policy implementation is the fact that these implementers must occasionally use their discretion to adhere to norms that reflect a kind of 'satisficing' behaviour (Simon 1976), that is not perfectly aligned with policy intentions from either the top-down or the bottom-up. That is, professional norms may dictate a threshold of optimality for implementation actions that is within the boundaries of resource and time constraints that come to bear on decision-making (see Wolfson 2020). For example, in austere developmental services environments, implementers such as social workers may be forced to make difficult decisions concerning who receives services, effectively employing their discretion to minimize the damage of spending cuts and the termination of programs and services. The rationale for these difficult decisions is based on professional standards or codes of conduct that can exist both formally through organizational procedures or informally through processes of deliberation or collective uses of discretion at the organizational level (Møller 2021). Moreover, this type of decision-making based on adherence to professional norms exists not just at the frontlines of policy implementation, but also higher up the implementation chain, where high level staff in implementation organizations act as ‘middle-level bureaucrats’ by exercising significant discretion on the implementation process while also exerting influence on policy design framing (Cavalcante and Lotta 2015). This section discusses the professional decision-making role by first describing horizontal adherence before examining how this occurs through reframing in the implementation of developmental services in the context of austerity.

a) *Horizontal Adherence*

The idea of horizontal adherence confounds some traditional approaches to policy implementation, which conceive of the process of implementation and public administration more broadly through the lens of principal-agent theory (see Miller 2005). This principal-agent orientation is most desirable to proponents of the top-down approach for whom the role of implementation actors is to execute the practical actions prescribed in policy design, and where divergence from policy intent represents a failure of policy design (Linder and Peters 1987; Mazmanian and Sabatier 1989). This focus was later extended beyond implementation actors to include implementation organizations as agents whose autonomy may – without effective mechanisms of coordination and accountability – result in divergence that confounds the effectiveness of implementation (May 1991; see also Bouckaert et al. 2010). This approach was further adapted to account for the bottom-up/hybrid approach to implementation by Maynard-Moody and Musheno (2000), who argue that in addition to the traditional ‘state-agent’ narrative, frontline implementers more commonly rationalize their decisions using a ‘citizen-agent’ narrative, which is the product of a normative commitment to the interests of the citizen-client with whom they are working. This is highly relevant to the developmental services landscape where implementers at multiple levels are entrusted with significant amounts of discretion to decide upon and influence policy outcomes.

Developmental services involve the provision of intimate and individualized care, meaning that implementers are definitively aware of their clients’ needs and wants. For these reasons, we should expect the ‘citizen-agent’ narrative – which aligns most closely to the proxy advocate decision-maker role discussed in the next section – to predominate among developmental services implementers. However, several of the implementers I interviewed discussed the significant role of professional norms and organizational culture in shaping their decision-making. Therefore, while their actions may reflect either the citizen-agent or state-agent perspective, the way they decide to use their discretionary authority adheres with horizontal framing of social inclusion policies.

> *"There's definitely barriers to the program too. But part of my thing is making sure that people who are eligible get it. Because that is a huge piece, right? If you are in a better financial space it provides you with more options. But then who does work that for you? And how do you have people who you can trust to do it? There's a whole bunch that goes with that right? But that has to be a big piece of it I would think"* (NS8 GOV)

> *Uh, it's like other, if you're speaking to other (managers), everybody fully acknowledges this is a very stressful hard job. As far as, like, the managers who are one level above, they will acknowledge that it's a difficult job. But, also there is a culture of pushing people: setting really high expectations and being very disapproving if they're not met, like using… using disappointment as a tactic to bring as much work out of people as you can. And then from, uh, really from like the upper levels there is the same thing down on toward the managers. So, at each step there are very high expectations. That means that the higher you go, the more stressful it becomes.* (ON26 SW M)

The first quotation comes from a provincial level civil servant in Nova Scotia, who discusses their commitment to overcoming the inherent barriers to program uptake contained within a specific poverty reduction program under the purview of the DCS. This is noteworthy because the implementer's commitment to informing service users and encouraging program uptake is designed to compensate for flaws within the program design. Typically, this role is performed by social workers, support workers or family and self-advocates situated further down the implementation chain. Moreover, financial support programs for Canadians with disabilities are often designed to be difficult to both gain and maintain access to (Kneebone and Grynishak 2011; Chouinard and Crooks 2005; Kimpson 2020); so this government worker's commitment to encouraging service uptake reflects a professional commitment to the program that contradicts the policy's intended exclusivity. This use of discretion is noteworthy because it is not rationalized using a client-centred justification, but rather a program-focused justification, thus demonstrating that this high-level implementer is dedicated to maximizing program effectiveness as a matter of professional pride. Throughout the interview this implementer expressed pride in the DCS's output, reinforcing that part of the department's role was to minimize the shortcomings of policy design, based on short-sighted, politically-driven commitments at the top levels. This is a hallmark of horizontal adherence, where professional pride and respect for organizational norms is a powerful motivator for implementers' use of discretion (Cecchini and Harrits 2022; Oberfield 2014; Møller 2021).

By contrast, the second quotation above demonstrates a wholly different mechanism for horizontal adherence, where the implementer – a manager at a developmental services agency – discusses a professional culture that is based on high stress and unattainable expectations. Specifically, this participant refers to an organizational culture that is based on upper management overloading bottom level managers with unsustainable responsibilities, and then expressing disappointment at their inevitable failures. Unlike with top-down accountability mechanisms where adherence occurs in relation to specific objectives, this unique decision-making context imposes unachievable expectations upon implementation actors. In a roundabout way, this context empowers implementers to use their discretion to prioritize the outcomes that they deem most important. This decision-making process is complicated by time and resource constraints and complicated further by the ambiguity of developmental services policy, specifically when aimed at promoting social inclusion. Raaphorst and Loyens (2020) argue that in situations of ambiguity, implementers rely on informal discussions with their colleagues to help make decisions less subjective, and to achieve timely and consistent outcomes. This same phenomenon was apparent in the present study, where managers discussed the importance of professional culture in guiding decision-making in sub-optimal environments of time and resource scarcity. Moreover, these collegial networks based on brainstorming and knowledge transfer among staff at the same level can lead to consistency in outcomes and may protect staff from negative repercussions for performance failure (Sandfort 2000). The two above quotations demonstrate how the horizontal adherence that informs the professional decision-making role can arise both from a normative commitment to program objectives and from entrenched social ties among implementers at the same level.

b) *Austerity and 'Moving Away from Clients'*

To expound how the professional decision-making role leads to policy reframing through implementation processes, this section addresses the impacts of austerity measures on developmental services, arguing that the resulting policy context necessitates the professional decision-making role. The concept of austerity is ubiquitous in the scholarship on developmental services in Canada, as the retrenchment of the social policy landscape has forced implementers to make tough decisions on where to allocate scarce resources (Kelly 2016; Courtney and Hickey 2016; Kimpson 2020; Levesque 2020). However, austerity is a problematic and murky concept to employ for two primary reasons. First, there are pronounced differences in provincial capacity for developmental services provision due to stark differences in both spending and political priorities (Levesque 2012). This is particularly problematic when comparing provincial effectiveness in achieving federal priorities, which is complicated by pronounced differences in fiscal capacity, political culture, and intergovernmental relations (Rice and Prince 2013; Simeon and Nugent 2012). Nova Scotia's inability to transition away from institutionalization and the sheltered workshop model are clear examples of incongruence between political priorities and system capacity. Specifically, 'austerity governance' – defined as a structure that attempts to reconcile a government's technocratic management of increasingly decentralized implementation by non-governmental actors contrasted with the necessity of retaining public support in a political climate that rewards frugal spending (Newman 2013, p.516) – creates greater challenges to achieving effective outcomes in provinces with less fiscal capacity.

Following from the essential contradiction of austerity governance, the second reason that austerity is a problematic concept to employ in the analysis of developmental services is the fact that this policy area does not receive much public attention, such that even obvious examples of inadequate funding are not often politically damaging. The lack of public attention lowers the political stakes for undergoing service cuts in the area of disability services, leading to what

Mitchell (2015) labels as the paradoxical ‘bait and switch’ of inclusionist politics, where governments provide rhetorical support for community living while systematically cutting the programs required to facilitate this shift (p.38; see also de Chenu et al. 2016). While policy advocates are well aware of this paradox, as was evident in previous chapter’s discussion of rhetorical frames versus action frames, the topic of program cuts and the broader impact of austerity were far more prevalent topics in the interviews with advocates than implementers, particularly in Nova Scotia where the lack of investment in the developmental services sector was the most apparent. For implementers in this developmental services context, austere spending by the provincial government is an ingrained feature of the policy environment that concretely shapes the decision-making context by limiting potential avenues for action. By contrast, in Ontario the cuts to existing programs were more jarring to implementers, who were comparatively more affected by cuts and changes to work dynamics (see Courtney and Hickey 2016), leading to a greater emphasis by interviewees on equitable service distribution and maintenance of effective programming in the face of cuts.

> *“Something else that I've experienced now and I don't know that this is necessarily across the board, but day supports and community inclusion, specifically day programs. Uh, some agencies are phasing that out. Which to some degree makes sense during the pandemic, but I don't know that it is coming back after the pandemic.”* (ON 26 SW9 M3)

In the above quotation a manager at a developmental services agency describes the abrupt closure of day program supports during the COVID-19 pandemic. This respondent was skeptical that these programs would reopen after the pandemic and identified this throughout the interview as a catastrophic development for older adults labelled with IDD, for whom alternative programming aimed at employment or education is undesirable and/or unavailable.

Despite the problems that the concept of austerity poses to the comparative analysis of developmental services policies, it is necessary to account for precisely because it affects the professional culture of policy implementation. For workers navigating a service system with scarce available resources, limited programming options, or facing cuts to essential existing programs, the prevailing professional culture may lead them to adopt strategies of ‘moving away from clients’ by rationing available resources according to strict organizational standards (Tummers et al. 2015). Where cuts to available resources are abrupt, this may lead to dramatic shifts in implementation strategies, thus disrupting the potential for client-centred outcomes.

This satisficing behaviour is evident in the above quote from a developmental services manager, who describes how taking a supported individual to an appointment is the only time that they can go shopping, thus they often combine the trips. While this professional strategy optimizes time management, it limits the engagement of the supported individual with the outside community. In this specific case, the manager works in a residential institution, making opportunities for community outings even more precious for the supported individual who is otherwise segregated from the community. In my interviews with people with IDD in supported living environments, going on more community outings was a common example of how they would like to increase their social inclusion. Therefore, denying these opportunities as a consequence of resource-scarcity is a decision that definitively moves away from the expressed interests of developmental services users.

> *"Everything is a distance from here, so we try to kind of get an appointment 10 minutes this way or 10 minutes that way. I think we try to take advantage of when we do go out, because so, for example, we have a client going to appointment this afternoon, it's also going to turn into a slash shopping trip this afternoon, right? So, you're just trying to find those opportunities wherever you can."* (NS11 M)

By contrast, where the resource scarcity is persistent and characteristic of the developmental services context, client-centred outcomes are less likely to exist at all, and thus austerity is less disruptive or transformative. This coincides to what Rice (2013) calls the 'micro-institutionalist context', where caseworker-client interactions are a key ingredient of the implementation context but are also susceptible to disruption when there are shifts in the professional/organizational culture of service delivery agencies (e.g., the influence of activation policies on welfare provision in Europe). Cross-provincial comparison of developmental services policies must account for this context by assessing the nature of interactions both between workers and clients, and also among workers for whom professional norms may significantly shape the framing they adhere to during implementation decisions.

5.5 The Proxy Advocate: Bottom-up Adherence

The proxy advocate decision-making role is common within the policy implementation literature, which emphasizes the potential of street-level bureaucrats and other empowered implementers to use their discretion altruistically to the maximum benefit of their clients. In this way, their decision-making is proximate to advocacy on behalf of service users, whose well-being is their primary motivation. This was the most common decision-making role discussed by interview participants across levels. Indeed, the expectation that implementation actors – particularly those working in the voluntary sector – will behave in a manner that ultimately benefits their clients most is reflected in the evolution of their role within the increasingly decentralized forms of social services governance (Laforest 2019). Decentralized governance arrangements can result in policy designs that are vague in terms of both instruments and outcomes, with a compensatory reliance on what Hill and Hupe (2009) call the co-production mode of 'operational governance', which manages implementation through a mechanism of trust (p.189). In this way, the discretionary authority of frontline implementers is increasingly important in the governance of social services.

Within the bottom-up literature, the tendency has been to look downward through the implementation chain as a means both to highlight how implementers exert significant discretion over policy outcomes and to identify what motivates their behaviour. Indeed, for bottom-up scholars the primary reason to look up the implementation chain is to identify a static policy intent that forms a backdrop to the study of frontline divergence (Gofen 2014). Recall that this chapter's central arguments are i) that policy intent in the social inclusion policy area of developmental services, as in many other policy areas, is never static, thus limiting the descriptive benefit of diagnosing divergence, and ii) to understand decision-making by implementers it is helpful to observe it as an act of adherence to the (re)framing of policy from one of three directions. To advance these arguments it is helpful to examine how governance structures foster discretion – both intentionally and unintentionally – across levels. Adhering to a policy frame from the bottom-up requires identifying unmet needs from the service user to fill in gaps in operational governance. Therefore, this section begins by looking up the implementation chain to examine where gaps exist to encourage the use of discretion by implementers. This is followed in the next section by discussing how developmental services implementers adhere to policy frames from the bottom-up, with a focal discussion of the role of families in shaping decision-making.

a) Bottom-up Adherence and Filling Policy/Governance Gaps

The 'proxy advocate' decision-making role is so named because bottom-up adherence characteristically employs some of the qualities of advocacy on behalf of the end users within a given policy areas. This is evident in the developmental services context where implementers often adhere to bottom-up framings to counteract the gaps within existing social inclusion policies. In practice, this can take the form of taking stock of a service user's unmet needs and implementing immediate and occasionally informal interventions to facilitate those needs that may fall outside the scope of professional practice. Interview participants provided numerous examples of these discretionary interventions, from activities as minor as support staff occasionally buying an individual they work with coffee or meals with their own money, to more major interventions like investing large amounts of personal resources to support the mobilization of self-advocates by facilitating meetings outside of work hours.

Although inspirational, these interventions by proxy advocates are typical of the use of discretion to fulfil the needs of deserving clients often discussed in the street-level bureaucrats literature (Ellis 2011; 2015; Jilke and Tummers 2018; Evans 2013; 2011; Maynard-Moody and Musheno 2000). A more surprising finding from the interview data was that there was also a tendency toward bottom-up adherence among upper-level bureaucrats working in provincial departments in charge of developmental services. Specifically, there was a willingness to critique government for implementation deficits, combined with an emphasis on the exceptional efforts of bureaucrats working within the departments to pick up the slack.

> *"No, but again, there has been a political commitment. The Premier said we're doing the roadmap, we are transforming the system, we are going to do it. But, there needs to be a commitment for more houses. The 8 are great, that has moved 30-some people out, that is good. They have got some innovative programming - well, I don't know if you would call it innovative- but they have got some programming that will allow people with developmental disabilities to move independently into there own apartments with support - that is great. So there is movement within the system, where for years there was no movement. But they are not doing a great job of communicating and they have agreed with me on that, and so the community thinks nothing is happening. But I see everyday the work that is going into all of this. Huge amounts of work. But it is not being well communicated to people."* (NS8 GOV)

> *"You know things just work slowly in government. I mean, and in autism they work more quickly than in a lot of other parts of the government because there's so much public focus."* (ON24 GOV)

In the first quotation, a civil servant within Nova Scotia's DCS argues that the perceived failure of the province's deinstitutionalization policy is a product of failure in communicating the program's incremental progress. At first glance this may appear to demonstrate top-down adherence, as the civil servant is attempting to deliver on the policy promises set forth by the Premier's transformation plan. However, a more nuanced reading of the quotation reveals that this bureaucrat is actually criticizing the government for not matching its political commitment toward deinstitutionalization with the necessary resource outlays to achieve it. As such, they argue that the DCS is actually moving towards client's needs by using its full capacity to facilitate transitioning people labelled with IDD into the community, and that the blame for failure should not fall on the Department.

The second quotation above, this time from an Ontario civil servant, echoes a common complaint by both implementers and IDD advocates that the reason changes are so slow to occur within the developmental services system is the lack of public attention, which disincentivizes political leaders from following through on their commitments. The small demographic size and persistent social exclusion of people with IDD renders them invisible within the broader context of Canadian social policy (Abbas 2014; Prince 2009). In both provinces, implementers expressed frustration that policy targeting autism-specific interventions such as investments in the training and practice of Applied Behavioural Analysis is fast-tracked owing to the greater visibility of autism advocacy (see Baker and Steuernagel 2009; Orsini 2012), while policy affecting the broader IDD community consistently lags. This broadens the gap between political commitments and delivered outcomes, and thus increases pressure on implementers across multiple levels to move towards clients.

b) Rule Bending and 'Moving Towards Clients'

The devolution and decentralization of governance not only increases discretionary authority down the implementation chain, but also creates opportunities for implementation that is flexible and responsive to the needs of service users (Skelcher 2005; Hooghe and Marks 2003; Dickson 2022). In the Tummers et al. (2015) study, upon which the typology of implementer decision-making roles introduced in this chapter is partially based, they list rule bending as the most common form of 'moving towards clients' exhibited as coping behaviour during public service delivery. Specifically, they state that rule bending behaviour is most commonly employed to mediate a 'role conflict' where existing rules are insufficient to meet the demands of their clients (p.1109). This specific behaviour has also been identified within the developmental services context, where workers describe the effect of austerity measures leading to underfunding of the sector in Ontario, leading to increased documentation requirements, higher caseloads, and a major shift away from the provision of individualized supports into a de facto 'caretaker' role (Courtney and Hickey 2016, p. 87). While implementers in both these studies articulate a clear preference for 'moving towards clients', the stark realities of role conflict, particularly in austere social services contexts, increases the likelihood of unmet client needs.

To counteract the pressures of role conflict, several of the implementers I spoke to emphasized the importance of creating allyship with the families of supported individuals. While worker-client interactions are the principal mechanism of bottom-up adherence mentioned in the implementation literature (Rice 2013, Jilke and Tummers 2018), several interviewees espoused the importance of family advocates in helping to identify client needs. The quotation below provides an account of discretionary rule-bending aimed towards increasing the voice of family members as a means to counteract the prevailing trends within developmental services towards invasive behavioural interventions.

> *"Within the agency that I work in, we're trying to do a big push and do an organizational shift for family engagement, and I think that that could apply more broadly to policymakers. But I think there has to be a genuine commitment to hear what's going on, and if I think to my government experience, you know we had an advisory panel that was in providing us influence into the design of the program. But the people who sat on the advisory panel were the people who were the biggest thorn in the government side. There was no fair and transparent process to get a diverse representation of people who didn't believe in in all of the same thing which was the most amount of services which perpetuated this idea that children with autism are problematic and must have 40 hours a week of therapy in order to normalize themselves into the standard that we have identified as what is typically developing. There was no parent voice there, that said, I really appreciate how quirky and unique my kid is in the unique way that they look at the world. And I would really like it if they didn't experience such difficulty going in the subway, because it's so sensorily overwhelming for them."* (ON25 GOV F)

This quotation comes from a civil servant who invokes rule bending to increase the representation of family voices within the policy advisory function, with a specific aim to curtail the dominance of ABA and other Early Intensive Behavioural Interventions[35] as the dominant focus of autism policy, and IDD policy more generally. They provide an example of how parent/family advocates would reframe inclusion policy based on their personal knowledge of the most pressing barriers, specifically addressing environmental barriers that make public spaces like the subway inaccessible to children with sensitivities to sensory stimulation. This is significant because it broadens the parameters of decision-making that moves towards clients and may prevent institutional bias of the type discussed in relation to the 'public servant' decision-making role. Møller and Stensöta (2019) find that interactions with clients are susceptible to capture by institutional biases when implementers feel organizational or state-centric solidarity that outweigh their commitment to meeting client needs. For people labelled with IDD, family (alongside support staff) are frequently their closest personal relations (Millner and Kelly 2009)

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[35] This reflects a common advocacy focus of autistic self-advocates, such as 'Autistics 4 Autistics' whose policy paper on social inclusion entitled "Not "Special": Equal Social Inclusion for Autistic People in Canada" was submitted in consultation for the Canadian Academy of Health Sciences (CAHS) 2022 report prepared for the Government of Canada to inform future policy directions (retrieved from https://a4aontario.com/wp-content/uploads/2021/04/2021_CAHS_Social_Inclusion_Submission_Autistics_for_Autistics.pdf). The CAHS report is also critical of the effectiveness of EIBI as a standalone approach, and makes reference to preponderance of accounts of trauma reported by survivors of ABA (CAHS 2022).

and are thus vital advocates in the pursuit of person-centred care (Dowling et al. 2007). Carving space for family in advisory and goal setting practices thus presents a promising avenue for the reinforcement of worker-client solidarity, and ultimately the pursuit of outcomes that move towards the needs and demands of clients/service users.

5.6 Conclusion: Implications for the Index

This chapter has invoked three different perspectives to answer the question of 'how do policy implementers reframe social inclusion in Canadian IDD policy?' The perspectives are differentiated in accordance with a novel typology that I have proposed to distinguish between decision-making styles among policy implementers. Acts of (re)framing in developmental services implementation processes – specifically those at the frontlines which result from the interpersonal relationship of support worker and service user – are highly contextual, and thus resistant to classification and comparison across cases. Rather than examine implementation as a potential act of divergence from static policy intent, I have argued that more is gained from identifying acts of adherence to specific (re)framings of policy from three different origins. Decision-makers adopting the 'public servant' role adhere to top-down policy framings. They may find their discretion constrained by rigid accountability mechanisms or they may feel a moral obligation to adhere out of a commitment to democratic principles. By contrast, the 'professional' decision-making role adheres horizontally to policy framing in accordance with organizational or collegial norms. This form of adherence can help workers to strategically manage outcomes in situations of scarcity – both of available time and financial resources. By contrast, the 'proxy advocate' decision-making role adheres to policy framing from the bottom-up, basing implementation decisions on meeting the needs of service users and their close supports. Through interviews conducted with actors working throughout the developmental services implementation chain, examples of all three decision-making roles were discussed.

First, the 'public servant' decision-making role can be highly effective where policy outcomes are well-specified, accountability mechanisms ensure compliance, and managerial competence promotes consistency. However, the confluence of these factors is rare within the current developmental services landscape, which is characterized by policy ambiguity and resource shortfalls (Courtney and Hickey 2016; Dickson 2022; Martin et al. 2012; Abbas 2014). To examine top-down adherence, I compared the implementation of annual support planning policies in Nova Scotia and Ontario. While the scope of the research does not allow comparative analysis between the two provinces based on explicit outcomes, among the implementers that I spoke to it was clear that Ontario's more rigid requirements around documentation and the presence of modest accountability mechanisms created less ambiguity about which framings of goal planning were intended in the province's Social Inclusion Act. By contrast, Nova Scotia implementers described limited accountability to the DCS with annual planning, instead emphasizing that developmental services agencies are given significant autonomy in reframing the design and measurement of annual goals. This has important implications for the Social Inclusion Services Index, as it demonstrates that in provinces where developmental services agencies are less constrained by accountability mechanisms in the areas of planning and reporting they are more likely to develop their own tools to fill the gap. While prior studies have espoused the benefits of ‘home-grown’ or agency-specific tools over the formal tools preferred by the ministry in the implementation of annual planning (Martin et al. 2012), comparison across provinces must account for both the resource capacity of developmental services agencies and the framings the employ in key dimensions of social inclusion.

The ‘professional’ decision-making role demonstrates the importance of professional norms in equipping implementers to overcome the challenges inherent to the devolution of responsibility through increasingly decentralized forms of developmental services governance. Again, there was an important contrast in the implementation styles evident in the two provinces. In Nova Scotia, there were several examples of how the professional cultures of implementers were resilient to the effects of austere spending and limited commitment to program rollout by the provincial government. This aligns with existing research which states that to navigate these gaps in service delivery, disability services organizations in Atlantic Canada have adopted an entrepreneurial approach that is less reliant on government funding and oversight (Levesque 2020a; 2020b). By contrast, in Ontario, the effects of austerity cuts were more jarring to implementers, who are comparatively constrained by accountability and funding mechanisms from the top-down. Of salience were the discussions surrounding program closures in the wake of the COVID-19 pandemic, with two Ontario interviewees indicating that key services were terminated. In this context, inter-organizational and collegial linkages were equally valuable in promoting policy framing, but more as a mechanism for moving away from clients in a manner that imparted minimal impact on the provision of supports. In this example, day program activities and social groups were often moved online, so that developmental services users did not lose access to valued social engagement with their peers.

Finally, the ‘proxy advocate’ role – which was most common among the implementers I interviewed – provided a useful lens for identifying and comparing the shortcomings of existing policies throughout the governance of developmental services. This form of bottom-up adherence begins with the identification of unmet needs, which entails a relationship of engagement between the implementer and the service user and/or their support network. Interviewees discussed bending rules to include family members in policy advisory roles as a means to counteract the dominance of medicalized, therapeutic framings, specifically within the domain of autism policy. Successfully addressing the most pressing barriers, as identified by those with experiential knowledge, will provide external benefits by making society more accessible and inclusive.

Modern social services governance configurations provide significant discretion to implementation actors, who play an important role in mediating the inherent paradox between occasionally contradictory aims of party politics and developmental services policy (Brodkin 2020; Mitchell 2015). The highly individualized nature of bottom-up adherence makes it difficult to observe. For example. one personal support worker may employ different framings of social inclusion for each of the clients they support. Nonetheless, proxy advocates – particularly those providing direct support – are uniquely positioned to move policy towards clients (Tummers et al. 2015). Given that the field of developmental services is mired by policy legacies of exclusionism and segregation, which are laid bare in the explicit ableism of existing Canadian policies that continue to devalue and demoralize people labelled with IDD, empowering proxy advocates is of vital importance to promoting best possible practices in the implementation of social inclusion policy.

CHAPTER 6: COMPARING EFFECTIVENESS CROSS-PROVINCIALLY – THE SOCIAL INCLUSION SERVICES INDEX

"In the context of Canadian disability policy, an aggregate index would aim to measure the level and distribution of inclusion in society, with advancing the inclusion of person with disabilities recognized as a central element in the larger process of realizing full citizenship."

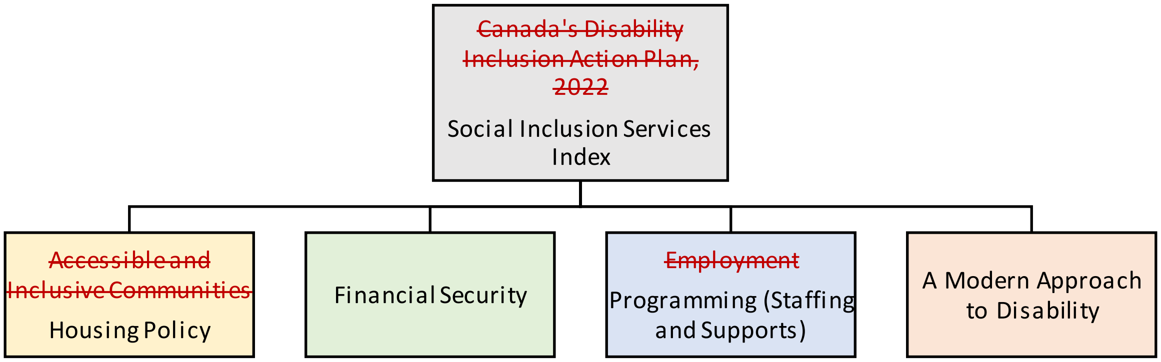
- Michael J. Prince 2009,
Absent Citizens: Disability Politics and Policy in Canada, p.96

6.1 Introduction: The Social Inclusion Services Index

In the above quote from his book *Absent Citizens* – which provides a comprehensive analysis of Canadian disability policy and politics – Prince (2009) advocates for the construction of a multidimensional index on social inclusion (p.91-99). He argues that a general index on social inclusion could be disaggregated to capture specific issues of disability politics and by extension to compare inclusion outcomes for more specific sub-demographics. This would have the external value of indicating which provinces are the most successful at promoting inclusion, thus creating a benchmark for policy learning. However, no national level multidimensional social inclusion index has been created thus far. Even if one existed, it is difficult to imagine how it could be disaggregated to apply to people with IDD, both because they represent a relatively small percentage of the total population, and because their experience of social inclusion is significantly shaped by attitudinal barriers about performativity (see section 1.1, footnote 1) that are both unique to people with IDD and difficult to measure comparatively. Moreover, these barriers are the product of systemic ableism, a phenomenon that is pervasive across Canada, and is also difficult to disaggregate. Therefore, and in keeping with this dissertation's broader focus, a social inclusion policy index for people with IDD requires building from contextually rich description. Rather than disaggregating a macro-level index, accounting for the social inclusion of people with IDD requires building a specific index from the micro level, drawing support for the selection and weighting of indicators from actors who are deeply implicated in the relevant policy processes and affected by their outcomes.

This chapter introduces a multidimensional index to compare the effectiveness of social inclusion policies across Canada's provinces: the Social Inclusion Services Index (SISI). The selection and weighting of indicators in the SISI is informed by the Critical Frame Analysis and the direct insights from study participants about how best to compare provincial policy systems in the promotion of social inclusion for people with IDD. Mirroring the recent federal report, *Canada's Disability Inclusion Action Plan, 2022* (DIAP) which outlines 4 central pillars to advance disability inclusion through public policy (Canada 2022), the SISI also employs 4 distinct domains to compare inclusion policies in Canadian provinces. As Figure 6.1 demonstrates, the SISI directly adopts two of the pillars as index domains, while adapting two others (in red text with strikethrough) to more specifically reflect the social inclusion priorities identified by respondents in the present study. Given that the DIAP pillars are national level guidelines, which are designed broadly for application to all types of disability, they do not directly translate to the SISI domains. However, the DIAP pillars of action were developed following extensive consultations with people with disabilities, advocacy organizations, service agencies, and researchers across the country, and are explicitly addressed at promoting social inclusion through intergovernmental collaboration in policy design and implementation (Ibid., 8-9). Therefore, consistent with the process of disaggregation described by Prince (2009) above, the SISI adapts the broad parameters of the DIAP pillars to fit the thick descriptive insights provided by participants interviewed for this thesis, to answer the question: how do Canadian provinces differ in the effectiveness of social services that promote the social inclusion of people with IDD?

Figure 6.1. The Four Domains of the SISI as related to the Four Pillars of the DIAP



The SISI is comprised of 13 measures combined to form 10 distinct indicators across 4 domains all representing the effectiveness of IDD policies in promoting social inclusion for people with IDD. It is worth emphasizing that the point here is not to compare social inclusion outcomes themselves, although this is a topic that has been covered in the scholarly literature (Shogren et al. 2015; Bigby and Wiesel 2019; Gaes et al. 2010; Schalock et al. 2008; Dickson 2016). While evaluating social inclusion outcomes provides valuable insights on the effectiveness of IDD policies, these outcomes are individually and contextually unique, and thus are not conducive to the type of macro-level, cross-provincial comparison sought by the SISI. To facilitate macro-level comparison, the SISI draws from a rich tradition of welfare state comparison (see Esping-Anderson 1990; Orloff 1993; Scruggs and Allan 2006; Pierson 2000; Weaver 2010), where social policy regimes are classified based on institutional characteristics. This analytical approach has enabled the comparison of welfare states based on their orientation towards policy areas such as gender (Lewis 1997; Bambra 2007; Nakray 2021), class (Korpi and Palme 2003; Ferrarini 2006), and aging (Anttonen & Sipilä, 1996; Lynch 2001). Disability policy has also been a focus of comparative welfare state scholarship, with authors locating the comparison within the domains of social protection, citizenship and labour market integration

(Waldschmidt 2009; Tschandz and Staub 2017). However, while these contributions inform the methodology of the SISI, their broader disability focus and application to national level comparison makes them of minimal utility in indicator selection.

The SISI is a multidimensional index, which aggregates scores across domains to form a composite indicator of effectiveness of IDD policies in promoting social inclusion. The OECD defines a composite indicator as being "formed when individual indicators are compiled into a single index on the basis of an underlying model (OECD 2008, 13). In the present case, the model originates in the four social inclusion pillars identified by the DIAP, which were then modified as necessary to fit the theoretical framework set out in section 1.3 by referring to the Critical Frame Analysis of policy texts (Chapter 2) and interviews with policy actors (Chapters 3, 4 and 5). Given its basis in a national-level policy framework that was itself developed following extensive consultation with relevant policy actors, the choice of domains was relatively straightforward compared to determining how domains would be weighted in the aggregate index. An extensive literature exists on weighting indicators, with a variety of approaches. Researchers who seek to minimize subjectivity in their weighting schemes may favour 'equal weighting' or an 'attributes-based weighting' which simply presents the average of normalized indicators (Karagiannis 2017). However, these schemes are highly conducive to measurement error, collinearity and minimize the descriptive power of statistical data (Greco et al. 2019, 65-6). Instead, the SISI acknowledges and embraces the inherent subjectivity of processes of domain aggregation, indicator selection and choice of weighting scheme because "these subjective choices are the *bones* of the composite indicator and, together with the information provided by the numbers themselves, shape the message communicated" (OECD 2008, 117). To address concerns about researcher bias, transparency has been sought in the justification of all choices involved in the construction of the SISI.

To facilitate transparency, each choice of indicator is supported using data from the interview analysis, including verbatim quotations from interview participants where appropriate. While numerous weighting methodologies exist for composite indexes, there is no perfect weighting system, and mathematically derived weighting schemes often hide the inherent subjectivity of indicator selection based on data availability and the enormous range of contextual factors that can cause variation within a sample (Greco et al. 2019; Booysen 2002). The SISI weighting schema draws from interpretation of the qualitative data gathered throughout the Critical Frame Analysis and from the direct insights of study participants regarding relevant domains, indicators and even measures. Indicators are weighted relative to one another within a given SISI domain, and these domains are classified into two weighting levels for aggregation in the final index. The two major domains are 'Housing' and 'Financial Security', which are each allotted 40% of the final value of the SISI. The two minor domains – 'Programming (Staffing and Supports)' and 'A Modern Approach to Disability' – are afforded 10% each. A rationale for selection and weighting is provided in each section[36].

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[36] Prior to beginning fieldwork, I participated in a workshop on the construction of composite policy indicators with a leading expert in the field, Dr. Lyle Scruggs. This practice-oriented 2-day session revealed the strengths and

It is important to begin the presentation of the Social Inclusion Services Index (SISI) with a discussion of its limitations. First, given that this project has prioritized the voices of developmental services users and implementers it is necessary to acknowledge that any cross-provincial policy index is inherently ill-equipped to speak to the complexity of frontline service delivery. Many of the indicators that comprise the SISI index are representative of current provincial spending commitments in the developmental services sector, which do not capture all qualitative aspects of service delivery or usage. Nonetheless, the actual choice of indicators and how they are comparatively weighted is a direct product of the thick description of the policy environment provided by the interview participants during field research. Moreover, the relative measures used to compare spending indicators was selected with a 'social inclusion framing' lens, meaning that the indicators are compared cross-provincially by their capacity to promote social inclusion in practice, rather than specific program targets or other measures that tap inclusion less effectively. For example, provincial disability income support programs are compared relative to the provincial average annual wage rather than the poverty line, because the former is more reflective of a standard of social inclusion with respect to income equality than the latter.

A second inherent limitation of the index is that it is presents a static measure of a policy context that is constantly changing. The present moment in Canadian disability politics is unusually dynamic, due to the opposing forces of emergent policy reforms at the federal, provincial and local levels – particularly in areas relevant to social inclusion, such as housing, income support, and citizenship (e.g., accessibility and legal capacity policies) – and the simultaneous retrenchment of disability services with austere policy regimes, magnified by the massive spending outlays on COVID-19 responses. Indeed, throughout the preparation of this dissertation, the values on the SISI index have changed periodically, and the domains presented within the current chapter may become comparatively less important over time as the IDD policy field evolves. This is a problem not just for the values of indicators, but for the choice of indicators and the relative weighting of domains over time, as different policy areas rise and fall in terms of their importance to the project of promoting social inclusion for people with IDD. For this reason, I intend to update the SISI bi-annually to reflect both changing values of the indicators and the potential emergence of new indicators or domains of indicators that are vital to the cross-provincial comparison of IDD social inclusion policies.

This chapter introduces the four domains of the SISI in turn. Each subsection begins by justifying the choice of domain, based on descriptive inference gained from the analysis of policy texts and interview data. A brief discussion of high performing cases follows the presentation of the aggregated score at the end of each section. The chapter concludes with the presentation of the final SISI and a discussion of the final ranking. This leads to a broader discussion of implications and limitations in the next, concluding chapter.

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weaknesses of existing approaches to weighting and selection of indicators, ultimately convincing me of the value of building a thick descriptive foundation through exploratory, qualitative research to inform index design.

6.2 Housing Policy

Housing policy was the most significant domain of social inclusion identified by interview participants, a finding that is consistent with its central role in IDD advocacy since the birth of the social movement in the 1970s. The most obvious reason for the persistence of housing policy at the forefront of the inclusion policy debate is that the IDD social movement has been unsuccessful in bringing to fruition the community living agenda, despite over 50 years of advocacy. The evidence of this failure is ample. First, residential institutions continue to exist in Canada. During my fieldwork, I toured one such largescale institution, interviewing residents, staff, and the chief executive officer. While the staff were well-intentioned, and demonstrated a commitment to progressive and inclusive programming, I observed all of the hallmarks of the very institutional model that catalyzed the Canadian community living movement: rural and exclusionary location; multiple residents housed within a single room even in situations where violence and aggression were likely; meals with poor nutritional value; over-medication; and strict limitations on the autonomy and mobility of residents.

While the failure to fully deinstitutionalize is the most obvious reason for the persistence of housing policy at the forefront of the disability policy agenda, other reasons also became evident through the interview analysis. The community living models that governments have employed to replace the institutional model have failed to deliver inclusive outcomes. Most notably, the group home model – predicated on housing 3 to 8 individuals in standalone community residence with requisite support staff – has largely failed due to a lack of public investment to provide staffing of a suitable quality and quantity coupled with a 'one size fits all' approach to service delivery that fails to capitalize on the flexibility of person-centred care practices, instead replicating the procedures and culture of residential institutions (Mansell 2006; Crawford 2008; Bigby et al. 2014). As a result, group home residents are often confronted by a lack of autonomy, both individually and relationally (see Ho 2008; Chattoo and Ahmad 2008), which fundamentally limits their potential for social inclusion (Gappmayer 2021). For example, without requisite support, people with IDD living in group homes are often denied the most basic opportunities for inclusion, such as the freedom to go to a café or do their own grocery shopping (Bigsby et al. 2014).

These minor activities take on major importance for people with IDD. During the individual interviews and focus groups with people with IDD, these activities were frequently identified and emphasized by participants. When asked "when do you most feel like part of the community?" and "what needs to change for you to feel more included?" numerous participants identified ordinary activities such as going to the local coffee shop or restaurant whenever they pleased as exercises of inclusion that are currently unavailable. This is significant because it demonstrates the extent of exclusionism in developmental services practice, where group home residents whose support services are rhetorically aligned with the promotion of 'community living' feel that they do not have the bodily autonomy to go to a café or grocery store when they want. While beyond the scope of the present contribution, future research must investigate the mechanisms that sustain exclusionism in the group home environment, specifically the technologies of monitoring and surveillance as they are applied to people with IDD (see Ho et al.

2014). Nonetheless, for the purposes of cross-provincial comparison of social inclusion, this project treats the group home model as roundly more inclusive than the institutional model.

The persistence of the institutional paradigm is also a product of the lack of viable alternatives in the field of housing policy more broadly. Indeed, the concept of social housing only gained widespread acceptance within Canadian social policy circles following amendments to the federal National Housing Act in 1949 which set the stage for public housing across the provinces; and, even then, the adoption of social housing was met with great controversy which dragged out the implementation of the amendments (Bacher 1993). This precarity has become characteristic of social housing policies, which have been constrained by neoliberal tendencies to both download jurisdictional authority from federal to provincial and local governments and offload responsibility for implementation to private sector housing actors (Suttor 2016). These tendencies have been further exasperated by the combination of the great recession and COVID-19, which have magnified social inequality and further limited available supported housing options for the most marginalized groups (Dantzler 2022). The review of provincial budgets conducted for this section demonstrates that costs associated with COVID-19 specifically, have come to dominate health and social services budgeting since the start of the pandemic, leading to stalls and retrenchment in many social services areas. As a result, current levels of social services expenditure on IDD housing are an important bellwether of cross-provincial commitments to inclusive housing.

a) Selection of Indicators

Three main indicators were selected to represent IDD housing policy for cross-provincial comparison. The first indicator – expenditure on residential care per capita – reflects the generosity of the residential housing policy regime relative to the general population. There are two primary reasons why the total provincial population was selected instead of the population of people with IDD, or even more precisely the population of people with IDD receiving residential services. First, there are not reliable statistics across the provinces for the total population of people with IDD. The Canadian Survey on Disability (CSD) 2017 – a post-censal survey instrument that is the most recent version of a series of surveys administered by Statistics Canada beginning with the 1983 Canadian Health and Disability Survey – provides inconclusive data on the number of people with IDD, especially when combined with demographic criteria such as age and location. This lack of reliable data on the number of people with IDD has been previously addressed by Ouellette-Kuntz et al. (2015), who criticize the reliance on a post-censal instrument to calculate the population of people with IDD, who are difficult to contact using traditional sampling methods. This lack of coverage was evident during my fieldwork, as I did not meet a single person with IDD who could recall completing the CSD, or any of its earlier iterations. Moreover, none of the support staff that I spoke to could recall if any of the individuals that they supported had completed the survey.

The second reason that provincial population data was selected as a reference point for IDD housing spending is that there was inconsistent data on the number of people with IDD receiving residential services and the number of people waiting to receive residential services. In some provinces, the size of waitlists for services has become a politicized issue, creating a negative incentive to report waitlist size. For example, in Saskatchewan the elimination of the waitlist for developmental services was a focal point of Premier Brad Wall's early tenure, with government[37] and media publications[38] both reporting the clearance of the province's waitlist of 655 people with IDD following an additional investment of more than $80M in residential services and supports over 5 years. However, since the completion of the Wall government's waitlist initiative in 2013, the province has not publicly released waitlist data, and the provincial disability strategy, released only two years later, already identifies waitlists as an area of focus in developmental services and supports (Saskatchewan 2015).

> *"We had a family who has just moved their daughter - the family has stayed, here and they have moved their daughter back to (another province) because she can't live in a small option home. She's on the 1500 plus wait list."* (NS AG1)

Comparing developmental service coverage is a key indicator for the effectiveness of social inclusion policies, however unavailable waitlist data was an issue across the provinces, with only Quebec providing a truly reliable and precise account of the exact waitlists for specific types of developmental services, and only five other provinces providing any indication at all of waitlist size through annual reports, program documents, media releases or information on government websites. In many of these cases the information was not complete[39]. For example, in Manitoba, the Ministry of Families annual report only shared data on new waitlist entries for the year of 2021 for the province's Community Living DisABILITY Services (Manitoba 2021, p.66), meaning that the actual list size is likely much bigger than reported. For this reason, comparing the size of waitlists was not possible, and instead the SISI compares provinces by the extent of their monitoring and disclosure of waitlist sizes as a means of gaining insight into the extent to which service coverage was a priority. In provinces where the data was not available, staff at the government bodies in charge of developmental service provision were either unable or unwilling to provide waitlist information in response to my inquiries. In British Columbia, waitlist data was only provided after an advocacy group filed a Freedom of Information request and a follow-up complaint with the Information and Privacy Commissioner when the provincial body in charge of developmental services – Community Living British Columbia – claimed that the data did not exist, and even then, the advocacy group claimed to have "very little confidence in the waitlist numbers"[40]. If provinces become more transparent with waitlist reporting, the SISI will be adapted to compare the size of the waitlist relative to the size of the population with IDD, but for now, mere disclosure of the waitlists is enough to warrant positive value on the index, albeit minor.

The final indicator in the domain of housing policy is whether publicly funded residential institutions are still active in the province. Essentially this indicator taps whether

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[37] https://www.saskatchewan.ca/government/news-and-media/2013/april/22/waitlist-initiative-completed--government-fulfills-commitment-to-citizens-with-intellectual-disabilities

[38] https://www.cbc.ca/news/canada/saskatchewan/service-waitlist-for-intellectually-disabled-cleared-1.1335311

[39] This is further evidenced by a policy brief prepared by People First of Canada and Inclusion Canada's Joint Task Force on Deinstitutionalization, which similarly provided waitlist data for five provinces, available online at: http://invisibleinstitutions.com/wp-content/uploads/2022/08/Policy-Brief-1-LongTermCare_200818.pdf

[40] Information on the timeline of this dispute is available here: https://communitylivingaction.org/facts/waitlists/

deinstitutionalization – the aspiration that catalyzed the IDD social movement 50 years ago (Park et al. 2003; Vanhala 2014) – was achieved within a province. The presence of residential institutions is a significant indicator of social inclusion policy effectiveness for numerous reasons. First, and most obviously, the institutional model contradicts the idea of social inclusion by its very design, prioritizing instead the segregation of people with IDD away from the community. Second, the presence of institutions casts a long shadow over a province's broader developmental services system because to many within the IDD community they are symbolic of abuse, neglect, and suffering.

Finally, and more practically, the process of deinstitutionalization places great strain on the provision of developmental services within a province, as tightly controlled budget allocations must be applied to the construction of group homes or semi-independent living facilities, and to the provision of a range of supports necessary to plan and implement the transition of institutional residents. This effect is evident in the developmental services budget of the province of Manitoba, a province which is actively attempting to create more inclusive housing spaces to transition the last remaining institutional residents (Manitoba 2021, p.62-3). For provinces who are further behind on this transition, their capacity to effectively implement social inclusion policies in the near future is limited by the impending strain that deinstitutionalization will place on the system. For example, in Ontario, a province which achieved full deinstitutionalization in 2009, public accounts show that spending in the Children and Social Services sector was $400M under budget due in part to "(l)ower developmental services spending with fewer clients coming into residential care" (Ontario TBS 2021, p.23). In this way, the presence of institutions is a negative indicator of social inclusion effectiveness in the present, while simultaneously portending ongoing difficulties in the sector for provinces who have yet to complete the transition to deinstitutionalization.

Table 6.2(a) Values of SISI Indicators for Housing Policy

Province	Population[41]	Developmental Services Expenditure + *Per Capita*	Waitlist Size	Residential Institutions
Alberta	4,543,111	$1B *$220.11*	2,357[39]	Y
British Columbia	5,319,324	$1.318B *$247.78*	2,958[39]	N
Manitoba	1,409,223	$453.3M *$321.67*	268 (2021)	Y
New Brunswick	812,061	$192.2M (disability supports) *$236.68*	N/A	Y
Nfld and Lab	525,972	N/A[42]	N/A	Y
Nova Scotia	1,019,725	$160.2M *$157.10*	1,915 (2021[43])	Y
Ontario	15,109,416	$2.9B ($2B for housing) *$191.93*	15,700[39]	N[44]
Prince Edward Island	170,688	$36M (disability programs) *$210.91*	N/A	Y
Quebec	8,695,659	$1.19B *$136.84*	1,162[45] (12,637)	N
Saskatchewan	1,194,803	$283.2M (disability programs) *$237.03*	N/A	N

Table 6.2(a) presents the raw values of the SISI indicators for housing policy, along with a recent population estimate for each province. The first indicator, 'developmental services expenditure', is drawn in all cases from either the public accounts budgetary filings or annual reports of the ministry or department with purview over developmental services. In three cases

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[41] Statistics Canada population estimates as of September 2022, retrieved from https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1710000901

[42] In Newfoundland, developmental services are split among two ministries. Health and Community Services former handles the bulk of residential support; however these supports are under the purview of 4 regional health agencies, who do not distinguish between disability supports and other supports in the annual reporting of their expenses. Children, Seniors and Social Development has a disability policy office with a meager operating budget, but the ministry's primary disability focus is the administration of income support, addressed in the next section.

[43] Disability Rights Coalition Nova Scotia. 2021. *Call to Action: The Road to Inclusion and Equality for People with Disabilities Government Accountability on the Roadmap Choice, Equality and Good Lives in Inclusive Communities*. Retrieved from: https://www.disabilityrightscoalitionns.ca/wp-content/uploads/2021/07/Disability-Rights-Road-to-Inclusion-2023-FINAL-REPORT.pdf

[44] The Child and Parent Resource Institute (CPRI) in London, Ontario meets many of the criteria of a residential institution considering that it provides congregate inpatient care to children with IDD. However, given that patient stays are temporary, and that the province considers the CPRI outside of its 2009 commitment to fully deinstitutionalize, it does not qualify for the residential institution classification in the SISI. Future work on practices of 'reinstitutionalization' would be well served to investigate CPRI.

[45] Data aggregated from publication of regional data by the Ministry of Health and Social Services, retrieved from: https://publications.msss.gouv.qc.ca/msss/document-003460/

(NB, PEI and SK), the developmental services data was not distinguished from the broader disability supports budget, and in the case of Newfoundland and Labrador, no spending data was available for both developmental services and disability supports for 2019 through 2021[42]. In these former cases, it is unfair to compare the entire disability support spending budgets of some provinces to the isolated developmental services or more precisely the housing policy budgets of others, so a disclosure measure was built into the indicator for the SISI. The aggregated scores listed in the Developmental Services Expenditure column in the Housing Policy domain of the SISI (see table 6.2(b)) combine scores based on an evenly weighted average of the generosity and disclosure indicators[46]. Manitoba has the highest score because it disclosed the most generous developmental services expenditure per capita of all provinces. Developmental services expenditure comprises 40% of the total score for the Housing Policy domain because it was frequently identified during the interviews as a significant factor in the provision of social inclusion services. Senior management and staff in developmental services organizations repeatedly referred to the limitations on their capacity to provide inclusive programming due to budgetary constraints on service provision. Developmental services expenditure per capita captures the extent of provincial commitments to funding the sector, and thus is an appropriate indicator of the sector's capacity to effectively promote social inclusion.

Table 6.2(b) Scores of SISI Indicators for Housing Policy

Province	**Developmental Services Expenditure[46] (40%)**	**Waitlist Data Reported (10%)**	**Residential Institutions Active (50%)**	**Aggregated Score**
British Columbia	0.59	1	1	**0.84**
Ontario	0.5	1	1	**0.80**
Quebec	0.33	1	1	**0.73**
Saskatchewan	0.42	0	1	**0.67**
Manitoba	0.88	1	0	**0.45**
Alberta	0.75	1	0	**0.40**
Nova Scotia	0.33	1	0	**0.23**
New Brunswick	0.42	0	0	**0.17**
Prince Edward Island	0.42	0	0	**0.17**
Nfld and Lab	0	0	0	**0**

By comparison, the SISI indicator on the disclosure of waitlist data was afforded less weight in the housing policy domain, representing on 10% of the aggregated score. This partly reflects the issues with provincial reporting. If more waitlist data becomes available through

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[46] The Developmental Services Expenditure indicator combines two measures that are equally weighted. First, the measure on specificity of reporting allocates a value of 1 to provinces that report the housing budget for people with IDD, 0.67 for reporting the developmental services budget, 0.33 for reporting the disability supports budget. Second, the measure for generosity allocates a value of 1 to provinces with a budget exceeding $300 per capita, 0.5 for a budget of between $200-$300 per capita, and 0 for under $200 per capita. The aggregated total of these two measures is presented in the final indicator value.

official releases, such as annual reports from the departments or ministries in charge of developmental services, the qualitative benefit of this indicator will increase, and it may be afforded more weight within the Housing Policy domain. As it stands, transparency of reporting remains an important placeholder, indicating a modicum of attention to service coverage in provincial reporting.

The most significant domain in the Housing Policy domain is whether residential institutions are active in the province. The topic of residential institutions was not referred to as frequently as budgets across the interviews. Given that some provinces have fully deinstitutionalized, advocates, implementers and service users in these provinces were more focused on increasing budgetary spending to key programs, specifically in the domain of housing. However, in places where institutions are still active, speeding the transition to deinstitutionalization is a central focus. As has been addressed numerous times throughout this dissertation, the institutional model is antithetical to the inclusion paradigm in Canadian IDD politics and policy. Moreover, the ongoing forced segregation of people with IDD in six of Canada's provinces is the single most significant negative indicator of the effectiveness of social inclusion policy. For this reason, this indicator is worth 50% of the aggregated score in the housing policy domain, making the effective transition away from residential institutions the single most progressive step any province can take to improve their standing on the SISI.

In the housing policy domain, British Columbia is the Canadian province with the highest SISI score. This score reflects the province's successful transition away from institutionalization and comparatively generous funding of the developmental services sector, which is in keeping with a broader policy orientation towards the provision of subsidized/supported housing. The earliest appearance of subsidized housing in the province occurred during the 1950s with Vancouver's Little Mountain project constructed in 1954 amidst a broader national trend toward small scale projects to address the need for affordable housing (Bacher 1993, 184-7). At the time, British Columbia was more laggard than leader due to the province's hesitancy to implement the public housing provisions of the 1949 National Housing Act, owing to the influence of a powerful real estate industry lobby (Ibid., 13). The push for subsidized housing was advanced by the NDP during their tenure as the provincial government from 1972-75; however, the NDP were also in power in 1994 when the province decided to pivot away from government administration over social housing following the withdrawal of federal funding for low-income housing, shifting administration over the housing dossier to non-profit organizations (Bendaoud 2018, p.177). The BC Non-Profit Housing Association was created at this time to pool member organizations with administration of housing programs facilitated by BC Housing, a crown corporation that liaises with partners in the non-profit sector.

In keeping with this broader governance model, Community Living British Columbia (CLBC) is a crown corporation with extensive purview over developmental services, specifically in its role as allocator of government funds to service agencies throughout the province. Both Manitoba and Saskatchewan employ similar governance structures, with specific agencies established to administer developmental services, rather than bundling these responsibilities under the purview of a broader disability office or specific community services portfolio, such as housing or day program supports. The advantage of this governance arrangement is that it maximizes expertise in the implementation of IDD-specific programs and services by operating at 'arm's length' from the partisan pressures of a politicized bureaucracy (Bernier et al. 2018). What separates BC from the other provinces employing this governance structure is the lack of residential institutions in the province. The completion of the deinstitutionalization process allows CLBC comparatively more freedom than its counterparts in Saskatchewan and Manitoba to pursue a more progressive community living agenda because organizational resources are not devoted to the development of community residences and planning/facilitating transitions out of residential institutions.

This is reflected in the appearance of innovative forms of community living arrangements, such as home sharing, where people with IDD share a residence with another unrelated person who is paid to provide supports, residential and otherwise. In a study of the home sharing model, Hole et al. (2015) find that it has a high potential for delivering inclusive outcomes, insofar as proper monitoring and suitable funding mechanisms are in place. According to the province's Inclusive Housing Task Force, a joint initiative between CLBC and Inclusion BC (the province's largest IDD advocacy group) the supply and demand for shared living spaces is rising in the province, portending a potentially significant shift in residential service delivery in the province (IHTF 2018). Given the ongoing criticism of the group home model addressed at the beginning of this section, the pursuit of new models of community housing may be crucial to the advancement of the inclusion paradigm in the IDD housing policy domain.

6.2 Financial Security

While housing policy was the most significant social services policy area identified by interview respondents, the SISI weights financial security equally as the two most important domains within the index. First, this is because financial security and the access to shelter are inter-related dimensions of social inclusion, especially for people labelled with IDD. This connection is laid bare in Canada's national housing strategy *'A Place to Call Home'*, which acknowledges housing insecurity for people with IDD owing to higher poverty rates among this population through its commitment to create at least 2,400 new affordable units for people labelled with IDD (Canada 2018a, 11). This federal-level commitment is especially significant given that IDD housing falls under the purview of provincial governments, signalling further that the lack of housing is more multifarious than a simple lack of supply.

Second, financial security is a significant social inclusion domain because people with IDD are far more likely to live in poverty than the general population (WHO 2011, Torjman 2017). This predicament is often attributed to the lack of labour market participation among people with IDD (Dinan and Boucher 2021; Prince 2014). Indeed, as the policy design framing analysis in Chapter 2 demonstrates, employment is a central focus of social inclusion policies at both the federal and provincial level. However, attributing poverty among people with IDD solely to lack of labour market participation ignores the broader context of systemic ableism in Canada, where people with IDD experience barriers to education, leisure, community participation and other fundamental entitlements of citizenship throughout the lifecourse, both before and after working age (Crawford 2013). While disability income support regimes are designed to explicitly compensate for the lack of opportunities in the labour market for people with disabilities, the phenomenon they actually address – the poverty of people with disabilities – can be attributed to this broader systemic reality of ableism. Therefore, the generosity of financial security policies appropriately captures the effectiveness of provincial commitments to remedy exclusion in an important policy domain.

Third, disability income support directly funds developmental services, especially in the housing arena. For people living with IDD who receive residential supports, often their provincial income support is directly controlled by the support agency. Provincial disability income support regimes can be broken down into various allowances targeting the provision of basic needs, such as the shelter allowance and the basic income allowance. These core allowances, which make up the bulk of disability income support schemes are directly controlled by residential support agencies, with only a small allowance passed directly on to residents (Linton and David 2022b). These allowances have different names in different provincial income support schemes, usually called either a 'personal needs' or 'comfort' allowance.

Finally, in many provinces disability income support regimes are directly tied to the receipt of disability support benefits, such as dental care or prescription drug costs, creating a disincentive to find paid work because once income exceeds the earned exemption amount people with disabilities lose access not only to disability income support, but the associated benefits (Stienstra 2020, 77). Even below the maximum earned exemption amount, disability income supports can be 'clawed back' when income exceeds a minimum exemption amount. The claw back threshold for exempted income varies cross-provincially and depending on family status, as does the ratio of income support reduction (Kneebone and Grynishak 2010). In total, the risk of losing access to income support and disability support benefits creates a strong negative incentive to find paid work for many people with IDD.

In addition to variation in the claw back ratios, disability income support programs in Canada also vary in terms of their program structure. In New Brunswick and Newfoundland and Labrador, disability income support is provided as an add-on to the broader social assistance scheme. In these provinces, the SISI includes the base social assistance amount plus the disability add-on. By contrast, a major benefit of the disability-specific income support schemes in the other eight provinces is that the claw back features are less punitive than those of more universal social assistance schemes. The New Brunswick Disability Executives Network (NBDEN) – comprised of ten disability organizations in the province – has made the structure of the province's disability income support scheme a central focus of their advocacy, as evidenced by a recent report that calls for immediate changes to the level of both overall support and exempted earnings[47]. While the Newfoundland and Labrador scheme benefits some people with disabilities with generous additional top-ups for rent and utilities (Laidley and Tabbara 2022, 81), the benefits of disability-specific income support schemes make them far more advantageous than schemes that supplement the base social assistance program.

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[47] NBDEN. 2021. *Social Assistance Reform Top Policy Issues Briefing*, prepared for: Minister Bruce Fitch, Department of Social Development, Government of New Brunswick, retrieved online from: https://nbacl.nb.ca/wp-content/uploads/2021/10/NBDEN-Executive-Brief-SA-Reform-Final-July-20-2021_final.pdf

a) *Selection of Indicators*

Several Canadian provinces have introduced new disability income support schemes, creating extra incentive for the cross-provincial comparison of financial security for people with IDD. However, the federal government is also presently undergoing parliamentary review on the Canadian Disability Benefit (CDB), in adherence with Bill C-22 which passed second reading in December 2022. The CDB is modelled to be a universal scheme that mirrors the federal General Income Supplement provided to recipients of Old Age Security Pensions in Canada. In this way, this forthcoming federal program is designed to supplement income rather than replace it. It remains to be seen how the CDB will interact with existing provincial disability income support schemes, specifically in terms of how it affects the calculation of claw back thresholds for earned income. Given the uncertainty surrounding the CDB at present, it is noteworthy that three provinces (MB, QC, PEI) have introduced new disability income support programs in the past 5 years, while others (AB, ON) have introduced indexation mechanisms to raise the level of support relative to inflation after years of stagnation. Nonetheless, in light of these changes, and given the importance of disability income support schemes to the promotion of social inclusion, the cross-provincial comparison of financial security is a significant domain of the SISI.

The Market Basket Measure – which represents the costs of goods and services required to meet basic needs and standard of living – is the poverty line officially recognized by the government of Canada in its national poverty strategy (Canada 2018b, 11). With broad federal level poverty reduction instruments, such as the forthcoming CDB, this measure is a suitable reference point because it sets comprehensive national and provincial benchmarks for the cost of basic needs. However, given that the focus of this index is social inclusion, the provincial average income was selected as a relative measure to gauge the generosity of provincial disability income support policies because this measure better reflects the amount that a typical, *included* citizen would expect to earn monthly (Crawford 2013; Frazer and Marlier 2016; Torjman 2017). To put it another way, people living at the threshold of the poverty line in terms of their ability to pay for their basic needs are not necessarily financially empowered to pursue full social inclusion.

Not having any disposable income above the poverty line inherently limits one's potential for types of community engagement, with some activities (e.g. attending movies or concerts, dining out, or playing in a sports league/maintaining a gym membership) incurring additional costs. Moreover, even the comparatively limited universe of free or subsidized activities such as community groups or social clubs incur additional costs for transportation, materials or staffing that may price out individuals living at the poverty threshold. For these reasons, the average wage was selected as a suitable comparison point because it shows what a person not constrained by the barriers that people with IDD face could expect to earn within a specific province. It is unrealistic to expect provincial disability income support policies to reach the level of average wages; however, the ratio of these provincial schemes relative to the average wage provides an excellent relative marker of their generosity, particularly insofar as they are framed as social inclusion policies.

Table 6.3(a). Values of SISI Indicators on Financial Security

Province ***(Disability Income Support Program)***	**Disability Income Support Amount[48] ($/month) (*% of Average Wage*)**	**Claw back Threshold[49] ($/month) (*Claw back Ratio)***	**Average Wage[50] ($/month)**	**Personal Needs/ Comfort Allowance[51] ($/month) (*% of Average Wage*)**
Alberta (*AISH*)	1,787.00 (32.9%)	1,072 (0.5:1) 2,009 (1:1)	5,437.12	342 (6.2%)
British Columbia (*PWD*)	1,358.50 (26.1%)	1,250 (*1:1*)	5,203.17	220 (4.2%)
Manitoba *(Manitoba Supports)*	1,205.04 (26.4%)	1,000 (1:1)	4,562.36	370*[52] (8.1%)
New Brunswick	805 (17.6%)	500 (1:1)	4,567.38	135 (2.9%)
Nfld and Lab	931 (18.4%)	150 (0.8:1)	5,060.60	150 (2.9%)
Nova Scotia (*DSP*)	950 (17.7%)	250 (0.75:1[53])	4,358.43	115[54] (2.6%)
Ontario (*ODSP*)	1,073 (20.3%)	200[55] (0.5:1)	5,285.67	149 (2.8%)
Prince Edward Island (*AccessAbility*)	1,219 (27.7%)	500 (0.3:1)	4,399.77	123 (2.8%)
Quebec *(Basic Income Program)*	1,475 (30.5%)	1,138 (0.55:1)	4,820.93	290[56] (6.0%)
Saskatchewan (*SAID*)	1,134 (23.1%)	500 (*1:1*)	4,905.21	265 (5.4%)

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[48] Listed is the monthly amount for a single adult. In provinces where the amount varies based on region, I have reported the amount from the most generous region. In provinces where the amount varies based on type of disability or residence, I have reported the amount allocated to individuals in residential care

[49] In provinces where income exemptions are calculated annually (SK), the annual sum is divided by 12. The province of Ontario has amended policy to increase the exemption to $1,000/month in March 2023.

[50] Calculated by multiplying the Statistics Canada 'average weekly wage' before tax and other deductions, by province for November 2022, by 4.3333 to equal a monthly average. Source data: https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1410006301

[51] Where current, and unless otherwise acknowledged, data for comfort/personal needs allowances was retrieved from: https://invisibleinstitutions.com/wp-content/uploads/2022/04/Policy-Brief-4-AllowancesInInstitutions.pdf

[52] It is unclear if the allowance will remain the same under the new income support program beginning Jan. 2023

[53] In Nova Scotia the claw back becomes gradually more severe above certain earning thresholds. There are also different earning exemptions for people requiring continuous support.

[54] As stipulated in (DSP 2012, p.92)

[55] Increasing to 1000 in February 2023

[56] It is unclear whether this will stay the same under the new Basic Income Program beginning January 2023, however this is the amount stipulated by the Régie de l'assurance maladie Financial Contribution Program for Accommodated Adults – available at: https://www.ramq.gouv.qc.ca/en/citizens/aid-programs/accommodation-a-public-facility

The second indicator selected in the Financial Security domain of the SISI combines the monthly level of earned income exempted by the disability income support scheme, and the ratio at which income exceeding the minimum threshold is 'clawed back' or deducted from income support. These values, reported in the 'Claw back Threshold' column in Table 6.3(a), vary significantly among the provinces, with the monthly minimum of exempted earnings ranging from a low of $150 in Nova Scotia to a high of $1,138 per month in Quebec's new Basic Income Program, and the claw back ratio ranging from the least punitive 0.3:1 in Nova Scotia to the most punitive 1:1 ratio in four provinces (BC, MB, NB, SK).

The personal needs/comfort allowance is a relatively minor aspect of disability income support when it comes to the total provision, but for people living in more institutional settings (including group homes), this allowance can be the only portion of their disability income support that they get access to (Linton and David 2022b). Moreover, due to the fact that this portion of the monthly support budget is allocated directly to the person with IDD or their substitute decision-maker, it is treated differently than the other parts of the disability income support scheme. This is particularly significant in cases where supported individuals are not financially autonomous. For example, in a report prepared by a residential services review panel for the (then) Ontario Ministry of Child and Youth Services, it was reported that group home staff would withhold monthly allowances to children who used more than their monthly allotment of toothpaste[57]. Moreover, there are misconceptions about the intended purpose of these allowances as they are considered by some as extraneous to the income support scheme:

> *"But our programs are all capped except for our very front-end programs where you live at home with parents and you get... a board rate. So, you get income assistance. This is a little bit better than income assistance because you get something called comforts, which is $115 a month. And it's an open program, so there is no (waitlist), we let everybody into that"* (NS3 GOV)

The above quote comes from a bureaucrat in Nova Scotia's Department of Community Services, who discussed the province's comfort allowance – the least generous in Canada – as 'a little bit better' than income assistance for people who live at home with family supports. Therefore, the fact that the comfort allowance is differentiated from the disability income support total, treated differently in practice, and is for some recipients the only government funding over which they have spending discretion makes it an appropriate indicator within the SISI financial security domain.

Table 6.3(b) shows the normalized values and aggregated score for the Financial Security SISI domain. The first indicator, 'disability income support amount' was scored based on generosity of the scheme as a percentage of provincial average wage. In New Brunswick and Newfoundland and Labrador, the totals reflect the combination of basic amount of social assistance and additional disability specific benefits. Schemes that offered recipients more than 25% of average monthly wage received a score of 1, while programs between 20%-25% received

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[57] *Because Young People Matter* (p.39), retrieved online from: https://cwrp.ca/sites/default/files/publications/residential-services-review-panel-report2016.pdf

0.5, and those under 20% received scores of 0. As presented, this indicator is a rather simplistic representation of generosity, however these supports represent the main source of income for the majority of people with IDD in Canada and are thus fundamental aspect of financial security. As such, this indicator represents 50% of the total score on the Financial Security domain, with more minor program factors like the claw back and personal needs/comfort allowance afforded 25% each. Once the CDB program features are announced and come into effect, it will be necessary to recalibrate this domain to account for how provincial schemes interact with the federal level benefit.

The 'Claw Back Threshold' indicator combines two measures, which are equally weighted to produce the normalized indicator value. The first measure is a generosity measure that, akin to the previous indicator, allocates three possible values based on relative cut-offs for generosity. The second measure compares the extent of income claw backs, with three possible values based on the severity with positive directionality corresponding to decreasing severity[58]48. The two measures are added together and aggregated into the normalized value reported in the 'Claw Back Threshold' column. Finally, the Personal Needs/ Comfort Allowance indicator is a generosity measure with three values based on comparative generosity as a percentage of provincial average wage[59].

Table 6.3(b). Scores on SISI Values for Financial Security

Province *(Disability Income Support Program)*	**Disability Income Support Amount (50%)**	**Claw Back Threshold[58] (25%)**	**Personal Needs/ Comfort Allowance[59] (25%)**	**Aggregated Score**
Alberta	1	1	1	**1**
Quebec	1	0.75	1	**0.94**
Manitoba	1	0.5	1	**0.88**
British Columbia	1	0.5	0.5	**0.75**
Prince Edward Island	1	0.5	0	**0.63**
Saskatchewan	0.5	0.25	0.5	**0.44**
Ontario	0.5	0.5	0	**0.38**
New Brunswick	0	0.25	0	**0.06**
Nfld and Lab	0	0.25	0	**0.06**
Nova Scotia	0	0.25	0	**0.06**

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[58] The 'Claw Back Threshold' indicator is comprised of two evenly weighted measures. First the generosity measure allocates a score of 1 to earned exemption thresholds exceeding $1000/month, 0.5 between $500-1000/month, and 0 for under $500. The second measure represents the extent of the income claw back. Provinces that claw back $0.50 and under for every $1 over the exemption receive a score of 1. Provinces that claw back greater than $0.50 but less than $1 receive a score of 0.5, while provinces with a $1:$1 claw back ratio receive a score of 0.

[59] Allowances exceeding 6% of the average monthly wage received a score of 1, while allowances between 4%-6% received 0.5, and allowances under 4% received 0.

Alberta's perfect score on the financial security domain of the SISI is reflective of the Alberta Income for the Severely Handicapped (AISH) program, which was created in 1979 and has long been an outlier in the Canadian disability income support landscape. First, the AISH program is distinct for its high level of generosity compared to other provincial schemes. Despite significant recent increases in the generosity of Ontario's ODSP and Saskatchewan's SAID, and complete overhauls of the income support systems in Quebec and Manitoba, AISH remains the most generous scheme in Canada in 2022. This is a partial product of a second distinct feature of AISH, which is that it is part of a two-tiered disability income support program in the province.

Third, AISH has long stood out for not imposing needs tests on recipients. Most other provincial disability income supports, which are more akin to traditional welfare programs, assess applicants on their needs for basic living, additional needs such as medication or physical supports, and other assets in determinations of the funding allocation (Mendelson et al 2010). As such, the only factor that can decrease the monthly AISH amount for an approved recipient is their income relative to the exempted amount. This leads to the final way that AISH stands out within the disability income support landscape: the relative leniency of its income claw back structure, which along with Quebec's Basic Income Program, sits a tier above all other provinces. Both provincial schemes set the exempted income amount above $1,000/month, and claw back income support at a ratio less than 1:1 per dollar earned.

It is nonetheless necessary to emphasize here that despite the comparative generosity of the AISH program, it still falls far short of fostering financial security of recipients, nor does it come close to raising them out of poverty. Moreover, the unique features of AISH, which cause August (2014) to qualify it as a passive categorical disability benefit, akin to a disability pension, create strong disincentives to leave the program. This creates a more daunting 'welfare wall' for AISH recipients by causing them to effectively avoid employment opportunities in excess of the maximum earning exemption (Torjman 2017). In addition to limiting their financial security, this also limits their potential to pursue other dimensions of social inclusion that come with labour market participation such as community participation through meaningful encounters (Bigby and Wiesel 2019). Finally, financial security programs are especially vulnerable to the ebbs and flows of provincial politics. Alberta's high score in this domain comes just 3 years after the previous provincial government threatened to de-index AISH from inflation as a deficit reduction strategy[60]. While there does appear to be a positive momentum towards increased generosity in several provincial disability income support schemes and the promise of a national level income supplement, the tides shift quickly in this policy area. Moreover, if gains in the level of income support are not matched by corresponding gains in Personal Needs/ Comfort Allowances, many of the most marginalized people with IDD, who rely on developmental services agencies to manage their funding, will not stand to benefit.

6.4 Programming (Staffing and Supports)

This SISI domain represents the most significant departure from the corresponding 'Employment' pillar in the DIAP. Employment was not selected as a distinct domain of the SISI

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[60] https://www.cbc.ca/news/canada/edmonton/aish-alberta-jason-kenney-1.5346856

for four primary reasons. First, the SISI was designed to be representative of all people with IDD, not just those who are working age and seeking employment. Older adults with IDD, who are less likely to join the labour force, are a highly marginalized segment of the IDD population (Bigby 2004; 2010; Dickson 2018; 2022), and thus should not be excluded in any SISI domain. Second, many people with IDD who are interested in gaining employment require additional supports, through vocational training and job-coaching, including on-site support. Therefore, just as the Financial Security SISI domain captures aspects of inclusive employment policy through its exempt income indicators, so too does the Programming domain by comparing staffing and supports cross-provincially. Third, while several interview participants emphasized the importance of holding a job as a personal indicator of social inclusion, many of the barriers they identified (e.g., transportation or the need for specific accommodations including on-site supports) are not directly addressed by employment policy tools. Finally, the policies referenced by the DIAP 'employment' pillar are federal-level programs. While administration of these programs is ultimately downloaded to the provinces through Labour Market Agreements for Persons with Disabilities (Dinan and Boucher 2021; Graefe and Levesque 2010), this implementation is carried out by the developmental services structures, which are already tapped by other SISI domains.

During the interviews, participants often emphasized the importance of staffing and support quality in promoting inclusive outcomes. These discussions centred on the tension in provincial approaches to support staffing between seeking to provide better staffing quality, while also recognizing that support work was not a highly sought after job. Participants revealed that tension arises when governments attempt to improve the quality of staffing by implementing training or education requirements for incoming staff, which can act to shrink an already small pool of interested applicants. This shortage of quality staff has been exasperated by the pressures associated with the COVID-19 pandemic, including the so-called 'great resignation' of care workers who faced dramatic increases in caregiver fatigue, under-staffing, and threats to their personal health during the height of the pandemic:

> *"Depending on how dire your staffing situation is, sometimes… a lot of it comes down to economics. And I mean right now is a terrible time because the great resignation is happening, and people can't staff anybody anywhere. But even in normal times like pre-pandemic, I know within (developmental services agency)… they constantly struggled to have staffing and I mean they were an organization that had lots and lots of staff who stayed for a long time. But still, the burnout rate is really high when you're dealing with individuals who are challenging emotionally, who are aggressive. And you know that the caring responsibilities can be wearing for some people, and so they're jobs that are difficult to staff and are notoriously underpaid for what they're doing."* (ON25 GOV F)

As the above quote demonstrates, participants also emphasized that support work is further disincentivized by the low wages that support workers are paid across the sector, making a career in developmental services less appealing compared to other similarly paying alternatives which impart less of an emotional toll. Intuitively, this sentiment was especially prominent among frontline workers, who described experiences of caregiver fatigue. One respondent described working alternating 60-hour and 24-hour work weeks, while another described the physical toll of working overnight shifts in between day shifts. Despite these harrowing accounts, the most consistent area of emphasis was on higher wages, with frontline staff frequently alluding to slow wage growth within the sector. For this reason, wages are a relevant indicator for staff quality, as provinces with higher wages provide added incentives for quality staff to remain in the developmental services system.

a) Selection of Indicators

The median hourly wage of the provincial labour force was selected as the reference point to compare wages in the developmental services sector. Unlike average hourly wages, which are skewed by values in the highest income categories, median wage provides a more suitable reference point what a working age adult in the labour market can expect to earn (Fortin et al. 2012; Milligan and Schirle 2019). The first indicator in the Programming (Staffing and Supports) domain measures the median hourly wage of developmental services workers cross-provincially as a percentage of the median hourly wage for the entire labour force. The level of wages paid to support workers has been found to be the strongest predictor of staff turnover, which is directly related to programming quality in developmental services provision (Friedman 2018; Bogenschutz et al. 2014). Additionally, one study found that in the United States, a $1 increase in support worker wages could predict a 3.61% reduction in turnover (Anderson-Hoyt et al. 2010, p.13; Powers and Powers 2010). Therefore, in lieu of reliable cross-provincial data on job retention in the developmental services sector, the comparison of hourly wages in the sector may also reflect the longevity of tenure for support staff.

However, relying strictly on wage data hides vital context in the qualitative comparison of staffing and supports. Existing research shows that support quality is also dependent on levels of training, amount of paid time off, and the percentage of part-time workers within the developmental services workforce (Houseworth et al. 2020). Additionally, the precise nature of the work also comes to bear, as strenuous reporting requirements or higher caseloads for support staff may also diminish the quality of staffing and support from province to province (Courtney and Hickey 2016). Due to lack of available data, these contextual factors could not be worked into the SISI, however, a cross-provincial study accounting for the precise nature of support work would be an invaluable tool for comparing the effectiveness of developmental services in Canada.

The second, and final indicator in the Programming (Staffing and Supports) domain is built to provide a broader picture of the developmental services sector by including the median wages of the lowest earning workers in the sector, home care attendants for persons with disabilities, and the median wages for group home managers who earn more than the support workers they supervise. As with the developmental services worker wages, the data was derived from the Statistics Canada Labour Force Survey, cross-referenced with National Occupation Codes for the relevant job titles. The impetus for this indicator came from a discussion with a former manager and support worker in Ontario, who described the lack of upward mobility in the sector:

> *Is burnout, inevitable? I think not in a perfect world. And I think part of that is training, opportunities for professional advancement, opportunities to move around to new locations and gain new skills. But what often happens is you have to kind of fight your way into your full-time role and then just hang onto that with everything you've got. Most people don't want to be a supervisor. Everybody just gets that full time and then you hang on to that. I had a staff who had worked at the same location with the same individuals for 25 years."* (ON 26 SW9 M3)

In the scenario described above the full-time staff are willing to remain in the developmental services sector so long as they are never promoted to a management position. The participant explained that the much higher workloads that managers endure are not considered to be worth the incrementally higher wages they receive, such that support workers are content to forego professional advancement.

Table 6.4(a). Median Wages for Developmental Services Sector Relative to Labour Market

Province	**Canadian Labour Force**[61]	**Developmental Services Worker (Ratio to Canadian Labour Force)**[62]	**Group Home Manager (Ratio to Canadian Labour Force)**[63]	**Attendant for Persons with Disabilities – Home Care (Ratio to Canadian Labour Force)**[64]	**Aggregated Average of Ratios**
Alberta	$28.77	$24.00 (0.83)	$38.46 (1.34)	$18.00 (0.63)	**0.93**
British Columbia	$26.92	$23.00 (0.85)	$38.85 (1.44)	$21.00 (0.78)	**1.02**
Manitoba	$23.08	$19.26 (0.83)	$35.00 (1.52)	$15.00 (0.65)	**1.00**
New Brunswick	$22.33	$17.50 (0.78)	$28.52 (1.28)	$14.80 (0.66)	**0.91**
Nfld and Lab	$24.73	$23.00 (0.93)	$36.06 (1.46)	$16.55 (0.67)	**1.02**
Nova Scotia	$22.00	$20.00 (0.91)	$33.65 (1.53)	$18.00 (0.82)	**1.09**
Ontario	$26.44	$25.50 (0.96)	$37.95 (1.44)	$19.00 (0.72)	**1.04**
Prince Edward Island	$22.00	$27.61 (1.26)	$34.00 (1.55)	$19.50 (0.89)	**1.23**
Quebec	$25.00	$24.00 (0.96)	$33.33 (1.33)	$17.28 (0.69)	**0.99**
Saskatchewan	$25.64	$21.27 (0.83)	$37.33 (1.46)	$19.00 (0.74)	**1.01**

The final column in Table 6.4(a) provides an average of the three median wages of workers in the developmental services sector relative to the median wage within the broader provincial labour force. The purpose of this indicator is to provide a rough composite of the generosity of wages in the developmental services sector that accounts for positions across the

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[61] Statistics Canada 2021 data retrieved from: https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1410034001

[62] Statistics Canada 2021 data retrieved from: https://www.jobbank.gc.ca/wagereport/occupation/5069

[63] Statistics Canada 2021 data retrieved from: https://www.jobbank.gc.ca/wagereport/occupation/1790

[64] Statistics Canada 2021 data retrieved from: https://www.jobbank.gc.ca/wagereport/occupation/20659

spectrum of direct service provision. This gives added descriptive value to the domain by capturing how generosity is spread across the sector, where higher average ratios represent a stronger incentive to retain employment.

Comparing the wages of developmental services workers is especially important at present because several provinces are recognizing the damage caused to the sector following mass resignations during the COVID-19 pandemic. In its most recent action plan, Ontario has announced a plan to invest "$700 million on temporary wage enhancements for personal support workers and direct support workers, including those in developmental services sector" (Ontario 2021, 14). This one-time investment comes as part of a longer-term commitment to promote better training for personal support workers so that they are more capable of providing person-centred planning. Manitoba outlined a similar commitment in the 2022 provincial budget, again emphasizing the use of funding to train support workers to provide person-centred planning[65]. Temporary investments aside, it remains puzzling that government responses to problems with staff quality and retention continue to focus on training rather than wage increases, effectively increasing the barriers to entry to an already undesirable profession[66].

Table 6.4(b) presents the scores on SISI values in the Programming (Staffing and Supports) domain. Both indicators are equally weighted in the aggregated final score for the SISI domain due to shared emphasis respondents placed on both wage levels and the incentives for advancement in the sector. The Developmental Services Worker Wages indicator is based on four values with thresholds based on the ratio of median hourly wages relative to the provincial labour force[67]. Similarly, the second indicator, Developmental Services Sector Wages, is based on three values assigned to different thresholds reflecting the distribution of median hourly wages for staff in the developmental services sector relative to the median hourly wage of the provincial labour market. In both cases the values on the indicators were selected to reflect provincial variation at present. As a consequence, the thresholds for scoring could warrant revision in future iterations of the SISI. In sum, this domain accounts for very specific aspects of staffing and supports – namely wages across the developmental services sector – which are amenable to cross-provincial comparison, but mask much of the contextual complexity of programming to promote the inclusion of people with IDD. Appropriately, this domain is assigned a minimal weight of 10% in the final index. Nonetheless, future iterations of the SISI should seek to provide additional explanatory leverage to indicators in this domain, to capture qualitative assessments of the type of programs offered across the country.

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[65] "As a first step, the Manitoba government has provided Inclusion Winnipeg with $100,000 to deliver person-centred planning training to direct service workers and community service workers across the province" (Budget 2022, p.150), retrieved online from: https://www.gov.mb.ca/budget2022/resources/budget-2022-web.pdf

[66] For example, following recent reforms the Canadian Union of Public Employers (CUPE), acting as Ontario's largest union representing developmental services workers, was vocal in its critique of the province's continued emphasis on training requirements and person-centred care despite growing program waitlists and unsatisfactory wages for personal support workers: https://cupe.on.ca/wp-content/uploads/webarc/archivedat6477.pdf

Table 6.4(b). Scores on SISI Values for Programming (Staffing and Supports)

Province	Developmental Services Worker Wages[67] (50%)	Developmental Services Sector Wages[68] (50%)	Aggregated Score
Prince Edward Island	1	1	**1**
Ontario	0.75	0.5	**0.63**
Nova Scotia	0.5	0.5	**0.5**
Nfld and Lab	0.5	0.5	**0.5**
British Columbia	0.25	0.5	**0.38**
Quebec	0.75	0	**0.38**
Manitoba	0	0.5	**0.25**
Saskatchewan	0	0.5	**0.25**
Alberta	0	0	**0**
New Brunswick	0	0	**0**

Several strategies were unsuccessfully pursued to add explanatory depth to this domain. First, consideration was given to adding an indicator on the presence of sheltered workshops within a province with a binary indicator akin to the deinstitutionalization indicator used in the Housing domain. Ultimately, it was determined that it is too difficult to successfully identify provinces with no active sheltered workshops, owing to ambiguity around volunteer and stipend employment and vocational support programs, even in provinces that have formally committed to end sheltered workshops (Lysaght et al. 2018). Moreover, some sheltered workshop programs have transitioned to alternative business models that uniquely privilege workers with disabilities to shape the organizational culture and daily administration, again muddying the waters of demarcation between sheltered work and inclusive employment (Hall and Wilton 2014). Ultimately the decision was made to exclude this kind of measure, with confidence that provinces with a heavy reliance on sheltered workshops would most likely be disadvantaged in other SISI domains related to exclusionist policy programs, particularly the binary deinstitutionalization indicator, which comprises 20% of the SISI index.

Another potential strategy was to compare the quantity and capacity of operational day programs within each province. This indicator would provide added value in capturing developmental services coverage with respect to day programs, thereby compensating for some of the missing data in the comparison of waitlist sizes in the Housing Policy domain. Participants repeatedly emphasized that day programs are an invaluable location and source of social inclusion for people with IDD, particularly older adults or others for whom labour market

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[67] This indicator presents scores based on the comparative ratio of developmental services worker median incomes relative to the median income of the provincial labour force. A score of 1 is given to provinces with a ratio of greater than 1:1; 0.75 for provinces with a ratio between 0.95-1:1; 0.5 between 0.9-0.95:1; 0.25 between 0.85-0.9, and 0 for under 0.85:1

[68] This indicator presents scores based on the aggregated average of developmental services sector median wages relative to the provincial labour market. A score of 1 is given to provinces with a ratio of greater than 1.2:1; 0.5 for a ratio between 1-1.2:1; 0 for less than 1:1

participation is not a desired outcome. However, accounting for day programs is also impeded by limitations on available data. Even in provinces like Nova Scotia, which made data available on the names and locations of its 46 day programs[69], there is no additional public data on program size and quality that would enable effective comparison on the promotion of social inclusion.

Finally, to gain further leverage on the quality of staffing supports, consideration was given to build an indicator on the level of accreditation required by developmental services staff within each province. This was motivated by the staffing Quality Assurance Measures (QAM) policy that was introduced following Ontario's *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*. These measures sought to increase the quality of developmental services provision through the imposition of explicit standards for person-centred planning in annual support planning and reporting (Joffe 2010; Bishop 2022). However, the implementation of the program has been impeded by the lack of accountability mechanisms to ensure effective monitoring, as well as the lack of top-down adherence by frontline workers (Dickson 2022). Moreover, a 2014 report prepared by a select committee organized by the Ontario Legislative Assembly found that developmental service agencies complained that QAM were impeding their ability to promote effective outcomes due to the rigidity of monitoring requirements. As a result, the committee recommended that QAM agency requirements be re-evaluated to improve their relevance and flexibility to service provision in practice[70]. This is consistent with the broader criticism of quality assurance mechanisms which are in their application to developmental services owing to their prioritization of protocol over responsivity in the promotion of social inclusion outcomes (Jade et al. 2020). As such, training and accreditation requirements do not necessarily connote effectiveness in service provision, and provinces seeking to improve social inclusion outcomes would be better served to prioritize other aspects of staffing and supports.

6.5 Modern Approach to Disability

The Canadian Disability Inclusion Action Plan pillar on 'A Modern Approach to Disability' is based primarily on broadening and simplifying disability eligibility criteria for federal level programs. This is partly derived from criticism of the Disability Tax Credit, which despite acting as the de facto gateway to eligibility for all federal level disability programs and benefits, has been found to impose extra barriers to eligibility for people with IDD[71]. The DIAP also uses the 'modern approach' pillar to commit to the application of a disability lens[72] to federal programs, many of which existed long before the adoption of language reflective of the social model of disability in federal policy design.

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[69] https://data.novascotia.ca/Community-Services/Day-Programs/99u3-pv3t

[70] The committee's full list of recommendations is available here: https://www.ola.org/sites/default/files/node-files/committee/report/pdf/2014/2014-07/report-1-EN-SCDSFinalReportEnglish.pdf

[71] The second annual report of the Canada Revenue Agency's Disability Advisory Group proposed sixteen recommendations to improve DTC eligibility. Report retrieved from: https://www.canada.ca/content/dam/cra-arc/corp-info/aboutcra/dac/dac-report-2020-en.pdf

[72] The application of a 'disability lens' in federal policymaking was focal point of the Liberal Party of Canada's successful 2019 election campaign.

The SISI adopts a broader conceptualization than the DIAP, creating the 'Modern Approach to Disability' domain to reflect current trends in Canadian provincial level policy that are conducive to the effective promotion of social inclusion for people with IDD. Indicators representative of the modern approach to disability must both reflect the ideational thrust of the inclusion era of Canadian disability politics and must also encourage the promotion of inclusion in practice. Returning to the typology of implementer decision-making styles in Chapter 5, policies in this domain are those that encourage top-down adherence by IDD policy actors seeking to promote inclusive outcomes. As such the Modern Approach to Disability captures progressive Canadian IDD policies outside the boundaries of the housing, income support and staffing domains.

The existing policies that are the most emblematic of the inclusion era in Canadian disability politics are accessibility policies. First, while social inclusion is widely referred to in Canadian disability policy and politics, accessibility policies are the only type of policies that explicitly address stigma/attitudinal barriers to inclusion, which disproportionately affect people with IDD relative to other forms of disability (Scior and Werner 2016). Second, as was revealed in the Critical Frame Analysis presented in Chapter 2, accessibility policies present the most comprehensive and multidimensional framing of the social inclusion concept of any Canadian disability policies. Finally, in practice, the requirements that accessibility policies pose on people and spaces also have the effect of calling into question ableist and exclusionary institutional norms and social practices that are otherwise unchallenged by policy instruments (Titchkosky 2011, 8). The first indicator in the Modern Approach to Disability domain in Table 6.5 is a binary indicator on the presence of a provincial level accessibility policy. Six provinces received a score of 1 for having accessibility policies in place, while three others received a score of 0 for having none. Saskatchewan was scored 0.5 because the Bill proposing the *Accessible Saskatchewan Act* was introduced in the provincial legislature in Fall 2022[73].

The second indicator in this domain 'IDD-Specific Governance' taps the presence of a distinct administrative body with specific function over the administration of developmental services. Provinces with a developmental services-specific body were allocated a score of 1, because the presence of this administrative department creates a hub for expertise in funding allotment and service provision, while also strengthening the policy community through direct dialogue with advocacy groups and service organizations (Evans and Wellstead 2013; Montpetit 2003). Provinces where these functions fall under the broader purview of a disability policy office or advisory council were scored 0.5, while provinces with neither administrative body received a score of 0. Given the complexity associated with service intake and referral, oversight of IDD-specific supports and the increasing volatility of the sector with respect to staff retention and shifts in housing models, the presence of IDD-specific governance organizations portends better administrative capacity and responsiveness.

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[73] Information on the Bill and the proposed act can be found here: https://accessiblesk.saskatchewan.ca/the-accessible-saskatchewan-act-summary-of-bill

Table 6.5. SISI Indicators and Values on Modern Approach to Disability

Province	Accessibility Legislation	IDD-Specific Governance	Aggregated Score
Alberta	0	1 (PDD – Disability Services)	**0.5**
British Columbia	1	1 (CLBC)	**1**
Manitoba	1	1 (CLDS)	**1**
New Brunswick	0	0.5 (The Premier's Council on Disabilities)	**0.25**
Newfoundland and Labrador	1	0.5 (Provincial Advisory Council on the Inclusion of Persons with Disabilities)	**0.75**
Nova Scotia	1	0.5 (Accessibility Directorate)	**0.75**
Ontario	1	1 (DSO)	**1**
Prince Edward Island	0	0	**0**
Quebec	1	1 (CRDITED)	**1**
Saskatchewan	0.5 (proposed)	1 (CLSD)	**0.75**

Future iterations of the SISI would be better served to examine not just the presence of accessibility legislation, but to compare the quantity and quality of accessibility standards developed by provincial accessibility councils. The Accessibility for Ontarians with Disabilities Act (AODA) has existed for nearly two decades, yet the standards that have been developed to date are limited in their application to people with IDD. Specifically, there is little within these documents targeting attitudinal barriers (e.g., discriminatory employment practices concerning the provision of on-site supports). Accessibility documents are representative of the cutting edge of Canadian disability policy at present, but it remains to be seen how successful they will be at addressing the major barriers to social inclusion for people with IDD. Moreover, this wave of documents is emblematic of a prevailing tendency towards framework legislation at both the provincial and federal levels, which are symbolically progressive (e.g. use social model language and provide rhetorical commitment to inclusion) but toothless in practice due to the lengthy process of creating implementation standards, which requires years of negotiation between incrementally established sub-committees within the accessibility councils and successive provincial governments with differing political priorities.

With respect to IDD-specific governance, consideration was also given to adding a SISI domain relating to the presence of direct funding systems within the provinces. Direct funding models purport to offer advantages in flexibility and empowerment by putting disability service users in direct control of the basket of services they receive and from whom (Kelly 2016). For people with IDD, whose needs can vary significantly from person to person, this model offers additional advantages in tailoring a support plan to the specific social inclusion outcomes desired by the service user and their relational network. Kelly (2021) identifies six individualized funding programs for people with IDD in Canada (p.633). One such program, Ontario's 'Passport' program is noteworthy both for its size, reportedly serving over 52,000 people (Ontario 2021, p.13) and its generosity with a baseline of $5,500 annually to a maximum of $44,275 allotted to approved cases[74].

However, in the context of social inclusion it is not clear whether direct funding delivers on its advantages. Indeed, downloading intake, referral and administration costs from government funded agencies to the service user can, in practice, serve as a 'Trojan horse' for program retrenchment in a context of austerity:

> *"What I hear a lot from my teams is that they work with a lot of families who do not want a fee for service approach. They don't want to manage. They don't want the cash in their bank account. They don't want to have to go and find service they don't want to have to reconcile dollars. They want to show up at a place and get the service their kid needs. But those families don't seem to have a platform to advocate against. So, it seems right now, the stronger advocacy is for a fee for service model. And I think most of us just assume the pendulum will swing back. You know that that over time you know that that message will get through. A change of government could move away from that approach. It's very much in line with the Conservative government"* (ON24 GOV)

The above quote comes from a civil servant in Ontario, whose critique of government priorities towards direct funding questions the effectiveness of the model in direct terms of the provision of appropriate supports. Within Ontario, another significant impediment to effectiveness for the Passport program specifically is the emphasis on training and accreditation within the developmental services staffing system. Discussing Passport specifically, Kelly (2016) argues "the benefits associated with the informal, unregulated model may be trampled by a dominating health discourse that includes a preference towards credentialism" (p.134). For these reasons, direct funding was not included as a positive (or negative) indicator of the modern approach to disability domain of the current SISI. However, ongoing evaluation and monitoring of the current individualized funding programs for IDD supports in Canada may allow the inclusion of a direct funding indicator in future iterations of the index.

6.6 Conclusion: The Social Inclusion Services Index

Table 6.6. presents the SISI with a finalized aggregation of scores across the four weighted domains. The final index accurately reflects cross-provincial effectiveness in the promotion of social inclusion policies for people with IDD, but it is important to emphasize once again that the SISI does not reflect social inclusion outcomes. For instance, the Atlantic provinces form a cluster at the bottom of the SISI owing to the austere spending and the persistence of the residential institutional model across the four provinces; however, this does not mean that people with IDD are less included in these provinces. Numerous factors outside the

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[74] 2022 amounts retrieved from: https://www.ontario.ca/page/passport-program-adults-developmental-disability

purview of public policies shape individual level experiences of inclusion. During my fieldwork in Nova Scotia, I was particularly impressed by the spirit of inclusion in one rural community that I visited, where local businesses and the citizenry more generally made deliberate efforts to facilitate inclusion through various mechanisms of informal interaction with the local developmental services agency. This belies a unique spirit of entrepreneurialism and innovation that is unique to disability services in the Atlantic provinces (Levesque 2020a, 2020b).

Table 6.6. The Social Inclusion Services Index

Province	**Housing (40%)**	**Financial Security (40%)**	**Programming (Staffing and Supports) (10%)**	**Modern Approach to Disability (10%)**	**Aggregated Score**
Quebec	0.73 (0.292)	0.94 (0.376)	0.38 (0.038)	1 (0.1)	**0.806**
British Columbia	0.84 (0.336)	0.75 (0.3)	0.38 (0.038)	1 (0.1)	**0.774**
Manitoba	0.45 (0.18)	0.88 (0.352)	0.25 (0.025)	1 (0.1)	**0.657**
Ontario	0.80 (0.32)	0.38 (0.152)	0.63 (0.063)	1 (0.1)	**0.635**
Alberta	0.4 (0.16)	1 (0.4)	0	0.5 (0.05)	**0.61**
Saskatchewan	0.67 (0.268)	0.44 (0.176)	0.25 (0.025)	0.75 (0.075)	**0.544**
PEI	0.17 (0.068)	0.63 (0.252)	1 (0.1)	0	**0.42**
Nova Scotia	0.23 (0.092)	0.06 (0.024)	0.50 (0.05)	0.75 (0.075)	**0.241**
Nfld and Lab	0	0.06 (0.006)	0.50 (0.05)	0.75 (0.075)	**0.131**
New Brunswick	0.17 (0.068)	0.06 (0.024)	0	0.25 (0.025)	**0.117**

Manitoba's placement as the third highest province on the SISI might confound expectations, given that the province's largest institution – the Manitoba Developmental Centre (MDC) – continues to operate. The province is currently undergoing a three-year transition plan to shut down the MDC, with fully transparent reporting of the transition rate made available through annual reporting (Manitoba 2021, p.62-3). However, Manitoba's high rank on the SISI reflects large investments made in the developmental services sector and the release of a comparatively generous disability income support scheme. From a policy perspective, the extent of Manitoba's investment in the sector increases the province's effectiveness in promoting social inclusion, and once the deinstitutionalization process is complete Manitoba may reach the top spot on the SISI.

At present, Quebec and British Columbia occupy the top two spaces owing to their comparative superiority in the domains of Financial Security and Housing, respectively. Re-assessing this ranking once additional values such as precise wait list size and a qualitative measure of day programming are eventually added to the SISI will provide important insights as to the validity of the current iteration. Moreover, forthcoming policy changes, specifically in the Financial Security domain following the release of the national CDB may have pronounced effects on the ranking of provincial disability income support schemes vis-à-vis their interaction with the income supplement. Specifically, the CDB interaction with claw back thresholds across the various provincial disability income support policy schemes will significantly shape the SISI Financial Security domain in the coming years.

The aggregate scores of the SISI significantly reflect the generosity of provincial IDD policy structures. Within the comparative social policy literature in Canada, there has been a tendency to explain provincial differences in welfare state generosity relative to the ideological affiliation of the party in power at the provincial level (Kneebone and McKenzie 2001; Haddow 2014; 2020). For example, Jacques (2020) finds that left-wing parties are more likely to prioritize social spending, while right-wing parties are more likely to retrench in this sector. Moreover, he finds that in periods of fiscal constraint, governments are more likely to prioritize health spending regardless of partisanship. The social spending measures used in the SISI lend some modest support to this finding, especially when we consider that this snapshot occurs during a period of intense fiscal pressures associated with the COVID-19 pandemic (Hanniman 2020), which have also necessitated extra investment in broader health and social services sectors (Béland and Marier 2020). British Columbia's NDP party represent the only left-wing party in power at the time of the present study, and the province ranks high on the generosity measures. However, due to the prevalence of right-wing parties at the provincial level throughout the rest of the sample, it is difficult to equate variation across the SISI to political ideology at a glance. Moreover, given that social spending has been observed to fluctuate with the ebbs and flows of election cycles (Haddow 2020; Kneebone and McKenzie 2001), a longitudinal sample of generosity measures would be required to conduct robust tests of government partisanship on SISI variation.

In addition to social spending, Canadian comparative social policy has also explained poverty outcomes due to shifts in provincial politics, though within this specific policy area the focus has been more on the external policy environment rather than shifts in partisan representation. For example, in a cross-provincial comparison of poverty reduction strategies, Plante (2019) finds that poverty levels most often drop prior to implementation, making the policies a sort of decoy for a pre-existing shift. By contrast, Haddow (2014) finds that the explanatory variables traditionally associated with power resource theory – namely union density and partisan incumbency – are powerful predictors of provincial poverty reduction. However, disability income supports are ill-suited to either form of explanation, as these policies do not explicitly focus on poverty reduction. This is evident in the design of the claw back thresholds, which disincentivize labour market entry by setting thresholds far below the poverty line (Kneebone and Grynishak 2010) and punishing recipients who exceed the threshold with the loss of benefits including coverage for medication and disability supports (Stienstra 2020). It is also evident in the personal needs/comfort allowance amounts, which are the only small fraction of disability income supports paid out to people with IDD who reside in congregate care. In practice, these meagre allowances are vastly insufficient to cover basic needs such as cell phone/internet access, transportation and clothing (Linton and David 2022b).

Nonetheless, Quebec's Basic Income Program portends a possibly significant shift in the sector, providing that eligibility is expanded, and the program remains viable moving forward. Quebec exceptionality is not unprecedented in the social policy landscape, as the province has long been an outlier in the governance, design and delivery of social policies (Van den Berg et al. 2017; Haddow 2015). However, following from recent momentum in the disability income support sector, including the forthcoming CDB program and shifts towards indexation in Alberta and Ontario, there is potential for a shift towards a poverty reduction focus cross-provincially. By contrast, Programming (Staffing and Supports) is the SISI domain that appears the most resistant to imminent change. This is partly down to the choice of indicators, and the SISI focuses on staff wages, rather than training or accreditation. There is a discernible shift towards person-centred care in policies concerning the training of developmental services staff across the country, which could portend a shift in the quality of IDD programming and supports. However, the early evidence from Ontario, which adopted this approach following the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*, does not suggest major shifts in the nature of frontline practice (Dickson 2016; Bishop 2022; see also Jade et al. 2020). Developmental services staff across the country emphasized wages and respite as the most significant areas of focus to improve staffing quality. Moreover, participants also emphasized that the developmental services sector must now contend with an additional shortage of quality staff resulting from the great resignation following the COVID-19 pandemic. Focusing on retention through appropriate compensation stands out as the most viable strategy for improving, or at least maintaining effectiveness in this domain.

The final SISI domain, A Modern Approach to Disability, is both the most forward-looking and the most likely to be expanded in future iterations. It remains to be seen if the current generation of broad rhetorical commitments to inclusive disability policy at the federal level – such as the DIAP, the ACA, and the CDB – withstand a potential end to Liberal incumbency at the federal level, or eventually affect policy design at the provincial level. At present, there is no emergent design frame available to succeed accessibility policies at the forefront of the inclusion agenda. Instead, IDD advocates are engaged on several fronts in efforts to curtail policy drift away from the advances of the inclusion era, most pertinently in the battles against re-institutionalization and the expansion of Canada's medical assistance in dying legislation. With an eye to the future of the inclusion era in IDD policy, the next chapter concludes this dissertation by expounding on the implications and limitations of the SISI both within the broader ideational context of Canadian disability politics and the more practical space of policy implementation.

CHAPTER 7: CONCLUSION

> *"When disabled people get free, everyone gets free. More access makes everything more accessible for everybody.*
> *And, once you've tasted that freedom space, it makes inaccessible spaces just seem very lacking that kind of life-saving, life-affirming love. Real skinny. Real unsatisfying. And real full of, well, hate.*
> *Why would you want to be part of that?"*
>
> - Leah Lakshmi Piepzna-Samarasinha 2018
> *Care Work: Dreaming Disability Justice*, p.78

7.1 Thesis Overview

The exclusion of people with intellectual and developmental disabilities is so entwined with Canada's history that the realization of 'full inclusion' for this population would entail an overhaul and reimagination of social and political institutions. This is the aspiration of the policy project that began with the *In Unison* report (ESDC 1998), commencing the 'inclusion era' in Canadian disability politics that has endured for the 25 years since. To this end, a central argument of this dissertation is that the policies of the inclusion era have failed with respect to people with IDD. This policy failure is evident throughout processes of policy design and implementation. The comparison of policy designs in Chapter 2 found that instruments targeting the stigma and attitudinal barriers faced by people with IDD were either non-existent or under-specified within provincial and federal level policy systems. This puts the onus on policy implementers to use their discretion to promote inclusive outcomes for people with IDD without the assistance of enforceable regulations or accountability mechanisms to guide their practice. In a sector constrained by austere spending in both programming and staffing, implementers are disincentivized to extend their practice beyond the scope of existing requirements, making inclusive outcomes even less likely. Within this policy context, this thesis sought to compare which provincial developmental services structures were most effective at promoting social inclusion. This concluding chapter returns to the central research questions, before discussing the empirical and theoretical implications of this research. It ends with a discussion of limitations and future directions for the study of IDD policy in Canada.

Two inter-related research questions guided this thesis: (1) 'how is the concept of social inclusion framed in the design and implementation of policies targeting people with IDD?', and (2) 'how do Canadian provinces differ in the effectiveness of social services that promote the social inclusion of people with IDD?'. Before answering these questions, this thesis began by explaining how they are inter-related. Social inclusion is a broad, amorphous concept that – while normatively attractive – is difficult to distill into policy instruments comprehensively and coherently without losing most of its scope. This 'magical' quality (Pollitt and Hupe 2011) allows for multiple potential framings of social inclusion in policy design. At the conceptual level, social inclusion is defined as *full participation in all aspects of society*; however, at the policy design level these aspects of society begin to be specified. By conducting a critical frame analysis of all disability policies in Canada, this thesis identified six social inclusion policy frames used in policy design. A key finding was that five of the six policy design frames were classified as 'policy action frames' (Schon and Rein 1994, 32), which through the act of defining and operationalizing the framing of a concept within a policy design thus act to narrow the universe of possible solutions. At the design level, provincial differences emerged in the type and frequency of policy frames. This initial Critical Frame Analysis formed the basis of cross-provincial comparison of policy design, which then enabled comparison of (re)framing in implementation processes. Ultimately, engaging with the thick descriptive context of implementation as an act of (re)framing social inclusion for people with IDD, with evidence drawn from the insights of key informants, informed the selection and weighting indicators for a composite index designed to answer the second research question.

In accordance with the research design, this project was separated into three phases, with the first two phases addressing the stages of policy design and policy implementation, respectively, to answer the first research question. The Critical Frame Analysis of policy designs in all Canadian disability policies, presented in Chapter 2, provided important foundational insights. It employed the 'frame institutionalization ladder' (Bjornehead and Erikson 2018) as a conceptual framework to understand how policy frames dominate and decline from the legislative agenda over time. The analysis pointed to the contemporary dominance of the 'Community Participation/Removing Barriers' framing within Canadian disability policy. This progressive framing aligns closely with the fundamental ideas of the inclusion era for several reasons. First, the language of this policy framing is consistent with the social model of disability, insofar as it defines disability as something external to an individual, and a product of disabling barriers which deny access to key social functions (Oliver 1983; Barnes and Mercer 2004; Oliver and Barnes 2012). Second, it reflects a preference among disability advocates for 'positive action legislation' (Prince 2009, 217), which aims to proactively reduce barriers as opposed to more retroactive design framings such as the declining 'Anti-Discrimination/Human Rights', which address barriers post-hoc through legal action. Finally, the 'Community Participation/Removing Barriers' framing is thematically aligned to accessibility policies, which have been an emblematic development of disability policy design in the inclusion era at both the federal and provincial levels.

A second key finding that emerged during the design framing analysis was the presence of weak or non-existent mechanisms for promoting inclusion, specifically for people labelled with IDD who are already marginalized in the disability policy landscape. Policies tended to make rhetorically broad commitments to social inclusion, while often privileging types of disability that are easier to accommodate – a phenomenon that Mitchell (2015) calls 'inclusionism' (p.36). While inclusionism was present in numerous policy designs, accessibility policies were a particularly interesting case. Operating as framework legislation, accessibility policies are designed to establish a regulatory framework prior to the articulation of specific standards. As a result, the development of accessibility standards falls to separate administrative bodies called 'standards development committees' who are tasked with designing regulatory standards for specific types of barriers (Jacobs 2019). In Canadian accessibility policies this process of standards development has been slow, and where it has occurred has favoured the removal of environmental barriers over attitudinal barriers. This inclusionism is evidenced by the standards developed following the *Accessibility for Ontarians with Disabilities Act 2005* (AODA), which have fallen far short of the legislation's progressive language on the promotion of inclusion, especially for people with IDD (Onley 2019). In this way, this inclusionist model of policy design encourages the distribution of benefits – in this case accessibility standards – to the subset of the target population (people with disabilities) who are easiest to accommodate, in effect further marginalizing people with IDD.

The lack of clearly articulated standards and targets for social inclusion policies contributes to frame ambiguity in implementation processes (Ellis 2015; Hupe 2011). In Chapter 3, the focus shifted from the outcomes of policy design (i.e., textual analysis of policy documents) to the processes of framing and reframing by IDD advocates and civil servants. This chapter began by providing a historical overview of the development of the Canadian welfare state with a specific focus on intergovernmental relations to demonstrate how the provinces became the main designers and administrators of developmental services, while also highlighting the evolution of the steering mechanisms that the federal government employs. This set the foundation for a discussion of IDD advocacy, which identified four distinct stages beginning with institutionalization, followed by the 'normalization' discourse that was typical of early welfare state programs, proceeded by the anti-discrimination/independent living era that birthed the self-advocacy movement, and culminating in the current inclusion era. In each era, IDD advocacy had to contend with a dominant conceptual framing of IDD vis-à-vis the welfare state, which acted to shape the political opportunity structure (Tarrow 1994) by constraining the universe of policy solutions available to advocacy groups (Smith 2008; Vanhala 2014). This historical background served as a descriptive foundation for the interviews with self-advocates, whose efforts are now similarly constrained by the dominant conceptual framing of the inclusion era.

During the interviews, IDD advocates (and all other participants) were asked to reflect on the quality of social inclusion as the guiding concept of IDD policy. Where possible, participants were asked to propose alternative conceptual framings that might better advance the aspirations of IDD advocacy. Many of the advocates interviewed were skeptical about the social inclusion framing, but for some it was considered the best alternative to advance the present policy agenda. By contrast, others suggested that instead of inclusion, IDD advocacy should focus on empowerment, with specific emphasis on increasing the role of people with IDD in co-creation and co-production through more effective consultative mechanisms in policy design processes. This focus on empowerment and recognition echoes a popular criticism within the disability politics literature that models of inclusion do not adequately accommodate the fundamental challenge that IDD – and neurodiversity more broadly – pose to social and political institutions (Mitchell 2015; Rapley 2004; Stainton 2005; Pettinicchio 2019). The conclusion of Chapter 3 draws from the interview data to discuss strategies for empowerment and recognition within IDD advocacy. The relationship between family-led advocacy and self-advocacy is addressed as a vital source of inter-connectivity within the IDD social movement, reflecting the centrality of relational autonomy in IDD identity politics. Equally, partnerships between IDD advocacy organizations are necessary to promote unity and avoid fragmentation when it comes to (re)framing the IDD policy agenda. Participants revealed frustration at the tokenistic involvement of self-advocates in recent policy consultations, and stressed the importance of unity among IDD advocacy groups to counteract the marginalization of developmental services within the broader landscape of social services provision.

Beginning in Chapter 4, the focus shifted from policy design framing to the processes of (re)framing in policy implementation. The first objective of this chapter was unpacking the concept of policy divergence as it is understood in the policy implementation literature. Identifying and explaining adherence/divergence from policy intent is essential to the study of policy implementation dating back to early studies in this scholarly tradition which sought to explain policy implementation 'failure' within the lens of representative democracy (Pressman and Wildavsky 1979). Within this lens, deviation from policy intent was seen to reflect a lack of public accountability by policy implementers (Lipsky 1980; Hupe and Hill 2007). This lens informed the top-down perspective on policy implementation which has a narrow normative understanding of the proper role of policy implementers and traditionally places a greater focus on the design of policy instruments to avoid implementation failure. By contrast, bottom-up and hybrid perspectives on policy implementation focus more on the significant discretionary authority that implementation actors have to shape policy outcomes. This in part reflects the decentralization of state authority and reliance on private organizations and actors as key stakeholders in policy implementation, particularly following new public management reforms in Canada (Aucoin 1990; 1995). These reforms only served to increase implementation deficits, as control over policy decision-making became increasingly centralized (Aucoin 2010), while implementation capacity in the public service and non-governmental organizations, respectively, became increasingly differentiated (Evans and Wellstead 2013). By conducting a literature review of implementation perspectives on policy divergence alongside a historical review of the actors and instruments that define the policy landscape, this thesis provided valuable descriptive context to explain the implementation of developmental services.

This descriptive foundation was complemented in Chapter 4 by empirical evidence drawn from interviews with IDD advocates, whose unique position at the nexus of policy design and implementation affords them insight into the nature of policy divergence in developmental services. Advocates identified three explanations for policy divergence in the current Canadian developmental services context. First, they pointed to implementation gaps arising from the lack of specific deliverables or accountability mechanisms to encourage social inclusion outcomes within relevant developmental services policies. Here the implication is that – from a top-down perspective – divergence is an unintended consequence of under-specification in policy instruments. This is problematic because it does not account for the agency of implementers, whose discretion to pursue outcomes that are responsive to the precise needs of service users may actually be encouraged by under-specified policy designs. Second, advocates pointed to the competing priorities of federal level and provincial level policy instruments as another potential factor creating policy divergence. This explanation was primarily related to the inability of frontline implementers to promote outcomes that mirrored the framing of social inclusion set forth by broad policy commitments such as the national level *Accessible Canada Act, 2019* (ACA), or the supranational United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). As in the first example, divergence in these cases relates to the under-specification of specific deliverables, but is further compounded by the lack of oversight over developmental services by governing bodies at the national and supranational levels. Finally, advocates pointed to the willing subversion of social inclusion outcomes by implementers to explain divergence. Specifically, advocates identified paternalistic practices such as 'gatekeeping' in the selection of community programming and activities by support workers.

While explaining divergence is useful in identifying sites of implementation failure, this perspective is overly indebted to a top-down perspective on implementation, insofar as it presupposes that policy intent is only communicated from this direction. In the context of policy framing, this implies that divergence is any implementation action that does not adhere to the policy design framing of a policy problem. However, this thesis observes implementation as an act of policy (re)framing, where in a context of high policy ambiguity and high discretionary authority, implementers are empowered to decide which policy framing they wish to adhere to. Adherence can occur from the top-down, but can also occur from the bottom-up (i.e. in adherence to the framing of policy provided by service users) or horizontally (i.e. in adherence to framing that is supported by organizational norms/professional culture). Moreover, the interpretation and choice of policy framing occurs throughout the policy process, such that the meaning of a policy frame can shift substantially as it is interpreted, translated and communicated by implementation actors.

To account for these dynamic processes of policy (re)framing, Chapter 5 shifts the focus from policy divergence to policy adherence, with an emphasis on the directionality of framing. Recall that the second central research question asks how provinces differ in the *effectiveness* of developmental services to promote social inclusion. In this thesis, effectiveness is defined using the classical implementation studies definition – 'the adherence of outcomes to policy goals' (Sabatier and Mazmanian 1981). The typology of implementer decision-making styles presented in Chapter 5 expands the notion of 'policy goals' to include (re)framings of policy, with adherence occurring from three directions. This has important theoretical implications – discussed in section 7.3 – but also contributes empirically to the cross-provincial comparison conducted by this thesis. Policy effectiveness need not be confined to mechanisms of top-down accountability, and also can be manifested in policies that empower implementers to adhere to professional norms or to the precise needs of service users. This broader vision of policy effectiveness informs the selection of indicators for the Social Inclusion Services Index (SISI) in Chapter 6, which is the primary empirical contribution of this thesis.

7.2 Empirical Contribution

This study contributes to the study of Canadian IDD policy through the creation of a composite index to measure and compare cross-provincially the effectiveness of policies promoting the social inclusion of people with IDD. This involves several significant empirical contributions. First, this thesis introduces the concept of 'the inclusion era' in Canadian disability politics by demarcating its origin with the 1998 *In Unison* report, and identifying the policies that are emblematic of this dominant conceptual framing. Numerous disability policy scholars have pointed to the significance of *In Unison* (Prince 2009; Crawford 2003; IRIS 2012; Levesque 2020a); however, by tracing the emergence and prevalence of social inclusion policy framing in IDD policy and situating this alongside a historical review of IDD advocacy, this study presents compelling evidence that *In Unison* portended a discernible shift in Canadian IDD policy design. This is significant for the development of the SISI because this study adopts the conceptual framing of social inclusion in *In Unison,* a vision of full citizenship that entails "full participation of people with disabilities in all aspects of Canadian society" (ESDC 1998, 7).

This conceptual framing of social inclusion is normatively attractive, thus contributing to the political sustainability of the inclusion era in Canadian IDD policy and advocacy (Pollitt and Hupe 2011). However, many of the policies of the inclusion era have stalled and/or failed in practice. Most notably, this is evident in the policies designed to end the explicitly exclusionary practices of the residential institution housing model and the sheltered workshop vocational programming model. Despite widespread rhetorical and legislative support for inclusive IDD policy models in housing (community living) and employment (paid employment), in several provinces the transition to these models has not materialized. Equally, there are examples such as the case of IDD housing in Nova Scotia, where the timeline of the transition to deinstitutionalization was described in meticulous detail by the Department of Community Services (Nova Scotia 2013), yet several residential institutions remain open in the province. While the frontloading of policy benefits is a documented strategy for maintaining the political sustainability of policy projects (Patashnik and Weaver 2021), the persistence of explicitly exclusionary practices in housing and day programming may portend policy drift away from the inclusion model. Drift exists where changes in the external policy environment cause policies – which have themselves remained static over time – to change in their implementation and/or their specific outcomes (Hacker 2004). This effect is reflected in the weighting and selection of indicators in the SISI, where provinces that have stalled or failed in transition away from exclusionary policy models fare comparatively worse in the index. The SISI thus provides a strong baseline for the study of policy feedbacks within developmental services policy domains.

In addition to measuring cross-provincial effectiveness in achieving specific outcomes emblematic of the inclusion era, the SISI is also comprised of indicators that tap the capacity of developmental services systems to flexibly respond to the social inclusion needs of service users. Specifically, the SISI uses indicators to capture both the existence of IDD-specific governance structures within provincial social services, and the comparative level of wages in the developmental services sector. Including administrative capacity makes the SISI more representative of the processes of promoting developmental services than relying strictly on aggregate measures of specific social inclusion outcomes. This sets the SISI apart from other composite indices that address the social inclusion as it relates to IDD policy. For example, Schalock et al. (2008) collect outcome-focused measures of social inclusion, which is presented as a quality-of-life indicator for people with IDD. However, despite an effort to relate these measures to programming options, their main takeaways rather intuitively suggest that inclusive outcomes are more likely to result from person-centred approaches and maximizing the capacity of support staff.

This outcome-centred approach was further advanced by Shogren et al. (2015), who point to the importance of integrating contextual factors such as policy goals and supports to complement outcomes in the study of social inclusion for people with IDD. Their study represents the closest analog to the SISI anywhere in the IDD literature, however it does not address any specific political or policy context and does not engage with public policy literature to explain contextual factors. Ultimately composite indexes are limited by their inability to capture the contextual richness of personal outcomes. It is impossible to create an aggregated score to measure the feelings of inclusion felt by all Canadians with IDD, and then attribute this to the specific mix of developmental services they use. In light of this weakness, prioritizing measures that capture the flexibility of administrative structures adds descriptive value to the SISI, and signals the importance of accounting for implementation effects in the broader discussion of IDD policy. In this way, the SISI can be used to complement outcome-focused measures to gain a more comprehensive understanding of how policy connects to lived experiences.

7.3 The Impact of COVID-19

The most significant limitation of this study is that it does not account for the dramatic changes in the developmental services sector that are likely to result from the impact of the COVID-19 pandemic, which began as fieldwork for this study was half finished. While there are numerous references to COVID-19 in the verbatim quotations of participants interviewed after the pandemic, as well as sections of this thesis that discuss the pandemic impact on housing policy options and spending in the developmental services sector more broadly, the analysis is incapable of accounting for the pandemic's impacts on policy design and implementation. COVID-19 also affected the selection of SISI indicators. For example, British Columbia would have fared higher on the Financial Security domain of the SISI had COVID-19 related benefits been added to the methodology. British Columbia was the only province that provided pandemic-related payments that would have presented additional benefits to provincial disability income support recipients in 2021, with a monthly benefit of $950 for single persons with a disability (Laidley and Tabbara 2022, 12). However, ultimately the decision was made to exclude this program because of its temporary nature.

Elsewhere, the impact of COVID-19 was felt in the retrenchment of developmental services, likely necessitated by huge budgetary outlays in the health sector targeted to pandemic responses. For example, in Ontario spending by the Ministry of Children, Community and Social Services shrunk by $400 million in the 2020-2021 budget, and $800 million in 2021-2022 budget, owing both to decreases in developmental services (Ontario TBS 2021, p.23) and to decreased uptake of social assistance due to incompatibility with federal COVID support programs (Ontario TBS 2022, p.17). Future research should address the compatibility of disability income support schemes with temporary COVID-19 supports to compare provinces on the retention of recipients, as this will be a key indicator of financial security cross-provincially in the immediate future. This research would be well complemented by research into the human impact of the COVID-19 pandemic, specifically insofar as IDD residences such as group homes and institutions were hotspots for infection, hospitalization and death (Majnemer et al. 2021; Lunsky et al. 2022). The impact of these outbreaks was magnified by the massive strain that COVID-19 put on the developmental services sector, which also dealt with high rates of infection in addition to caregiver fatigue and precarity of staffing (Brotman et al. 2021; Redquest et al. 2021). Preliminary evidence of this impact was observed during the interviews:

> *"It has shed light on things that we already knew were issues, but has maybe put them more out to the public domain so, you know, there has been further acknowledgment about the risks associated with congregate institutional living, right? We've seen the way COVID has spread and resulted in deaths in institutional settings. So, I think you know, we always knew, right? That there was increased risk in institutional living but this has kind of brought that to the forefront I think in a more public way"* (FED21 AG F SW)

> *"What we heard about a lot was social isolation. So, on the two sides: one was what we just talked about in terms of access to day programming. So, lots of people at home all day with a caregiver. No break for the caregiver, but no opportunity to interact socially for the individual. And then on the residential side, people who were not able to see their families. So those residents, for a long time they weren't able to go home. You know, for those who go home to their parents' homes on weekends, or you know a couple of times a month, or whose families visit them. But all that all got shut down."* (ON24 GOV)

> *"So I have experienced firsthand that during an outbreak, sadly the supported person who had COVID, or a couple of people I actually have seen this for, was receiving less support because the staff were afraid to be around them. I mean, that's obviously not across the board, that's just one situation. But it's a situation where, as a manager I had to make a point of going in there frequently and saying to the staff that he actually needs more support now than he did before."* (ON 26 SW9 M3)

Each of the above quotations reflects a different type of trauma confronted by developmental services users during the pandemic. Clearly, the impact of COVID-19 on developmental services, and health and social services more broadly will continue to be an object of intense scholarly interest in the coming years.

As the pandemic unfolded, the scope of this thesis was affected, as it became increasingly important to create a baseline for the effectiveness of social inclusion policies against which to comparatively assess the impact of COVID-19 on the developmental services sector cross-provincially. This had several important impacts on the substance of this research. First, with the onset of the pandemic it became no longer safe or appropriate to conduct in-person interviews with developmental services staff or people with IDD. New measures were quickly put in place to limit outside access to residential and day program locations, and staff working in these locations were confronted by dramatic shifts in the nature of their work (Desroches et al. 2022; Lunsky et al. 2021). People with IDD – especially in congregate care facilities or residential locations where they were likely to interact with multiple staff – were subject to heightened risks of disease and death (Lunsky et al. 2022; Lake et al. 2019). Not only did this make interviewing staff and service users impossible and inappropriate, but it also dramatically changed the context of service provision to the extent that new data on the provision and use of developmental services would be thematically incompatible with pre-pandemic interviews. This necessitated a long-pause in the field work for this thesis, and when it resumed again in the comparatively safer format of online interviews, the decision was made to recruit mostly longer-tenured managers and advocacy group workers who could speak about the nature of developmental services pre-COVID 19. This does not mean that this thesis attempts to ignore the effects of the pandemic. References to and analysis of pandemic responses in the developmental services sector can be found throughout this work, specifically in the chapters on policy implementation and the presentation of the SISI.

7.4 Theoretical Contribution

Lasswell and Rubenstein's (1966) book on power sharing at the Yale Psychiatric Institution has been a foundational text for this dissertation because of its ground-breaking discussion of inclusion as a process of empowering target populations in decision-making processes related to the policies that affect them. Drawing from the idea of power sharing, a more interesting avenue of future inquiry is power *ceding* as a strategy to effectively increase the inclusion of marginalized groups. For example, processes of community consultation are commonplace in the leadup to major disability policies in Canada. Notably, consultations were employed in the recent *Accessible Canada Act* and the development of *Canada's Disability Inclusion Action Plan* (Canada 2022). Bringing advocates to the table to suggest areas of emphasis for impending policy designs is a clear example of power sharing; however, as the interviews with advocates shared in Chapter 3 indicate, these deliberative processes are mostly tokenistic and have not significantly shaped the legislative acts that follow. Instead, power ceding is required, based on the acknowledgement that policies are currently made (designed, budgeted, implemented, and so on) within a political institutional context that is demonstrably ableist. Without ceding policymaking power away from this machinery, its ableism cannot be circumvented, and inclusion cannot occur. In this way a central theoretical contribution of this thesis has been that the *empowerment* of people with IDD in policy processes – specifically, policy design – is not only crucial to achieving the aspirations of the inclusion era in Canadian disability policy, but also has the potential to supplant this dominant framing and signal a new era of disability policies that explicitly articulate mechanisms for IDD empowerment and recognition.

This thesis has also advanced a burgeoning literature that observes policy implementation as an act of policy (re)framing. Critical Frame Analysis, as a methodological approach, exists to help navigate the complexity of ambiguous implementation environments, as is evidenced in the following quote.

> "Under conditions of multilevel governance, implementation is a complex process of transfer and translation: unitary concepts or frames, as presented in political decisions and policies at (sub) national and supranational levels contrast with a dynamic reality of multiple frames at national levels. This contrast between an assumed stable unity and a real dynamic diversity is seen as a «black box» of distortions in the implementation of policies" (Verloo 2005, p.18-19)

To clarify processes of implementation within this 'black box' of distortions that destabilize implementation processes, this thesis introduces a typology of implementer decision-making styles. The typology is designed specifically for implementation contexts of high ambiguity, and which impart significant discretionary authority throughout the implementation chain. In contrast to a traditional street-level bureaucracy, this typology begins with the understanding that policy can be (re)framed at several points throughout the implementation chain. This problematizes the study of divergence in policy implementation studies by challenging that there is ever a stable or static framing of a public policy.

Frontline implementers such as personal support workers rarely engage with policy documents; therefore, their understanding of a policy framing is highly contingent on their interpretation of information passed to them through different relationships of practice. The typology focuses on the directional origin of the framing that implementers choose to adhere to. This can occur from the top-down (i.e., through a supervisor's direction or through the explicit requirements of a job task), horizontally (i.e., adherence to organizational or professional norms) or from the bottom-up (i.e., through adherence to the framing preferred by a sub-ordinate or a service user). While the actual outcomes of policy (re)framing are highly contextual, and thus resistant to comparison across cases, comparing the directionality of adherence provides valuable descriptive leverage to assess the effectiveness of both policy designs and implementation processes within a specific policy context. For example, within the developmental services context, accounting for top-down adherence demonstrated the benefits of IDD-specific governance structures, where managerial competence on issues affecting developmental service users is situated higher up the implementation chain. Similarly, accounting for horizontal adherence highlighted strategic coordination among lower-level managers seeking to optimize service uptake in the wake of program closures following austerity measures. Finally, accounting for bottom-up adherence illustrated how frontline workers can rule-bend to empower service users and family-advocates to reframe policies to reflect their personal needs and preferences, thereby opposing dominant models of behavioural intervention in IDD support provision.

7.4 Limitations

Over the course of fieldwork, the scope of this thesis expanded. The original research design posed the same two central research questions, but instead of applying them to people with IDD broadly, the proposed research focused only on older adults with IDD. Prior to the COVID-19 pandemic, the life expectancy of Canadians with IDD was steadily increasing (Shooshtari et al. 2012; Statistics Canada 2015). This had the effect of increasing the current cohort of older adults with IDD, who are caught between the separate 'silos' of disability and aging services (Dickson 2016; 2022). Promoting the inclusion of older adults with IDD is urgent because, cross-provincially this cohort contains the survivors of residential institutions and an era of explicit exclusion and state violence. The COVID-19 pandemic did not disrupt this urgency, but the pressures of austerity are shifting developmental services systems such that negative outcomes are being distributed more evenly across the lifecourse. Specifically, there has been an increase in the inappropriate placement of younger people with IDD into long-term care facilities designed to provide support to older adults. This has been described as a process of 're-institutionalization' by scholars (Ouellette-Kuntz et al. 2017; Barber et al. 2021) and IDD advocates (Linton and David 2022a) alike, a development that further signals policy drift in the inclusion era. Future research should observe and explain policy drift in IDD housing policy.

The developmental services system remains marked by pronounced biases against older adults. For example, recent changes to improve quality measures in residential supports in Ontario are geared only to children and young persons in licensed residential settings, making this ageist bias explicit in the very design of the policy (MCCSS 2020). These ageist biases have been further exacerbated during the pandemic. Participants described the onset of social isolation following the closure of day programming for older adults during the pandemic. They also described the anxiety and fear that resulted from outbreaks throughout the sector, with a greater likelihood of fatality for older people with IDD who contracted COVID-19. Finally, they pointed to a trend of increased re-institutionalization – a fate that must be particularly devastating for institutional survivors:

> *"And it's a whole re-institutionalization. So, sometimes we're seeing people who were institutionalized when they were younger, and with the move towards deinstitutionalization they're out there in the community. And now that they're older and their needs are changing, we don't know what to do with them and are placing them back in institutions. And so, I've seen that happen to a number of people and it's just such a depressing way for them to spend their final years."* (FED22 AG SW)

In addition to capturing the sadness of re-institutionalization, the above quotation also reveals how developmental services structures continue to be unprepared to support older adults with IDD. This is reflected in the total absence of policies within the sample analyzed in Chapter 2 that specifically target older adults with IDD. While ultimately the decision was made to broaden the scope of the SISI to compare the developmental services across the lifecourse, indicators were selected so as to not impart an ageist bias on the index. Specifically, the decision was made to exclude a domain on inclusive employment policy, given that this would bias the index towards working age service users. Nonetheless, there remains a pressing need to address the negative outcomes that are disproportionately experienced by older adults with IDD within the Canadian developmental services landscape. Given the lack of policy design framing specifically targeted at this population, future research should address the framings adopted by implementation actors supporting older adults with IDD, specifically.

Another limitation of this study is that it does not account for important dynamics pertaining to the enactment of inclusion at the local level. Given provincial purview over much of the developmental services landscape, this was the main level of analysis for the Critical Frame Analysis of disability policy designs, and the level of comparison employed by the SISI. However, local governments also play a role in the provision of developmental services. First, they have direct oversight over policy areas such as transportation and urban planning, which significantly shape the social inclusion of people with IDD (Jacobs 2018; Bickenbach and Cieza 2011). Local governments also fill the gaps created by neoliberal policies, which favour the devolution of social policy responsibility without the transfer of necessary resources to effectively design and implement these polices at the local level (Joy and Vogel 2021; 2022; Lucas and Smith 2019). The sheer diversity of multilevel governance arrangements across Canada makes the comparison of provincial-local coordination difficult; however, as Smith and Spicer's (2018) comparative study of local autonomy for policy responsibility in Canada's largest cities demonstrates, there is a potential for aggregation and analysis of key variables.

This increased scholarly interest in the decentralization of social services authority suggests that there is a potential to incorporate dynamics of local IDD governance into the comparison of Canadian developmental services systems moving forward. However, an equally promising aspect of incorporating the local level into discussions of IDD policy is the potential that this lens provides to prioritize the lived experiences of people with IDD in the discussion of social inclusion outcomes. While this thesis filled a gap in the Canadian and international IDD policy literature by comparing implementation dynamics with a view to the performative features of different developmental services systems, this broad analytical scope prevented deep engagement with the actual outcomes of people with IDD navigating these systems. This limitation constrains the applicability of this thesis to the daily experiences of Canadians with IDD. Fortunately, social inclusion outcomes for people with IDD have received significant attention in the Canadian literature (Simplican et al. 2015; Wilton et al. 2018; Cushing 2015), leading to growing consensus on the broad parameters of how these outcomes can be achieved. Lord (2010) concisely describes these broad parameters for IDD social inclusion in the two 'pillars for the future' forwarded by the Canadian independent living movement: community and self-determination (p.272-5).

The local level of analysis affords a unique analytical lens to engage with these broad aspects of social inclusion. For example, recent international IDD scholarship has homed in on the promotion of social inclusion through specific acts of 'convivial encounter' within public spaces at the local level (Bigby and Wiesel 2019; Wiesel et al. 2013). What is noteworthy about the typology of convivial encounters forwarded in this research is its integration with policies at the local level, including the provision of shared spaces and non-competitive environments, and the role of support work practice in promoting community building based on recognition and the fostering of common interests (Bigby and Wiesel 2019). This lends support to a key finding from this thesis that IDD advocates preferred an empowerment/recognition (re)framing of social inclusion from the bottom-up. As such, the concept of convivial encounter represents a promising descriptive foundation for future work that seeks to integrate both local level governance and a greater focus on social inclusion outcomes into the comparison of IDD policy in Canada.

7.5 Concluding Thoughts

Throughout this thesis, I have pointed to the thematic synergy between the inclusion era in Canadian disability politics and the social model of disability – the conceptual framework that popularized the notion of disability as socially produced through barriers, both environmental and attitudinal (Oliver 1983; Oliver and Barnes 2012). This fundamental idea fuelled the creation of the field of (critical) disability studies, and has dramatically impacted the language of advocacy, policy design and disabled self-concept internationally since its appearance (Goodley 2013). Simultaneously, the social model has been frequently critiqued for several shortcomings that have emerged through its misapplication as a grand theory of disability and identity politics[75]. One such critique, argued by Shakespeare (2006), is that the 'barrier-free utopia' that the social model implicitly imagines – where environments and attitudes are universally accessible – is impossible in practice. To make his point that some barriers are ultimately insurmountable, and some accommodations incompatible, Shakespeare invokes an example of blind peoples' preference for raised curbs and wheelchair users' preference for curb cuts (p. 201). If the accommodations are incompatible, someone will invariably be disabled. This line of thinking resonates with a thought that was the catalyst for beginning this research: is a world that is fully inclusive of people with IDD possible, or even imaginable? People with IDD are an incredibly diverse population, and this is not just limited to manifestations of neurodiversity or intersectional identity, but also expressions of relational autonomy and individual performativity. In my past as a developmental services worker, I was often frustrated by the total incompatibility of social norms with the very basic needs of the people with IDD that I supported. I also witnessed how stigma, stereotypes, and discriminatory attitudes towards people with IDD often manifested in fear and discomfort, and sometimes hatred.

In light of the policy failures of the inclusion era, imagining a more inclusive future for people with IDD requires disrupting the continuity of the failures of the present. Making imagined futures performative requires what Oomen et al. (2022) call 'techniques of futuring', collective projects that rely on dramaturgical regimes that employ familiar logics to become persuasive, because – building on the work of Hajer (2009) – "the politics of the future revolve around who can make their imagined futures authoritative in the scenes and stages that matter"

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[75] Shakespeare (2006) identifies four main critiques of the social model of disability including – most notably – its failure to acknowledge the personal effects of impairment, which although individually-bound, can significantly shape the experiences of people with disabilities. Oliver (2013) responds to critics of the social model by arguing that it is not a grand theory, but merely "a tool to improve peoples' lives" (p. 1025), as evidenced by its positive impact on advancing the scholarship and framing disability within international political discourse.

(Oomen et al. 2022, p.266). Disability studies also seriously considers the implications of imagined futures, with visions of disabled futurity that radicalize and expand the concept of accessibility to build broad coalitions to disrupt and destroy systemic barriers (Kafer 2013; Titchkosky 2011). Drawing from the social model of disability's central thesis that disability is socially constructed, disability futurism contends that "(i)f it is indeed within relations that disability emerges, then that is where the fight is to be had" (Fritsch 2016).

Recent developments have problematized imaginations of disability futurity. As is discussed in Chapter 3, the enactment of Bill C-7, Canada's medical assistance in dying (MAID) legislation has made advocates call into question the government's commitment to disability inclusion. The bill qualifies people with disabilities as the only group that is eligible for assistance in dying, even when death is not imminent. For the advocates I interviewed, this bill was symbolic of a fundamental devaluation of disabled lives:

> *"I don't know how the federal government can talk about a policy of inclusion in the face of Bill C-7. I just, I don't know what to do with it."* (FED23 AG)

Coupled with an awareness of the deleterious effects of recent austerity measures on the developmental services sector, the IDD advocates interviewed shared the common sentiment that Bill C-7 is evidence that the government would rather people with disabilities die than provide them with necessary supports. This sentiment is supported by early evidence, as 4.3% of MAID recipients reported that they required disability supports that were not received in 2021[76]. In this way, MAID represents a new form of malignant inclusionism, which confers disadvantage and death to disabled people at the far margins, echoing eugenics policies of the past in the designation of non-productive bodies (Mitchell 2015, 214-216). This is emblematic of the ableist ideas that continue to pervade Canada's social and political institutions – enduring barriers from a time when IDD policy was explicitly exclusionary. Overcoming these barriers requires power-ceding, not power-sharing. As such, the path to achieve the transformation to full inclusion and to bring to fruition the rhetorical commitments of the inclusion era in IDD policy is through discontinuity. Rather than wonder whether a fully inclusive society is possible, let us instead imagine a future era of Canadian IDD policy framed by a politics of empowerment and recognition.

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[76] Government of Canada. 2021. *Third Annual Report on Medical Assistance in Dying 2021*. Retrieved online from: https://www.canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying/annual-report-2021/annual-report-2021.pdf

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