DISABILITY, DISPLACEMENT, AND THE BIOPOLITICS OF BELONGING

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ABSTRACT

This dissertation is concerned with the multiple ways in which formal and substantive citizenship are regulated among migrants with disabilities and non-migrants with intellectual disabilities. The focus of this analysis is twofold and is centred on medicalized assessment practices supported by government agencies at the federal and provincial level. These are Immigration, Refugees and Citizenship Canada (IRCC) and Ontario's Ministry of Community and Social Services (MCSS). A multi-layered and historically informed analysis that reads first-person interviews alongside legislative and policy developments situates lived experiences with assessment regimes within a broader theoretical discussion of displacement. First, access to developmental services among adults with intellectual disabilities in Ontario is addressed, with a special focus on the MCSS Passport Program and Ontario's implementation of the Supports Intensity Scale™. Immigration medical testing and particularly the IRCC's medical inadmissibility criteria are then considered in detail. While careful attention is given to the unique ways in which immigration medical testing and developmental services assessments are experienced, these examples are treated through an integrated analysis that draws upon the inter-related concepts of (in)capacity and (under)development.

The framework forwarded in this study suggests that hierarchical understandings of (in)capacity and (under)development organize opportunities for belonging in translocal and transnational contexts, impacting migrants with disabilities and non-migrants with intellectual disabilities. A 'governmentality of (in)capacity' that emphasizes the intersectional potential of intellectual disability is proposed as a means of exploring decision-making within and across these contexts. To account for the similarities as well as the differences between various modes of exclusion, this study also builds upon previous work in critical migration and critical disability

studies, contributing to the development of a displacement framework that encompasses spatial and subjective dimensions of translocal and transnational disability experiences. Through this framework, lived experiences with Canadian immigration practices and Ontario developmental services are analyzed to reveal how diverse and deeply marginalized – but by no means mutually exclusive – communities can be placed at risk of displacement.

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TABLE OF CONTENTS

Part I – Developing a Framework for Understanding Disability Displacement

Chapter One: Regulating Citizenship Across Jurisdictional Boundaries

Introduction

In the Spring of 2018, as writing for this dissertation was underway, federal and provincial governments were touting major milestones for two deeply marginalized communities: migrants with disabilities and persons with intellectual disabilities (ID).[1] The first of these separate announcements, addressed in detail below, indicates incremental reforms to the medical inadmissibility criteria used by Immigration, Refugees and Citizenship Canada (IRCC) to determine eligibility for permanent residency based on potential service-use. The second applauds a budgetary increase and the availability of additional funding through Ontario's Passport Program – a key reimbursement program overseen by the Ontario Ministry of Community and Social Services (MCSS), the agency responsible for housing and supports for adults with ID. Not coincidentally, the use of 'passport' language by MCSS resonates strongly with IRCC's practice of determining permanent residency and citizenship status for migrant applicants. As this dissertation demonstrates, the provincial ID funding program and federal immigration medical criteria can each be characterized as 'passport systems' that play a critical role in shaping the presence and non-presence of disabled people in Canadian society. Behind the decision-making practices active within these systems, we can detect a shared reliance on

[1] The decision to employ "intellectual disability" over "developmental disability", the term most commonly used in Ontario, stems from an effort to respect self-definition by adopting the language used by the largest Canadian advocacy organization led by people with intellectual disabilities, People First of Canada, which employs the term "labeled with an intellectual disability". Additionally, "intellectual disability" is used outside of Canada more often than "developmental disability", while often appearing alongside or in lieu of "developmental disability" in other Canadian jurisdictions.
Relatedly, the focus of this dissertation relates to contemporary experiences of ID. This discussion employs a historically-informed analysis to reflect these experiences, but without entering into the more nuanced aspects and many debates around naming and historically identifying this community. While these crucial considerations demonstrate the historically variable and contingent means by which people labelled with an ID have been identified, they are beyond the scope of the present study.

evaluative medical technologies that seek to measure and predict service usage among target populations. These evaluative tools and the processes, policies, structures, and values that support them, shape the focus of the following chapters.

This dissertation places MCSS and IRCC assessment regimes in historical and conceptual context, presenting an in-depth study of the evaluative technologies and processes they employ that is attentive to their mobilization as biopolitical tools. I present a snapshot of these dynamics that considers earlier practices as well as changes made up until the spring of 2018. The overarching goal of this analysis is to account for the often-hidden, widespread, and everyday reliance on hierarchical ordering devices that are ideologically invested in specific conceptions of human and economic development, capacity, and progress. Throughout this discussion, the inter-related concepts of (in)capacity and (under)development will be used to articulate the practical consequences of medicalized hierarchies and assessment practices across two policy settings: Ontario's Passport program and the IRCC's medical inadmissibility screening process. Some of the most profound consequences of these assessment regimes can be expressed through a theoretical framework that centres displacement and non-citizenship, as discussed below. First, however, this chapter provides a brief sketch of these policy contexts and evaluative technologies, along with some key concepts that will facilitate a critical analysis of their central problems; these include the notion of the conditionality of non-citizenship (Goldring and Landolt, 2013), as well as the importance of ID and the related concepts of (in)capacity and (under)development as a lens of analysis for addressing experiences of non-citizenship. The next section takes a closer look at recent changes to the Passport program and IRCC medical inadmissibility criteria and related forms of administrative decision-making. Following this, we will see how biopower operates through displacing processes that impact both people with ID

and migrants with disabilities by shaping their non-presence, before turning to an in-depth discussion of displacement theory, its applicability to disability studies, and the important connections between ID and migrant realities. This chapter closes with a discussion of the methodological approach that structures this dissertation – which includes an analysis of legislation, official documents, and participant interviews – and presents a summary of the chapters that make up this study.

Conceptualizing Displacement Through a Political Economy of Medical Decision-Making

To begin, the specific evaluative methods employed by the Ontario and federal governments in relation to ID and migration set out a test-and-cap system which regulate service usage to meet the distributional goals of governing agencies. In Ontario, MCSS relies on non-profit private agencies, collectively referred to as Developmental Services Ontario (DSO) or Developmental Services Offices (DSOs), to assess people with ID for service eligibility and to test their level of need in order to assign them a Passport funding level. The arrangement between the DSOs and MCSS is set out in the governing legislation, the 2008 Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (SIPDDA). DSO assessments include implementation of the Supports Intensity Scale – Adult Version™ (SIS-A™)[2], a tool owned and developed by the American Association of Intellectual and

[2] Hereafter referred to simply as "SIS". Note that while the Supports Intensity Scale – Adult Version (SIS-A) is owned by the AAIIDD and trademarked, with the previous version (SIS 2004) being registered, the trademarked and/or registered symbols are only included in the first mention in order to facilitate reading. Furthermore, and while acknowledging the current use of the SIS-A, the SIS will be discussed in terms of a general approach and methodology by drawing upon different versions of the Interview and Profile Form, but by referring to these collectively as the "SIS". Please note as well that the AAIDD (2019) employs the term "SIS" to refer to the suite of SIS tools, which includes:

- Supports Intensity Scale-Adult Version™ (SIS-A™, 2015),
- Supports Intensity Scale-Children's Version (SIS-C™, 2016)
- SIS-A Annual Review Protocol (2017)
- Associated electronic software (SISOnline ® and SISVenture®) and
- Associated reports, manuals, guides, training materials, and training and quality assurance protocols

Developmental Disabilities. Turning to the federally regulated immigration sector, applicants for permanent residency must meet admissibility criteria by passing an immigration medical exam that considers their level of need and then decides whether they represent an 'excessive demand' on health and social services. These criteria are governed by the 2001 Immigration and Refugee Protection Act (IRPA). Even while these systems seek to structure the use of limited public resources, the deliberate and unintentional consequences of their policies are not simply the result of budgetary constraints. Instead, the distributional goals that shape these assessment processes can be read as manifestations of broader cultural and economic values that are intrinsically linked to the medicalized evaluative methods used to justify decision-making around eligibility in these sectors.

Chapters in this study outline the displacing effects of these tools and their underlying logic in biopolitical terms, showing how the precarious status and 'non-presence' of migrants with disabilities and people with ID with permanent status are linked to an exclusionary citizenship culture shaped by passport systems that attempt to regulate disability service usage. By taking up the SIS and immigration medical exam as evaluative technologies and considering the documentary identities that are produced through these assessment processes, this analysis develops a framework to study the translocal and transnational dimensions of disability displacement; it then situates diverse experiences of marginalization in a political economy of medical decision-making that is shaped by a citizenship culture which, through institutionalized and culturally-sanctioned practices, influences the production of various forms of 'non-citizenship' and displacement among persons with ID and migrants with disabilities. Non-citizenship, as conceptualized by Goldring and Landolt (2013), is a diverse and negotiated category and experience that can be characterized by the "conditionality" related to "the

contingency surrounding an individuals' ongoing presence in a legal status category and jurisdiction, as well as the uncertainty of accessing rights or exercising substantive citizenship" (p15). From a critical policy and critical disability perspective, these challenges around presence, status, and access can be viewed as manifestations of eugenic discourses and profound forms of disability exclusion that require comprehensive study.

To account for the ongoing influence of eugenic discourses, this dissertation asks how harmful evaluative practices become entrenched in law and policy, drawing connections across space, time, and historically siloed communities. As this discussion unfolds, we will see that MCSS and IRCC practices are each vested with a predictive ability that gives rise to claims about individual eligibility for and access to resources and social membership based on a standardized measure of their 'capacity'. The consequences are articulated and assessed in relation to the lived experiences of persons with ID and migrants with disabilities, with particular attention being paid to those who are framed by either system as 'incapable' and who experience precarious status or 'non-presence' as a result. The analytical framing of these experiences through the lens of (in)capacity brings the concept of ID to the forefront.

In the critical disability studies literature, assumptions of incapacity have been linked to the "contested agency" (Rapley, 2004, p6) of people with ID and relate to a range of ways of conceptualizing this impairment label that include "'defective 'intelligence'" and incompetency (Rapley, p48). In addition to the supposed underdevelopment of people with ID, their lack of potential for 'normal' human development has also been used to characterize them as non-human (Carlson, 2010a, p142), and as radically 'dependent'. Goodey (2011), for example, has shown that under liberal models of personhood, self-direction – described as "autonomy, consent, and rational choice" (p346) – have served as hallmarks of the human species. The absence of these

qualities, he explains, has shaped conceptions of people with ID (p356), further supporting their non-human status. As we will see, the citizenship cultures explored in this dissertation reflect many of the same qualities and preconceptions outlined by Goodey. Indeed, dominant citizenship cultures present independence and intellectual ability as natural indicators of human capability and normative development, converting these into standards that can be used to screen prospective citizens. Despite changing medical definitions, the relationships between these overlapping and imprecise standards point to the centrality of ID as their embodied representation. These themes will be explored throughout this study through the inter-related concepts of (in)capacity and (under)development.

As one dimension of capacity, the notion of progress can be linked to both individual and economic development (Chen, 2016), as we will see below. Meanwhile, the supposed incapacity of people with ID and others assessed through this paradigm in relation to their ability to be productive and contribute to economic development has justified their exclusion. The fact that this thinking extends well beyond the ID community can be seen in historical research exposing how capacity assessments have shaped the treatment of other groups, working to grant or deny them access to opportunities to be present, as has been the case with women's paid work and employability (Stephen, 2007). Stephen argues that "assessing worker capacity" (p32) through such means as aptitude testing was a central aim of highly gendered governance strategies that were developed to regulate labour during wartime and in the immediate post-WWII period. This dissertation turns to contemporary law and policy to consider the legacies of such practices, promoting an intersectional framework for analyzing diverse forms of exclusion that is built around the social situation of persons with ID and the ongoing imperative to measure (in)capacity in development terms.

A comparative analysis shows that migrants with disabilities applying for permanent residency are assessed in similar ways as people with ID seeking to access provincially funded services. The ascribed radical outsider status of people with ID as 'non-human' and the evaluative tools that legitimize this understanding thus illuminate broader exclusionary citizenship cultures which simultaneously shape 'who gets in'. This impacts, for example, the sub-human treatment of migrant workers on the basis that they are "out of place" (Holmes, 2013, p180), while simultaneously influencing the view that migrants with disabilities are 'outsiders' who are undeserving of public resources and who can be deemed 'medically inadmissible' based on their perceived level of need. The chapters that follow demonstrate that the framing of migrants with disabilities as 'alien' and 'inadmissible' is structured by many of the same processes and ideological assumptions that are particular to the historic subject position of people with ID, thus making the category of ID a productive lens of analysis. The inter-related experiences of displacement and non-citizenship help clarify the connections between these communities and the evaluative practices that seek to regulate their lives. Although, as this chapter will show, such experiences are not without their theoretical ambiguities. Importantly, the forms of displacement and non-citizenship experienced by persons with ID and migrants with disabilities are unique, marked by intersectional realities that cannot be conflated. Nevertheless, there are close parallels between the non-human status historically accorded to persons with ID and anti-immigrationist ideologies that draw upon capacity hierarchies in order to frame migrants with disabilities as inadmissible and underserving of access to formal rights. As the next section demonstrates, reform-oriented changes and incremental efforts to improve the position of these communities tend to reproduce the underlying problems described so far, largely on account of

their failure to recognize how a political economy of medical decision-making enacts capacity hierarchies premised on taken-for-granted views of people with ID.

Snapshot of Recent Policy Changes – Evaluating Excessive Needs in Translocal and Transnational Contexts

As part of the 2018 Ontario budget, MCSS announced a $1.8 billion investment in developmental services over a three-year period. This news followed a mounting volume of publicized accounts documenting the severe housing and support crisis facing people with ID and their families, including a scathing Ombudsman's report (Ontario Ombudsman, 2016). At an individual level, part of the Ministry's new investment translates into $5000 for every eligible adult with an ID to be issued through the MCSS Passport program. According to official narratives, these changes mark several firsts in the province, including "the single largest investment to developmental services in the province's history" (DSO, Transforming Developmental Services). What has not changed, however, is how the Passport program is managed, what services are eligible for reimbursement and, along with this, the insistence on a maximum of $10,000 to $35,000 in funding per year per individual, depending on the results of the intake and evaluation process (MCSS, Passport Program Guidelines).

Importantly, access to Passport, which is managed by the DSO, requires a two-part assessment underpinned by a medical diagnosis of ID and an evaluation of the level of support required by an individual for daily living. These now-entrenched aspects of the program, unaltered by the recent re-investment, reflect an approach to resource management that subjects persons with ID and their families to harmful eligibility standards and testing methods and similarly tight budgetary restrictions. Within the ID community, many organizations are concerned that current approaches within the developmental sector limit the exercise of choice

and opportunities for belonging among persons with ID; these groups remain skeptical that developmental services programs will ever meet their needs and, driven by these concerns, they continue to promote alternative solutions, such as "Microboards™", that look outside of government for support. At the same time, many continue to advocate for direct and individualized approaches to funding to meet their most urgent daily needs. [3]

On April 16th, 2018, not long before the MCSS announcement, the IRCC responded to the 2017 recommendations of a Parliamentary Standing Committee on Citizenship and Immigration concerned with how migrants with disabilities apply for permanent status in Canada. Some of the Standing Committee's research and recommendations contributed to heightened pressure by advocacy groups to repeal the excessive demand provision of the IRPA (see Parliamentary Standing Committee, December 2017). This provision, laid out in Section 38(1)(c) of the IRPA, allows people with disabilities to be deemed medically inadmissible to Canada based on their potential 'excessive' use of health and social services. Rather than abolishing the practice of excessive demand screening by repealing the provision, the IRCC chose to adjust how this aspect of medical inadmissibility testing takes place. This will be done by raising the cost-benefit threshold used by immigration medical officers to determine excessive demand as well as by redefining which services will be subject to such an evaluation. And while the Minister held out the possibility of a future repeal, political opponents remain doubtful that this will take place, claiming that the promise "rings hollow" (Harris, 16 April 2018).

[3] Consider, for instance, recent Microboard sessions hosted by Pooran Law in collaboration with disability community organizations that are taking place across Ontario: http://www.pooranlaw.com/microboards-sustaining-your-future-tuesday-november-21-at-7pm/. Calls for direct and individualized funding have been voiced by multiple family coalition across Ontario. See for example, the Individualized Funding Coalition for Ontario: https://blog.individualizedfunding.ca/about/.

Following findings that the former cost threshold, which reflects the annual use of health and social services of an 'average' person residing in Canada, was inaccurate (Russell and Hill, 4 July 2017) – at least according to its own logic – the IRCC raised the amount from $6604 to $19,965. In an interview with the Toronto Star, the Minister of Immigration claimed that this update reflects "a major step forward in ensuring our immigration system is more inclusive of persons with disabilities" (Keung, N., 16 April 2018). Yet, the rules of the game have not changed for migrants with disabilities and their families. In a joint press release, migrant and disability organizations referred to the changes as 'disappointing' (Caregiver Action Coalition et al., 16 April 2018) and indeed, disabled migrants will be left to wonder whether their permanent residency application will meet the required test or if their disability-related needs will be deemed 'excessive'.

In addition to revealing how policy change interacts with the work of civil society groups, the above examples from two separate jurisdictions show how the imagined impact of reform can be over-stated to the point of masking existing inequities. Despite recent moves to raise the thresholds associated with disability costs, the exclusion of 'some' disabled people on the basis of their disability-related needs still fits within the logic of the reformed programs. For many persons with ID and migrants with disabilities, access to formal and substantive citizenship, to the all-important 'passports to belonging' that are determined through assessment processes, remains precarious. Recent changes notwithstanding, members of these communities remain at high risk of marginalization by citizenship regimes that employ both overt and subtle, administrative means of exclusion (Kelley and Trebilcock, 1998, p36, as discussed in Wright, 2013, p44). To this end, this dissertation describes how incremental changes and reform-oriented discourses end up entrenching the problem of disability exclusion when they are motivated by an

understanding of 'progress' that is defined in opposition to the concept of ID and incapacity and through racialized views of (under)development. These ideologies will be challenged from an ID perspective that centres intersectional and transnational dynamics related to the potential and real presence of these communities.

In very concrete terms, the presence of persons with ID and migrants with disabilities is still curtailed by caps that are assigned to their service usage – $10,000-35,000 and $19,956, respectively – and associated predictions of their disability-related needs. These limitations mean that not all disabled people will be deemed eligible for inclusion or provided with the resources they require to access their rights in substantive ways. Further, such restrictions reflect attempts to enact an inclusivist agenda by refining processes that flow from flawed law, policy, and harmful cultural assumptions, while failing to address the basis by which individuals are unjustly marginalized.[4] More specifically, MCSS and IRCC test-and-cap systems arguably reinforce disability intolerance through their reluctance to accept disability supports not only as a natural human need, but as necessary in allowing disabled people to access and enact citizenship rights in substantive ways. These systems employ the SIS and the immigration medical exam and incorporate toolsets that encourage assessors to categorize, describe, and rank the perceived traits of their subjects in relation to capacity hierarchies. The end result is a disaggregated summary of the individual that is often accompanied by numeric scores. As this dissertation demonstrates, these results are fed into algorithms that work towards an official MCSS or IRCC decision about the level of need an individual presents. Findings are used to determine, for example, how much funding an individual will receive or how much they might require. These funding amounts are considered in relation to an established threshold, such as the maximum dollars available through

[4] This critique draws upon Mitchell and Snyder's (2015) discussion of "inclusionism", which will be explored in further on.

certain categories of the Passport program, or the maximum in health and social services that is considered 'reasonable' under excessive demand criteria. By actively measuring and limiting the use of disability-related supports, these systems participate in a eugenic rationale that pathologizes disabled people as costly and burdensome.

Decision-making in this area carries profound repercussions for the legal status of individuals and their ability to enact formal status and access rights. However, decisions made in relation to accessing and practicing formal and substantive citizenship have much to do with administrative forms of assessment and fall under an area of "soft law" where it becomes much harder to challenge wrongful outcomes. Soft law, according to Sossin and Pottie (2005), means that manuals, directives, and other documents not commonly considered as 'legal' regulate resource provision. Delegation and devolution of government responsibility can be read as another dimension of this softening trend, and Ontario's decision to have the DSO perform SIS assessments parallels the use of 'panel physicians' who are not employed by the IRCC to perform immigration medical exams. MCSS and the IRCC both play an arms-length role in assessments by providing training to DSO assessors and panel physicians, respectively, while delegating the actual assessment work to these private providers. As Sossin and Pottie explain, such a devolution of responsibility creates greater barriers in accessing justice. These potential barriers raise many concerns, given both the contentious nature of developmental services and decision-making around immigration, as well as their relationship to experiences of non-citizenship and displacement. By focusing on the medical decision-making tools that enact displacing processes, this dissertation seeks to bring into relief the often-hidden biopolitical technologies that shape everyday practices and experiences.

Technologies of Displacement

The biopolitical processes described in this study are spread across different jurisdictions and policy domains and will be treated as potential technologies of displacement that are active translocally and transnationally. Just as theorists of the state and governmentality employ 'technologies of governance' to denote the everyday processes involved in 'the government of conduct', technologies of displacement can draw attention to similar networks of power and to what Rose and Miller (1992) refer to as "the complex of mundane programmes, calculations, techniques, apparatuses, documents and procedures through which authorities seek to embody and give effect to governmental ambitions" (p175). In their discussion of governmentality, Rose and Miller emphasize the role of expertise within governmentality, while qualifying this by drawing upon Foucault's later writings on the diffuse nature of power. Since power is generated through discourses that circulate and are mobilized within multiple practices and technologies, a top-down view of social control would attribute too much authority to the role of expertise. Instead, we can see that expert knowledge-claims participate in the broader generation and mobilization of normative standards by and according to which individuals are compelled to shape their own conduct. From a governmentality perspective, developmental services and immigration systems depend upon the production of knowledge about persons with ID and migrants with disabilities that are drawn from evaluative procedures and standardized measures bolstered by various claims to expertise. The SIS and the immigration medical exam are cornerstones of these processes and are thus implicated in the "calculated administration of diverse aspects of conduct" (p175). The displacing technologies linked to these practices can be broadly viewed as manifestations of governmentality that are caught up in a biopolitical project that is concerned with "power over life" (Rose, 2007, p53; Foucault, 1990, p133). Foucault's

model of biopower, which accounts for the management of individual bodies as well as national bodies (Rose, 2007, p53), is instrumental in understanding how the provision of provincial developmental services is connected to an immigration regime that tests eligibility for national membership. At stake in both contexts are access to formal status and the ability to make substantive claims upon the state – claims which effectively shape one's (non)presence in society.

Opportunities to access and enact rights are not evenly distributed, and it is increasingly recognized that disabled people, including recent migrants and refugees, face significant barriers to formal citizenship and to substantively claiming the rights associated with this status. This is partly a result of deep poverty, unemployment, discriminatory treatment, and inequities, both market-generated and status-affiliated. The depth of these barriers is such that members of these communities face heightened and institutionally-facilitated forms of deep segregation, the threat of disenfranchisement and forced confinement or removal – for instance, in institutions for disabled people and migrant detention centres, as well as through deportation. These dimensions of non-citizenship shape individual interactions within Canadian society across multiple domains, rendering their presence precarious and their access to rights most uncertain.

In her compelling account of 'the end of the social contract' for persons with disabilities living in the United States, Russell (1998) describes the dynamic processes that have worked to keep disabled people on the margins of society despite civil rights legislation, such as the Americans with Disabilities Act. Without discounting the importance of civil rights (p127), she promotes more fundamental changes by showing how existing rights regimes simply do not benefit the majority or "change the reality of those on the bottom" (p132). One of the key problems she identities relates to how economic development is conceptualized (p143) and the

emphasis that is placed on disabled people as a source of "profitability" (p126). Part of Russell's legacy has been to encourage us to consider those who those 'on the bottom' are, and to ask how we can change their reality by challenging neoliberal economic formations and their development-related goals. Relatedly, we will explore the exclusion of people with ID and migrants with disabilities through the theme of economic development in greater detail over the course of this dissertation.

Persons with ID, who are rarely viewed as 'profitable', are disproportionately represented among the homeless population (Furie, 2012). There are also heightened concerns around housing, securing human supports that would allow for a dignified life, and obtaining recognition of the inherent capacity of people with ID to make decisions and to direct their own lives. Debates around (in)capacity have been taking place across Canada and within Ontario. In 2017, the Law Commission of Ontario concluded its study on capacity law and reviewed the option of instituting a decision-making framework for persons with ID (LCO, 2017), which is promoted by the UNCRPD as an alternative to substitute forms of decision-making. A substitute decision-making model, however, remains dominant in the Province and effectively removes persons with ID's decision-making power if 'incapacity' is suspected – an issue that is taken up in this study. Meanwhile, Ontario advocacy groups continue to demand direct and individualized forms of funding for persons with ID to meet their housing and support needs. These approaches to funding have long been discussed by researchers (see Lord and Hutchison, 2003; Stainton et al., 2009; Stainton and Boyce, 2004; Stainton, Asgarova and Feduck, 2013), and organizations both within (Individualized Funding Coalition for Ontario) and outside of Ontario (North Shore Disability Resource Centre, 2005; Qin, 2017).

The understanding of direct funding that tends to guide advocacy work is nicely articulated by Stainton and Boyce (2004) as "a direct cash payment in lieu of services" (p443). Examples of direct funding that are promoted by ID advocates include the 1200 Microboards™ currently active in British Columbia, which are made up of individuals with ID and their support networks, and which act as non-profit corporations that receive funding directly from government (Pooran, 17 October 2018, personal communication [cited with permission]). Confusingly, within MCSS there is no agreed-upon definition of what a direct funding approach actually entails, and thus programs such as Passport may be classified as a direct form of funding by both the Province and researchers (see for example, Qin, 2017), while being rejected by advocacy groups for failing to reflect their understanding of a direct funding model. This dissertation seeks, in part, to add clarity around direct funding debates, promoting a definition that matches what many groups representing persons with ID are actually calling for, while contesting official claims that the Passport program constitutes direct funding. But defining direct funding should not be so complicated if we focus on the literal meaning of the term 'direct', which suggests the basic principle that funds flow *directly* to service users and/or their support network, rather than to an agency. Conversely, as a reimbursement program, Passport funding channels money through non-profit organizations. But since these organizations are not controlled by individuals or their support network, the Passport program fails to meet one of the most straightforward standards of direct funding; and because the program uses categorical-based assessments and funding formulas, as we will see in Chapters Three and Four, it does not represent an individualized approach to funding.

Adding to the challenges faced by persons with ID is that fact that the Passport application process, which is centred on the SIS and participates in the general eligibility

assessment process that determines access to all MCSS-funded services, is so problematic that it can generate harmful and displacing effects, while failing to address the community's key concerns around individualized services and funding. A class-action lawsuit launched in 2018 by Ontario families – and certified while this dissertation was in progress – takes aim at the "indeterminate wait-lists, flawed computer programs and bad databases, and poor prioritization of matching available resources" confronting individuals transitioning from child to adult developmental services (Pooran Law, 21 December 2018). An earlier statement by an Ontario-based advocacy group, Families Matter Co-op, describes some of these failures:

> Once you reach the age of 18, you are triaged through a rigorous assessment process managed through a government agency. This assessment dictates what services and support will be the most useful. It does not promise their availability. In a nutshell, this is the gauntlet that parents and their offspring have to navigate. The wait for an assessment is somewhere between 6 months and 3 years, once the individual is 18. Once the assessment is written up, the wait for services can be anywhere from 1 year to 10 years and more. Just as an example, there are approximately 900 people in the queue for residential support in the Ottawa area (FMC, About Us).

The long wait times and "rigorous assessment process" described in the above quote is not dissimilar from what migrants with disabilities experience under the excessive demand regime governed by Section 38(1)(c) of the IRPA. News stories emerging over the past several years detail how migrant workers who are mothers have been separated from their disabled children and denied opportunities for reunification because their children are deemed medically inadmissible (for a summary, see Spagnuolo, Graham, Hussan, 2018). These mothers spoke out against Canadian immigration's refusal to grant status to disabled people on the basis of their imagined disability-related needs. Their stories of forced separation are part of the ongoing impact of including certain medical assessments in decision-making around immigration status. A review of case law that I previously conducted (Spagnuolo, 2016b) details how some of the hotly contested claims about applicants made by immigration medical officers have been

challenged through judicial review. Many of these cases turned on the need for more individualized assessments of a disabled person's needs – a requirement that was set out in a Supreme Court case in 2005 (Hilewitz v. Canada, at para. 53). As this earlier review of appeal cases and more recent findings from this dissertation suggest, individualized assessments are still not taking place and instead, there is a risk that categorical and discriminatory thinking is being applied against disabled applicants.

A new report from the International Human Rights Program that focuses on automated decision-making in Canada's immigration and refugee system touches on some of the problems inherent in categorical thinking. The report, which draws attention to "bias and discrimination" in automated decision-making (Molnar and Gill, 2018, p33), is largely concerned with the use of computer algorithms. Similar biases and errors also exist in human forms of decision-making based on medicalized, categorical views of migrants with disabilities, making the report's findings highly relevant to the current situation of disabled migrants. Automated decisions participate in stereotyping and the results can be inaccurate portrayals of realties, according to the report. These misleading or invented realities are very similar to the results generated through current excessive demand evaluations and they certainly share in similar trends. Importantly, the move towards automation has been underway since 2014 and is bound up with predictive technologies. The report, explains, "Since 2014, IRCC has been in the process of developing a 'predictive analytics' system to automate activities currently conducted by immigration officials and to support the evaluation of immigrant and visitor applications" (p14). Throughout this dissertation, we will see how human forms of decision-making and biopower harness similar predictive techniques and shape "displaced realities" (Spagnuolo and El-Lahib, in press) for many disabled migrants. Perhaps not surprisingly, similar predictive techniques are used by

Canada Revenue Agency to investigate non-compliance and within Employment and Social Development Canada's investigations of over-payment (Molnar and Gill, 2018, pp14-15). The use of monitoring technologies applied by the Canadian government for the explicit purpose of catching infractions within assessment and medical eligibility testing, suggests that disabled people are part of the perceived threat posed by illegitimate or mistaken financial exchanges – a link that drives home the political economic dimensions of biopower and related efforts to regulate the reality of disability.

Behind precarious access to rights and substantive citizenship among persons with ID and migrants with disabilities are shared efforts to regulate resource allocation through evaluative methods that employ predictive thinking around disability. Standardized testing, points-based systems, and grading scales that measure disability support needs are the reality that connects diverse experiences of non-citizenship across developmental services and immigration sectors. The chapters that follow look both individually and structurally at the evaluative tools and documentary methods involved in shaping belonging through MCSS and IRCC practices, framing these tools as eugenic instruments of displacement. This study presents a critical policy analysis that employs a multi-layered framework drawing on interviews, official documents, information obtained through access to information requests, and historical research to reveal how processes linked to evaluative tools can displace disabled people and render them non-citizens. Both transnational migration and the deportation orders that result from Section 38(1)(c) of the IRPA are readily understood as having displacing effects, but it is much less common to claim that persons with ID with formal permanent status can experience displacement and non-citizenship. Yet this is exactly what is suggested by the qualitative data collected for this study.

Theoretical Grounding: Situating Disability Displacement and Putting an Emerging Framework into Action

The analytical foundation developed throughout this study draws upon an existing collection of research, demonstrating Bakewell (2011), myself and El-Lahib (in press), and other critics' contentions that displacement can occur even when transnational migration has not, and that it can be experienced by groups who are not formally considered displaced people, including internally colonized and inter-generational people who have not migrated (Castles, De Haas, and Miller, 2014; Bakewell, 2011; Barcus and Halfacree, 2017). By extending these interpretations of displacement, this dissertation provides an entry point into conceptualizing the experiences of disabled people who have not crossed national or other geographic borders and who do not fit within UN Human Rights Council categories of displaced people, such as internally displaced people.[5] I forward this reconceptualization through the notion of "displaced realities" and building on claims presented by myself and El-Lahib (press). In doing so, I advance an approach that brings together policies and practices experienced by persons with ID and migrants with disabilities, taking up a recent call issued by myself and El-Lahib (in press) to think of translocal disability realities through a transnational disability framework centred on displacement and displaced realities. My recent chapter with El-Lahib draws particular attention to possibilities to "help bridge the gap between local and transnational advocacy efforts" by outlining the "conceptual common ground" (n.p.) between non-migrants with ID and migrants, thus encouraging further study of these marginalized communities that avoids a siloed approach. Such a framework expands displacement theory, which has hitherto been applied to conceptualize and debate the nature of forced migration but which has not explicitly incorporated a translocal or

[5] UNHRC categories of "forcibly displaced" people include refugees, asylum-seekers, and internally displaced persons (UNHRC, 2017).

expansive transnational disability perspective that can "account for disabled people who have not crossed geographic borders" (n.p).

Transnationalism, simply put, refers to "various kinds of global or cross-border connections" (Vertovec, 2001, p573). These connections also shift research perspectives away from the nation state and "critically test prior assumptions that the nation-state functions as a kind of container of social, economic and political processes" (p575). Transnational orientations are also evident in research focusing on global processes such as colonialism and that include factors impacting movement across national boundaries. When I refer to translocal realities, I am invoking a much newer term and one that often appears within transnational studies as a way of showing how migrant experiences in specific places shape transnational networks. This form of translocality has been described as a "grounded transnationalism" in the sense that it connects local places to wider transnational networks (Brickell and Datta, 2011). Brickell and Datta expand this notion of the translocal to include non-transnational movement and experiences that occur on different scales, including urban to rural movement and, in their words, the experiences of "supposedly 'immobile' groups", who nevertheless, "negotiate different kinds of local-local journeys" (p4). This translocal notion of migration is used in the present study to characterize the forced and coerced movement, or the lack of movement, that results from the radical isolation of persons with ID (Spagnuolo and El-Lahib, in press) and to link these experiences to the transnational movement of migrants with disabilities. At the same time, rather than presenting translocalism and transnationalism as distinct experiences that correspond to different groups, my analysis recognizes the strong degree of overlap between these processes. For example, the translocal experiences of migrants with disabilities are closely connected to their transnational identities and to transnational processes, all of which can shape displacement experiences even

after permanent status is obtained. Similarly, the status of people with ID is impacted by the intersectional possibilities of this impairment category, which is shaped through transnational and colonial processes. This dissertation thus draws upon multiple understandings of translocality and provides a way of conceptualizing translocal (im)mobility in relation to transnational experiences as a form of displacement.

As Bakewell (2011) acknowledges, citing and earlier critique by Hathaway (2007), there are concerns that expanding the definition of displacement risks eroding the protections afforded to groups who make use of existing designations (see also Spagnuolo and El-Lahib, in press, for a discussion of these authors). However, this dissertation consciously expands existing notions of displacement with the hope that such a move will illuminate the experiences of marginalized groups who fall outside of certain protective categories and who have been hitherto neglected. Furthermore, as Koser and Martin (2011) suggest, there are problems with current distinctions between categories of forced migrants which, while helping draw to attention to certain groups, can also fail to capture an important reality of the displacement experience and can negatively impact the nature of services that are intended to provide support (p3). To this end, this dissertation contributes to the emergence of a new and unique framework by building upon existing theories of non-citizenship to better account for disability displacement, forwarding a multi-layered analysis of official documents and first-hand experiences that is attentive to translocality as well as transnationality, and to their many intersections. Such a methodology leads to new questions about citizenship rights and regimes that can help clarify the nature of the culture change that is needed for more inclusive policy formations; this carries potential benefits for diverse marginalized groups who experience precarious membership and whose realities are simultaneously displaced.

To conceptualize how individual realities interact with institutionalized biopolitical practices related to the SIS and immigration medical exam, this study develops a broad view of displacement that builds upon critical migration and critical disability studies to account for translocal as well as transnational realities. As previously suggested, the relationship between displacement and non-citizenship is a circular one, and it is impossible to identify clear boundaries between the two concepts or determine a causal relationship in any context where they may be experienced. For example, data gathered for this study suggests that social services systems displace persons with ID by facilitating their coerced or forced movement to places that are not of their own choosing, while simultaneously denying them the supports they require to access the places and communities they prefer. These examples of displacement both permit and are supported by the non-citizenship status of persons with ID, characterized by the overall limitations they face when attempting to exercise substantive citizenship and equal recognition before the law in the form of the right to decision-making and self-realization.

In the above example, social services constrict opportunities for agency and control. And just as persons with ID experience displacement and non-citizenship as inter-related (and non-linear) processes that shape their relationships to space, the formal non-citizen status of migrants with disabilities who cross national borders and arrive without permanent residency can be linked to the initial dislocation they may have experienced (whether through coerced or forced migration). These risks exist in addition to the risk of deportation they face under Section 38(1)(c), which constitutes forced movement in the most traditional sense of the term. Related to the precarious status of these migrants, on a translocal scale their inability to access disability supports works to maintain their non-citizenship status in a substantive way. This can be the case even after permanent residency is obtained, as interviews for this dissertation reveal.

Beyond Spatial Boundaries: Expanding Displacement Theory Through Critical Disability Studies

In terms of evaluative measures, the immigration medical exam and the SIS support gate-keeping practices which are implemented by the federal and Ontario governments to regulate resource allocation, shaping a biocitizenship based on notions of belonging that can limit the presence of disability communities in Canada. Interviews conducted for this study suggest that the impact of the SIS and immigration medical exam are manifest both spatially in terms of how they affect disability presence and mobility, and subjectively in terms of how they are intimately experienced. This layered approach to displacement closely resembles Bakewell's formulation of displacement and notions of internally displaced people (2011). While displacement is often linked to forced forms of transnational and intra-national movement caused by genocide, war, and environmental injustice, for example, Bakewell expands the concept to encompass the subjective state and "self-perception of being out of place" (p23) and relates this to a lack of agency in movement, the involvement of institutions in this movement, and the nature of the change that the individual experiences.

Persons with ID and migrants with disabilities involved in translocal and transnational processes of coerced or restricted movement can thus be included under these expanded terms. As mentioned, my recent work with El-Lahib (in press) argues for the need to broaden displacement studies to include persons with ID with formal permanent status who experience isolation and spatial segregation through institutional arrangements. Our study provides the impetus for developing a framework that explores lived experiences of migration and ID together. As I argue with El-Lahib, migration studies have not sufficiently expanded to account for experiences of displacement among groups who formally hold permanent status, and

particularly persons with ID with Canadian citizenship or permanent residency. As we point out, persons with ID can experience coerced movement in translocal contexts, such as confinement in institutional settings, including group homes. Furthermore, our work suggests that persons with ID who survive institutionalization can share similar settlement needs as migrants largely as a result of trauma, dislocation, and other processes associated with institutionalization. We also suggest that existing and community-based services can be displacing as a result of a continuation of institutional features that limit opportunities for choice and belonging.

Building upon the institutional histories and the supported housing arrangements for persons with ID that myself and El-Lahib evoke in our initial work on the topic, displacement can be theorized as a process that includes methods of segregation that inhibit or prevent mobility and undermine individual choice and agency. In this sense, displacement encompasses translocal processes that limit an individual's ability to be 'present', in the socio-political sense, with substantive citizenship; that shape perceptions of them as 'outsiders'; and that use these perceptions to justify decisions that can undermine their agency. As I argue with El-Lahib, these forms of displacement impact persons with ID who are not 'settled' in Canadian society, who experience profound isolation as a result of the neglect of their disability-related needs, and whose decision-making power is not recognized either formally or in practice. Their precarious presence as non-citizens constitutes a form of displacement because, to return to Bakewell (2011), they are at once subjectively "out of place" and, partly as a result of their lack of choice, are caught up in coerced relationships to the spaces they occupy. Despite an absence of research that conceptualizes the segregation of persons with ID as a form of spatial displacement, theorizations of ID as a radical form of outsider status, as 'non-human', and as a threat to national identity help expand the subjective nature of these displacement experiences. I make a

similar claim in my work with El-Lahib, pointing to "the sense of not being human" experienced among people with ID. The identification of these discourses provides further justification for pushing displacement studies in a direction that considers relationships among people with ID to citizenship cultures, space, place, and mobility.

To address these possibilities, this dissertation employs a displacement framework that centres ID and accounts for (trans)institutionalization, while attempting to move beyond overt forms of spatial segregation. While (trans)institutionalization remains an underlying issue affecting persons with ID, interviews conducted for this study reinforce the need to re-conceptualize displacement, pushing the boundaries of the term by revealing how the displacement of persons with ID occurs even when (trans)institutionalization has not. As will be discussed later on, participant narratives and insights speak to the importance of framing displacement in translocal terms and point towards key concepts that aid in the development of a new understanding of non-citizenship that incorporates this dimension of displacement theory. My development of a framework for understanding disability displacement picks up my work with El-Lahib (in press) and marks a unique attempt to explore displacement through the lived experiences of disabled people who have not left their country of origin. The analysis chapters that follow also expand on existing theories of displacement through a critical disability analysis that centres experiences of both migrant and non-migrant disability communities, reinforcing the importance of looking at shared experiences across different categories of identification. Including experiences of ID alongside those of migrants with disabilities marks an attempt to build connections across longstanding boundaries in research and policy, enabling us to overcome siloed approaches that have traditionally defined studies of disabled and migrant communities. The few exceptions include recent and very promising advocacy work and related

to this, doctoral research that seeks to "unify women labeled with "mental" disabilities, indigenous and migrant women to challenge structural violence" (IRIS, Doris Rajan).

My earlier research exposing the deportation of naturalized citizens with ID confined in the Toronto asylum (Spagnuolo 2016c; 2018) further strengthens the importance of locating common ground by revealing historic intersections between local forms of eugenic incarceration directed at persons with ID and immigration systems during the 1920s. This research points to the asylum's role in diagnosing patients as mentally defective – a label that resembles and is genealogically linked to ID – and then deporting them on these grounds despite their naturalized status. In these cases, medical inadmissibility policy and the asylum's role as a designated immigration station allowed for the movement between permanent and non-status among foreign-born patients with ID through biomedical assessments, thus "link[ing] the asylum as [a] site of power and discipline to bio-citizenship as it was practised outside its walls" (Abstract, Spagnuolo 2016c). The deportation of persons with ID with naturalized status amounts to the spatial displacement of a citizen group over transnational borders and offers a historical basis for future research into these practices.

Histories of persons with ID being expelled from local asylums also fit within a smaller body of research that looks at how custodial institutions for disabled people facilitated their deportation from Canada (Joseph, 2015; Spagnuolo 2016c; 2018; Reaume, 2014; Menzies, 2002; Dowbiggin, 1995; Stephen, 1995). The studies I cite here can be viewed as path-breaking, as it remains the case that contemporary Canadian iterations of medical inadmissibility and the undesirability of migrants with disabilities are not widely recognized within migration studies, nor within the critical disability literature. There is nevertheless a small community of scholars who take up this topic and their findings, in addition to providing an important foundation for the

present study, suggest the need for a closer look at the immigration medical exam and its related assessment tools. Extant work on Canadian migration and disability, reviewed up until 2017, includes studies that look specifically at migrants with ID (Spagnuolo 2016c; Spagnuolo 2016b) and refugees (Mirza, 2014), while a much broader branch takes up the issue of medical inadmissibility as it affects migrants with disabilities, tracing iterations of excessive demand in policy and practice (for example Chadha, 2008; Hanes, 2009; Wong, 2009; Capurri, 2010; El-Lahib and Wehbi, 2012; El-Lahib, 2015; 2016a; 2016b).

Other work considering the construction of disabled migrants as 'undesirable' looks at the situation in Australia (Soldatic and Fiske, 2009;) and the United States (Baynton, 2001; 2016; Richards, 2004; Dolmage, 2011). Contributions to broader issues of disability and migration (Grech and Pisani, 2015), and transnational disability theory more generally (Soldatic, 2013; Grech and Soldatic, 2014), sharpen our understanding of migration and disability in settler colonial contexts, especially as this relates to the differing treatment of racialized migrants. As summarized by Spagnuolo, El-Lahib and Kusari (2019), a body of migration research that considers disability from an anti-colonial perspective is also traceable (pp4-6). Research by Soldatic and Fiske (2009), Joseph (2015), and Dolmage (2011) is notable here for the emphasis placed on the co-constituted nature of race and disability. Most relevant to the present study is an article by El-Lahib (2016b), taken up in later chapters, which forwards an anti-colonial critique that employs first-person interviews to study how certain migrants with disabilities relate to official discourses around immigration and disability. A closer look at the immigration medical exam through an ID lens that centres hierarchies of (in)capacity builds upon these existing contributions by honing in on the medical testing requirement of the immigration application process, its role in producing non-citizenship, and its relationship to disability displacement on

translocal and transnational scales. As I demonstrate in my work with El-Lahib (in press), we can productively begin to think about space and (dis)location through translocal and transnational disability experiences; such a move invites new ways of theorizing displacement, understanding issues of marginalization beyond spatial parameters, and engaging in research that is oriented towards lasting change.

A Multi-Layered Methodology: First-Person Interviews and Official Documents

The next seven chapters trace the inter-related processes that are involved in assessing persons with ID for funding and eligibility through Ontario's Passport program, and migrants with disabilities for medical inadmissibility through practices set out in the IRPA's excessive demand criteria under Section 38(1)(c). To capture the complexities of non-citizenship and front-line interactions between persons with disabilities and assessors, this study employs a multi-pronged approach that considers institutional histories and official documents, including law and regulation and information intended for public dissemination, alongside findings from eighteen separate semi-structured interviews that were conducted with twenty-two participants. Participants identified as persons with ID, migrants with disabilities, their immediate relatives, or individuals who work with these communities. The interview process is described in more detail below.

As the above discussion suggests, secondary research around ID and disability and migration provides an invaluable foundation for analyzing primary source materials and participant narratives. Given that ID and migration are such broad and interdisciplinary research areas that intersect with many disciplines and subfields, more focused literature reviews were only conducted around the SIS and Canada's excessive demand regime. The results revealed important gaps in each area. With these findings in mind, this dissertation closely engages with

scholarship directly related to specific thematic areas such as Canadian histories of institutionalization, histories of ID, and research related to ableism and racism in immigration policy and practice. Overall, the body of scholarly literature cited throughout this study is primarily derived from reviews and scans of the academic literature that were conducted up to and excluding 2017, while only some of the research that emerged as writing for this dissertation was underway has been included.

The analysis presented in this study focuses on both frontline interactions and official documents and in this sense, gives rise to nuanced details related to the interpretation and application of law and policy; it looks at key assessment tools as well as beyond these tools, asking how they are negotiated and experienced by various stakeholders. As Goldring and Landolt suggest (2013), experiences of (non)citizenship are characterized by conditionality and are not simply the result of official law; instead, they involve work by a multitude of actors in negotiating the boundaries and epistemological constructions that shape belonging (see especially p20). Findings from this dissertation thus point to the complex work carried out by multiple actors and agencies and by persons with ID and migrants with disabilities in negotiating the boundaries of belonging, highlighting the role of medical decision-making and situating assessment tools within a political economy of medical, moral, and disability knowledge production. These insights are arrived at through the application of a disability displacement framework that employs the critical concept of non-citizenship and that is centred on the ID-related concepts of (in)capacity and (under)development.

Survey of the literature

This study shows how individuals and individual circumstances interact with structural factors and methods of exclusion that are institutionalized and articulated in the day-to-day

operations of government agencies and other relevant professionals whose work informs the network of actors involved in assessment practices. As previously mentioned, the specific technologies of displacement under consideration consist of two medicalized evaluative practices and their associated tools and guidelines: the Supports Intensity Scale (SIS) and the immigration medical exam. The SIS, which is a popular testing tool for persons with ID used across Canada, the United States, and globally (Weiss, et al., 2009), has been largely overlooked by non-clinical researchers. There is however an abundance of clinically-oriented studies integrating quantitative analysis and largely concerned with the nature of the tool (e.g. Claes et al., 2009; Brown et al., 2009), its accuracy in testing (e.g. Wehmeyer, et al. 2009; Weiss et al., 2009; Schogren et al., 2017) and its applicability towards other disability groups (e.g. Bossaert et al., 2009; Arnkelsson and Sigurdsson, 2014; Smit, Sabbe, and Prinzie, 2011). Other clinically-oriented studies explore possibilities for adopting the SIS in different regions (e.g. Chou et al., 2013; Giné et al. 2014; Verdugo et al. 2016), and in applying the tool to assess the impact of services such as vocational training (e.g. Gomes-Machado et al. 2016). At the same time, some researchers have detected shortcomings with the SIS. These observed limitations have led some clinicians to recommend applying the SIS in tandem with other forms of assessment (Simoes et al., 2016), while others, such as Guscia et al. (2006) and Brown et al. (2009), who share concerns around "the ease of administration of the SIS", have found strong parallels between adaptive functioning and SIS testing. Indeed, some suggest that use of adaptive functioning testing may even be more practical and yield similar results (Brown et al., p954). Given its global reach as well the fact that endorsements of the SIS also appear in recent policy-focused writing aimed at promoting more individualized and direct forms of funding in other Canadian regions (Qin, 2017), it is high time for critical engagement with this biopolitical tool from a non-clinical perspective.

Critical scholarship around the SIS is easily outweighed by literature related to excessive demand testing. But despite its long-standing place in Canadian history, this form of immigration screening has only been considered by a small group of scholars from a Canadian perspective (notably Chadha, 2008; Hanes, 2009; Capurri 2010; El-Lahib and Wehbi, 2012; El-Lahib, 2015; 2016a; 2016b; Wong, 2012; Joseph, 2015; Spagnuolo 2016c; 2016b; 2018; Reaume, 2014; Menzies, 2002; Dowbiggin, 1995; McLaren, 1990). Even fewer studies look at the personal experiences of migrants with disabilities and their families who are living in Canada (e.g., Dossa, 2009). Within this body of scholarship, which has yielded many productive and invaluable insights, the immigration medical exam is recognized as a pivotal aspect of the excessive demand regime. Surprisingly, however, little to no attention has been paid to how immigration medical screening is actually implemented, marking this as an important site for analysis. The chapters that follow fill critical gaps in research by providing a close and comparative analysis of the overlooked yet influential evaluative tools that target people with ID and migrants with disabilities, looking at the ways the SIS and immigration medical exam are experienced and asking how individuals and families are affected by these rights-mediating and medically-informed testing methods.

As mentioned earlier, to appreciate the inter-related layers that shape non-citizenship and displacement we must consider the range of actors involved in ground-level interactions and decision-making as well as the legislative backdrops against which they operate. Front-line assessors play a unique role in the diverse network of actors who interact to produce non-citizenship. The SIS and assessments related to the immigration medical exam are often procedural in the sense that they are carried out by these front-line bureaucrats, whose actions are largely informed by guidelines and manuals. However, through their exercise of "administrative

discretion" (Pottie and Sossin, 2005, p150), assessors mediate access to rights and social participation and can shape non-citizenship status. As the authors demonstrate, "soft law", an area that involves day-to-day decision-making, is often overlooked by the justice system, despite the powerful legal effects it carries.

Participant Interviews

The interview portion of this study, discussed mostly in Chapter Seven but woven throughout all chapters, relies on eighteen in-depth discussions held with twenty-two participants in person and over the phone. Participants are adults who reside or who recently resided in Ontario and identify either as a) persons with ID, b) migrants with disabilities, c) relatives to persons with ID or migrants with disabilities, or d) someone who works with persons with ID or migrants with disabilities and their families. In addition to informants with lived experience with ID and migration, key informants include both a current and former employee of a DSO agency and other individuals who work in the developmental services or migration sector. Importantly, migrants with disabilities can also be persons with ID as these categories are not mutually exclusive, and this overlap is reflected in the design of the present study. Similarly, the participant group includes individuals who identify along intersectional lines: as LGBTQ+2S, racialized, women, members of religious and linguistic groups who face discrimination, and as both newcomer and disabled person. Persons with ID who are migrants and immediate relatives of persons with ID form a special subset of this participant group.

As a result of my involvement with disability organizations and communities and the small and deeply marginalized nature of these communities, it is important to point out that prior connections exist between myself and some participants. Specifically, I maintain a friendship with one participant and active collegial relationships with four other participants. The majority

of participants are individuals with whom I have had no to minimal prior contact (fourteen participants), or prior collegial relationships that have since ended (three participants). To date I have not encountered any competing interests or forms influence, and I remain watchful and reflexive in case these should arise. Further details related to the recruitment process employed in this study are shared in Chapter Seven, along with a focused analysis of interview findings.

Participants were invited to attend interviews alone, or with someone they trusted who could lend support. Most of the interviews were held as one-on-one conversations, while three were held in groups that included members of the same immediate family. Out of these three group interviews, two included participants with ID whose relatives attended to both participate in and facilitate the interview process. The third group interview was held with the immediate relatives to a person with a disability. Most interviews lasted approximately one hour and ranged from approximately one to two hours, and I recorded and transcribed all interviews myself. I removed identifying information such as names of people and places, and often did so with input obtained through discussion with the participants around anonymity and strategies for preserving their identity.

A constructivist grounded theory approach informed the interview process, meaning that conversations were guided by the explicit recognition that knowledge can be co-constructed by researchers and participants (Charmaz, 2014). Rather than positioning the researcher/interviewer in a knowledge-extraction role whereby they simply gather pre-existing and fixed information from participants, a constructivist grounded theory approach to interviewing requires careful attention to the interactions between participants and researchers and to the mutual influence they carry in shaping the research process. Knowledge, in this view, is collaboratively-produced rather than 'fixed'; it is both fluid and relational (Charmaz, 2014). Respecting the role of

participants in the knowledge-production process also encourages researchers to remain responsive to these interactions and to allow their research plans to be shaped by these conversations. For these reasons, interviews conducted for this study only loosely followed interview guides, while the guides themselves were continuously re-evaluated based on issues and insights identified by participants. Put another way, the collection and analysis of interview data took place simultaneously and in turn shaped the research and analysis of other sources of primary data, such as policy directives (p15).

Summary of Chapters

The simultaneous collection and analysis of qualitative data supported the emergence of an interpretive framework for reading participant narratives. This framework is introduced in Chapter Two and will anchor the analysis chapters (Chapters Three, Four, Five, Six, and Seven) that follow. Chapter Two is dedicated to an in-depth exploration of the possibilities for reading ID and migrant experiences alongside each other and through a displacement framework that centres (in)capacity and (under)development. Further justification for this comparative reading is presented through the concept of the conditionality of non-citizenship (Goldring and Landolt, 2013) and a discussion of the precarious presence of people with ID with formal permanent status and migrants with disabilities; this chapter then is concerned with the applicability of displacement theory to these contexts.

Part II of this dissertation is focused on the actual mechanisms by which people with ID can be become displaced. Chapters Three and Four consider how legislative changes to developmental services in Ontario, which include the introduction of the DSO and the SIS as an assessment tool, reinforce hierarchies of (in)capacity that can potentially exclude people with ID as non-citizens. Both chapters draw upon official documents and first-person interviews with key

informants who work in the developmental services sector and situate these in historical and ideological context in order to interpret the current system's view of itself. Chapter Four presents a more focused discussion of the SIS and the Passport funding program that is supported by insights gained through historical research into other ordering devices that are experienced by ID communities and which centre linear views of (in)capacity.

Part III shifts the conversation around displacement towards the excessive demand provision in Canada's immigration act and broader transnational and (neo)colonial processes that shape displacement and non-citizenship. Chapter Five forwards an intersectional understanding of (in)capacity that is attentive to colonial practices and various strategies aimed at 'containing race'. This chapters expands our understanding of (in)capacity by drawing upon the inter-related concept of (under)development to show that the hierarchies and ordering principles presented during Chapters Three and Four's discussion of developmental services also shape dynamics between Global North and Global South. Explicit recognition of these ordering devices is then used to assess the differential impact of excessive demand testing on racialized migrants and migrant with ID. Towards the end of Chapter Five, close attention is paid to recent reform efforts directed at the excessive demand regime and arguments are offered to help account for the persistence of medical inadmissibility practices. Chapter Six turns to the recent Parliamentary review of the excessive demand provision and argues that many of the discourses involved tend to reinforce dominant and hierarchical understandings of (in)capacity and (under)development. The second half of this chapter looks at the specific medical screening tools employed during the immigration medical exam to show how the concept of ID structures decision-making around inadmissibility for all migrant applicants.

The power of ID as a concept that can shape displacing experiences in both translocal and transnational contexts is pursued through an analysis of participant narratives in Chapter Seven. In this chapter, interviews conducted with non-migrant persons with ID and migrants with disabilities, their relatives, and those who work directly with them, are analyzed through a constructivist grounded theory approach that is attentive to subjectively and spatially displacing processes. This comparative analysis reveals that medical assessment tools can displace disabled people in a multitude of ways. It also demonstrates that inter-related dimensions of spatial and subjective displacement can be productively analyzed through the concept of (in)capacity that has been so central to ID identity-formation. Participant narratives provide specific examples of the displacing processes discussed throughout this study and add an important layer to the critique that is developed through a close-analysis of other primary source materials. These narratives also reinforce my work with El-Lahib (in press), which argues that spatial and subjective forms of displacement impact disabled people who have not crossed borders, and are manifest in translocal dimensions of displacement that shape the experiences of migrants after they arrive in Canada. Lastly, the concluding chapter presents a summary of key findings that highlights some of the possibilities for expanding the analytical framework developed over the course of this study.

Chapter Two - Situating Displacement, Non-Citizenship, and Evaluative Practices Within Policy Realities

Introduction

The importance of studying non-citizenship at the individual level cannot be overstated: testing regimes affect the movement of persons with ID and migrants with disabilities between citizenship and non-citizenship status in unexpected, informal, and often hidden ways that reflect individualized and unique circumstances.[6] Thus, the particular situations of persons with ID and migrants with disabilities give rise to differing needs and forms of oppression. Importantly, experiences of non-citizenship are also shaped by individual contexts that include intersectional factors such as class, race, gender, and sexuality. The analysis developed in this chapter and briefly introduced earlier builds upon historic links between ID, racialized, and migrant communities. It also follows earlier and intersectional histories of eugenics and considers how ID and other forms of difference such as race and nationality are co-constituted at the conceptual level through settler colonial discourses and processes of differentiation that mobilize and shape disability and other forms of difference. Previous research by Chen (2016) shows powerful connections between race and ID, demonstrating what they term "the germinal interarticulation of race and disability" (p236). The argument that people with ID experience displacement regardless of whether they formally hold permanent status is not, however, entirely evident. For this reason, the present chapter is dedicated to exploring why a displacement framework is appropriate for interpreting lived experiences within the ID community. Within this chapter, the rationale for a comparative reading of displacement among migrants with disabilities and non-migrants with ID is introduced in order to clarify the value and purpose of this research.

[6] Here it is worth noting that Goldring and Landolt's (2013) study of migration draws attention to how "the porous boundaries between categories and trajectories result in a complex, multi-entry and multi-directional set of legal status trajectories and negotiations" (p9)

Additionally, the analytical and methodological framework applied throughout this study is unpacked.

Purpose of Study

As previously explained, the framework forwarded in this dissertation is centred on the concept of (in)capacity and the ways in which it can be mobilized in translocal and transnational contexts. The urgency of probing MCSS and IRCC programs and their medicalized evaluative practices in greater depth is driven by the ways in which the official narratives surrounding them appear to clash with the reality of their policy effects. These differences are significant in that they continue to shape the precarious status of many persons with ID and migrants with disabilities. On the surface, recent program changes seem to respond to the criticism of civil society groups by tackling the long-standing exclusion of persons with ID and migrants with disabilities, and thus re-orienting policy towards a greater acceptance of disability. After all, the recent upgrades to Ontario developmental services and to Canadian immigration practices expand the costs that governing agencies allocate towards regulating the lives of disabled people. These changes ought not to be dismissed lightly, as they will certainly benefit some persons with disabilities by increasing eligibility and access. The additional $5000 in Passport funding, for instance, will bring relief to persons with ID in dire need of support, while the higher threshold set by the IRCC will likely lead to fewer migrants with disabilities being declared medically inadmissible. However, and as mentioned in the previous chapter, the changes do not alter more fundamental and problematic practices – and namely the evaluative methods that shape and often limit the presence of persons with ID and migrants with disabilities in Canada. The rationalization for these practices and their participation in resource management efforts premised on discriminatory views of disabled people also remains unaffected by the reforms.

As described earlier, this dissertation argues that persons with ID and migrants with disabilities are subject to assessment regimes that organize their needs according to normative understandings of human and economic development and capacity. These needs-based and eligibility testing methods are biopolitical tools that shape relationships to displacement and non-citizenship in ways that generate profound forms of exclusion within ID and migrants communities. Many of the problems caused by these particular examples of biopolitical regulation also bring to light more pervasive symptoms that can be witnessed across disability and immigration sectors. Non-citizenship, understood as precarious presence, status, and access to rights, is indeed experienced within these broader disability and migrant communities. This problem is evident in ongoing struggles for accessible and affordable housing and adequate social and disability assistance rates, the threat of deportation and institutionalization, and struggles to obtain permanent status to achieve family reunification. Such varied examples of precarious access, status, and presence are part and parcel of the much broader problem of exclusionary citizenship regimes addressed throughout this study. These regimes, however, reflect citizenship cultures that carry distinct repercussions for persons with ID and migrants with disabilities that merit closer study and that require us to incorporate a displacement lens within our discussion of non-citizenship.

Layered Experiences and a Comparative Focus

Rather than drawing up hard and fast rules to determine whether certain communities may be viewed as ‘displaced’, we can apply a displacement framework to ask critical questions about belonging and then consider the extent to which (the risk of) displacement is present. The characteristics that define relationships between persons with ID, migrants with disabilities, and Canadian citizenship can thus be extended to analyze experiences of exclusion among

communities and individuals who may not view themselves as displaced persons. At the same time, there are compelling reasons for focusing a discussion of displacement on people with ID and migrants with disabilities. In this chapter, we will see that it is the degree to which displacement and non-citizenship are experienced as inter-related processes by persons with ID and migrants with disabilities that raises unique and urgent concerns for these groups. The perpetual outsider status of persons with ID as 'non-human', and of migrants with disabilities as 'burdensome' and 'undeserving', are among the many characteristics that mark these identities as particularly susceptible to displacement and non-citizenship. In this way, and as we will see below, the reasons for signalling out persons with ID and migrants have to do with the definitive qualities of their displaced realities. These realities include, among other factors, the degree to which individuals may be segregated from society, the impact of efforts to shape their self-understanding, and the extent to which their relationship to space is coercively managed.

As suggested earlier, MCSS and IRCC practices bear close resemblance in terms of the processes they employ and the impacts they shape. They each presume and then seek to measure an individual's level of dependency, quantifying their disability-related needs, and weighing these against standards that define what is considered reasonable based on a medicalized model of normalcy. Assessment practices directed at persons with ID and migrants with disabilities do however vary in their stated intent. Testing for persons with ID can be read as an attempt to facilitate access to supports based upon the quantification of impairment-related needs, while immigration services blatantly strive to 'preserve' Canadian health and social services by preventing migrants whose needs are deemed to be 'excessive' from (formally) entering the national body and/or, where possible, excising them from the national body through deportation. Yet the differences between these systems, taken together, still reflect the Foucauldian

formulation of biopower with its tendency to target both individual and population efficiencies. More specifically, Rose's (2007) reference to "health" as a "transactional zone" between these two nodes (p59), helps tie together MCSS and IRCC biomedical evaluations. Also valuable are the ways in which the contradictory intentions that have historically surrounded social policy directed at persons with ID, stemming from paternalistic motivations to help and control, have been articulated in histories of asylums and institutions (see Radford, 1991, and Ferguson, 2004). These suggest the importance of subjecting 'helpful' intentions and their harmful eugenic effects to further critical analysis.

My close study of the lived experiences of persons with ID and migrants with disabilities based on interview data, presented in detail in Chapter Seven, considers how needs-based and eligibility testing shape displacement and non-citizenship and asks how these practices have become entrenched in law and policy. This research has much to tell us about the impact of non-citizenship and unstated cultural values that centre notions of development and underdevelopment ; it can also help account for a lack of policy progress for these marginalized communities in many areas. Related to this, the project of critically analyzing assessment policies and practices is deeply concerned with the cultural authority of biomedical knowledge and biopower. This approach is not, however, reflective of a blanket effort to do away with assessments, bureaucracy, or biomedical evaluations. Rather, by recognizing that such evaluations are not inherently harmful, the goal of this dissertation is to draw upon lived experiences to demonstrate the potential limitations and impacts around the implementation of specific evaluative tools and processes – namely the SIS and immigration medical exam – that have not yet been critically studied.

Findings from this work suggest that MCSS and IRCC evaluative practices are in need of heavy revising if they are to meet their stated goals of helping persons with ID, neutrally reviewing applications for national membership, and achieving the broader anti-discrimination goal of better reflecting – rather than displacing – disabled realities. As a result of deep tensions between disability identity and medical knowledge – tensions that have been forcefully articulated by disabled persons' movements and which can be found within academic and community research – evaluative practices that are directly aimed at disability communities must be subject to an analytical approach that accounts for eugenic legacies and the cultural authority of medicine. Such an approach ought to remain attentive to how medical authority can conflict with the ways in which persons with disabilities frame their experiences and support needs through social and relational contexts.

Access and Approaches to Justice and (Non)Citizenship for 'Out-Groups'

Evaluative practices in social services and immigration take many forms and can include approaches that overlap and are applied in tandem, such as eligibility testing, medical exams, needs-based assessments, and other biomedical assessments of daily functioning or adaptive ability. Yet these methods have shared roots in eugenic practices and a shared reliance on predictive claims that presuppose a static and unchanging life trajectory for disabled people. Importantly, they also share the tendency to define the need for disability-related services and supports as an extension of an individual's inherent 'defect', rather than an investment in human capital based upon an acceptance of disability as an aspect of diversity. Given these preconceptions, it is perhaps unsurprising that the predictive techniques underlying cost assessments and resource allocation draw close associations between persons with disabilities and the debt that their anticipated service-use and social presence is imagined to accrue,

emphasizing both the imagined deficiency associated with disability and the 'abnormal' nature of this supposed deficiency. When persons with disabilities are viewed as defective and their needs are framed as "exceptional costs", their lives can indeed be treated as burdensome (Titchkosky, 2011, p34). When this occurs, the services they use become stigmatized and presented as an extraneous cost to be managed, offered only when it is deemed fiscally reasonable. In contrast, critical research proposes that including disability as a form of diversity and viewing disability accommodations as a matter of justice, or "simply providing what is necessary to enable people with disabilities to function as equals", removes any justification for viewing them as something "that must be subjected to a cost-benefit analysis" (Malhotra, p91, 2008).

However, the move towards a justice-framing of disability may at times appear cosmetic or contradictory, as has been made apparent by the presence of the more common deficit-framing of disability alongside newer rights-oriented policy talk. Drawing upon quantitative research carried out by Duffy (2013), Dodd (2016) suggests that such rhetoric is of growing concern in times of austere measures and welfare reforms that disproportionately target the supports used by disability communities (p153). Neoliberal policy reforms that seek to shrink the pool of eligible recipients through service denial (McBride and Whiteside, 2011), also reflect long-standing trends in immigration policy and anti-immigrationist sentiment that raise alarmist concerns around the supposed rising costs of supporting disabled people. In recent years, far-right extremist, white nationalist, fascist, and illiberal movements, along with alt-right populism, encourage an intensification of fear of 'the other' in the interest of preserving an imagined, monolithic nation state (see Ramadam and Shantz, 2016). This is perhaps exemplified by the Trump presidency and his administration's protectionist economics, isolationist strategies, and anti-immigrationism. Islamophobic attacks, aggressive deportations, and migrant detention are

all symptoms of these illiberal ideologies. In many instances, these symptoms are manifestations of the targeting of racialized and migrant communities through laws, policies, discourses and practices centred on the 'securitization' of migration. In national contexts, attempts to 'secure' borders often involve white-dominant cultures signalling out migrants and racialized communities as threats. From waves of hate crimes by alt-right European organizations against Muslim communities, to the recent terrorist attack against a mosque in Quebec City, we have seen how this form of 'othering' is active across the Global North. Reflecting on illiberal nationalist politics, Gray (2018) draws attention to how, "the saliency of national identity (at times with an ethnic/racial undercurrent) has increased in recent years" (p141), creating a dangerous situation where "in-group/out-group dynamics" carry increasing importance (p144).

Noticeable within Canadian immigration systems is the demarcation of disabled people as an out-group that poses a threat to the country's resources. This form of alarmism dates back to Canada's earliest immigration practices (Chadha, 2008; Hanes, 2009), and is concerned with preserving services and programs that support social citizenship by denying access to supposedly underserving migrants and other designated 'outsiders'. Such thinking, which grows out of the Poor Law tradition that separates supposedly deserving and undeserving recipients of relief, can motivate states to deport imagined social burdens (Wright, 2013); very often, these 'burdens' also happen to be disabled people (See Menzies, 2002; Spagnuolo 2016c; 2018; Dowbiggin, 1995; Reaume, 2014; Baynton, 2001, Stephen, 1995). The reason this form of deficit-thinking has come to coexist alongside rights-based claims that purportedly seek to accept disability as a form of diversity can be explained by the continuation of a citizenship culture that represents unchallenged and even unstated standards that are dangerous to disabled people. According to Mitchell and Snyder (2016), these standards inform the neoliberal practice of making

nonconforming bodies "expendable" (p44); they can be traced across policy domains and are apparent in the evaluative practices applied towards persons with ID and migrants with disabilities.

The chapters that follow consider how evaluative practices and biopolitical tools that are grounded in deficit-oriented views of disability can radically exclude disabled people as a matter of routine administration and everyday bureaucracy, rendering their presence in Canada both precarious and impossible, and shaping particular forms of displacement. As stated earlier, efforts to control resource allocation are better understood through a displacement framework whether they involve assessing persons with ID for services, or determining if migrants with disabilities will place an 'excessive demand' on existing services based on their imagined future contributions and needs. Such a framework helps account for the production of non-citizenship on translocal and transnational scales. Front-line and medically informed decision-makers regularly participate in processes that shape these inter-related experiences of non-citizenship and displacement, informing fluid trajectories and relationships to belonging. Addressing the fluidity and conditionality of social location, Goldring and Landolt (2013) provide an insightful review of existing research that demonstrates that non-citizenship is not an absolute category, as citizenship and non-citizenship are neither fixed nor binary positions. Reviewing "non-binary approaches to non-citizenship" (p12) as well as research related to "the precarity of citizenship in North America" (p13), the authors develop "the concept of the conditionality of legal status" (p15). This formulation emphasizes that (non)citizenship status is not irreversible or permanent but is about the uncertainty or "conditionality" surrounding both an individual's presence in a given jurisdiction (p3), as well as the "uncertainty of access" (p4).

The conditionality of non-citizenship can be readily extended towards the situation of persons with disabilities with formal permanent status. After all, disability studies has already shown how access to rights and substantive citizenship among disabled people is precarious, reducing them to "absent citizens" (Prince, 2009), or "dis-citizens" (Devlin and Pothier, 2006), who are unable to experience meaningful participation. Devlin and Pothier briefly introduce the concept of dis-citizenship in their work to indicate unequal citizenship regimes which deny persons with disabilities meaningful participation along with both formal and substantive citizenship (p17). They dedicate the rest of their edited volume to exploring examples of these inequities and barriers to participation. While the authors do not elaborate upon the idea of dis-citizenship, the brief description they provide can be viewed as complementary to notions of non-citizenship and even as a form and condition of the precarity associated with the latter concept. As this dissertation demonstrates, practices that shape 'dis-citizens' interact closely with non-citizenship by displacing persons with disabilities on a translocal and transnational scale. Experiences of non-citizenship within these regimes appear more pronounced in communities of migrants with disabilities and persons with ID partly as a result of dominant perceptions of these groups as natural outsiders. A closer consideration of the 'otherness' of migrants with disabilities and people with ID will inform the next section of this chapter.

Scope of Study: Justifying a Comparative Approach

Intellectual Disability and the Problem of (In)Capacity

Existing research has shown that the ID label, while a "historical contingency" and highly "unstable", [7] is often associated with a radical outsider status (Goodey, 2016, p15). Yet when

[7] See for example Carlson's (2010b) discussion of feeblemindedness, where she notes "its instability and the permeability of its boundaries" (p316); see also Goodey (2016). For a discussion of the many challenges historians face in researching ID, see Spagnuolo, 2018.

compared to migrants, it is perhaps less obvious why persons with ID who hold permanent residency or Canadian citizenship ought to be considered at risk of non-citizenship and displacement. Further justification is required as to why we should view the ID community through such a lens, and why a comparative analysis between the evaluative tools applied towards people with ID and migrants with disabilities can lead to more equitable outcomes for both groups.

To begin, existing historical scholarship traces differing perspectives related to the status of persons with ID (see for example Radford, 1994; Trent, 1995; Stainton, 2001; 2008; McDonagh, 2008; O'Brien, 2013; Noll and Trent, 2004). Some of this research shows how the acceptance of persons with ID as members of the human species and as individuals capable of exercising choice has been threatened, undermined, and even denied both historically and globally (see Goodey, 2011; 2016; Carlson, 2010a; Metzler, 2016). These issues also exist within current community-based policies and programs practiced in Canadian contexts. Some of these practices segregate persons with ID from other disabled people on the basis of their perceived incapacity (see especially Kelly, 2016), and can work to deny them decision-making power and erase their potential to be recognized before the law. Contemporary examples of this form of dehumanization abound and many can be found in Canadian histories of institutionalization (Radford and Park, 1993; Reaume, 2009; Malacrida, 2015; Dyck, 2013; Abbas and Voronka, 2014; Rossiter and Clarkson, 2013; Burghardt, 2014; 2017; Spagnuolo, 2016c) and narratives of institutional survivorship (Scott; 2017; Hutton et al., 2017), including those forwarded by persons with ID who were forcibly confined in mega-institutions such as Huronia and Rideau Regional, in Ontario.

Survivors of these institutions, the last of which closed in Ontario in 2009, describe having been denied basic rights and even human status. An account by Peter Park, a person labelled with an ID who survived Huronia, draws together these threads quite poignantly: "Well, to start with, human rights were basically non-existent in the institution ... You can't even say I 'lived' in the institution. I simply existed. We weren't treated as human, in every single way" (Hutton et al., 2017, p39). Park is describing an overall lack of rights and total lack of privacy, stating that life in the institution was worse than living in a jail (p40) or a hospital (p41), largely because "you have no control" (p44). He explains that individuals were not allowed to leave and were confined indefinitely, with no information about their potential release. Escaping, for Park, was a constant thought (p41). In a related account, survivor Martin Levine shares details about "water torture" that was used "[i]f you didn't do what you were told at Pine Ridge [institution]" (p49). This form of torture included being tied to a stretcher and being put in a shower with freezing cold water, yelled at, and then publicly humiliated by being placed in solitary confinement without food or clothing where others could easily view you:

> They stripped me – took all my clothes off. They laid you down on a stretcher, tied your body down right across your chest so you couldn't move, and tight across your legs. Then they rolled you down the hall with you all tied down. They'd take you right into the shower. Then, while you're all tied down and not able to move or get away, you'd suddenly have freezing cold water coming down on you. You were freezing and couldn't move cold and naked, soaking wet, and restrained down on the bed. They would yell, "What do you think of this now! Do you want to apologize to us now!" After that, they'd put you in the side room in isolation. They leave you there just shivering. Everyone could look through the window at you all naked lying on the floor. You didn't even get fed when you were in the side room like that (p49).

The extent to which persons with ID are dehumanized is unfortunately not limited to institutional arrangements and harmful social services programs. Problematic and harmful forms of treatment can also be found in academic research and Western philosophical traditions. Take, for example, the work of Peter Singer. Singer argues that species privilege, or the automatic

valuing of human life, ought to be replaced with intelligence as the measure of value. Singer's formulation, according to Carlson (2010a), is intended to elevate certain 'intelligent' non-human animals above the status of humans with ID. Singer states: "That the imbecile is not rational is just the way things have worked out, and the same is true of the dog" (Carlson, 109, quoting Singer, 1974, pp124-125). The link being drawn here between persons with ID and animals is not a new one, and it has also been experienced by self-advocates with ID in recent times. Park (Hutton et al., 2017), for instance, recalls how the term "retarded" made one feel "knee-high to a grasshopper" (p45).

Carlson's (2010a) historical research shows that persons with ID who were considered to be 'profoundly' disabled were often animalized, "described as human only in form, empty shells of humanity" (p31). These themes of dehumanization based on capacity hierarchies are largely supported by O'Brien's (2013) extensive study into metaphoric framings of feeblemindedness and McDonagh's (2008) analysis of the cultural coding of ID. As Carlson's research demonstrates, Singer and his co-author McMahan (2017) pick up the idea of an 'empty shell' when they suggest that acts of rape committed against persons with ID are not in fact criminal since the victim unlikely understood the nature of the violence. McMahan and Singer's reasoning is not unique among contemporary thinkers. Providing another example, Goodey (2016) points to work by Firestein (2012), which positions persons with ID as existing below animals. Goodey and others consider how persons with ID came to play the role of species outsiders, arguing that the denigration of persons with ID is based on certain positivist, post-Enlightenment cultural valuations of rationalism (Radford, 1994; Kittay and Carlson, 2010a; Goodey, 2011; 2016). While this periodization has been contested (see Metzler, 2016), the emphasis on rationalism as an exclusionary concept is nevertheless useful. Closely related is the enduring notion of a "ladder

of nature" that positions "logical reasoning" as the paramount human quality (Goodey, 2011, p319). In this configuration, intellectual impairment and persons with ID are at the bottom of an imagined hierarchy and closest to non-human animals. These ideas are active today, according to Goodey, as we occupy "a liberal society that defines human ability in terms of autonomy, consent and rational choice" (p346).

It is certainly the case that hierarchical understandings of capacity reflect dangerous lines of thinking. Histories of eugenics have shown that perceptions of persons with ID as sub-human have resulted in their violent treatment and extreme forms of segregation that include incarceration in large institutions, forced sterilization, (Trent, 1995; Radford and Park, 1993; Burghardt, 2014; Rossiter and Clarkson, 2013; Ferguson, 1994; Malacrida, 2015; Dyck, 2013; Spagnuolo, 2016c), and community-based forms of spatial segregation (People First of Canada; Spagnuolo and Boulanger, 2018; Spagnuolo 2016a). While Ontario closed the mega-institutions that housed persons with ID in 2009, the threat of coerced placements in congregate settings, both large and small, remains very real and takes the form of transinstitutionalization in nursing homes, hospitals, group homes, and other institutional settings where individuals are denied choice and control over their lives (People First of Canada; Spagnuolo, 2016a; Spagnuolo and Boulanger, 2018).

The ongoing risk of spatial isolation is directly linked to the sub-human status ascribed to persons with ID, as survivor accounts such as Levine's and Park's reveal (Hutton, et al., 2017). Levine felt he was denied respect because he was viewed as being "retarded". He goes on to recall that a psychologist advised that he be "put away" because "[h]e doesn't belong in society" (p48). Similarly, Park explains that those inside the institution were not viewed as humans (p39). Within an institutional context, individuals can be radically cut off from the outside world, just

as Park describes: “listening to the outside world, knowing what was going on in the world, wasn’t an option” (p41). Given this risk of isolation, I argue with El-Lahib (in press) that institutionalization and other forms of spatial segregation are in fact acts of displacement that reflect the need for settlement services for the ID community and that are also connected to “a sense of not being human” (n.p.). Such services would help address some of the harmful effects of displacing processes and support persons with ID in feeling more ‘at home’ and establishing a greater sense of belonging.

As previously explained, persons with ID experience particular forms of displacement that are inseparable from the processes that produce non-citizenship. These include reduced access to rights and barriers to enacting substantive citizenship that are related to a range of practices, such as deep segregation in congregate care facilities and forced or coerced sterilization. Connecting all these injustices are capacity laws that formally remove decision-making power from persons with ID through substitute decision-making frameworks and that subject them to ‘best interest’ solutions that can include some of the harmful paternalistic practices already noted. This legal framework, which is still in place in Ontario and in most other provinces, has been critiqued by the CRPD Committee, which has urged Canada to amend these laws and respect Article 12 of the Convention (CRPD, 2016, pp.1-2). The effects of capacity removal are such that persons with ID may not be equally recognized before the law. And even while this dissertation does not emphasize capacity laws, they provide a crucial backdrop to understanding how technologies of displacement operate through medicalized assessments. In brief, existing capacity laws target persons with ID for scrutiny and call into question their status as legally capable subjects; as a result, individuals may be denied opportunities for self-direction and experience displacement and non-citizenship.

As we have seen, self-direction or "autonomy, consent, and rational choice" (Goodey, 2011, p356), are often treated as the hallmarks of the human species. Denial of these possibilities amounts to a formal denial of status that goes far beyond issues of substantive and even formal citizenship, entering into bioethical debates around human nature (Goodey, 2011, p346), as Singer's views on ID suggest. Substantive citizenship, albeit an elusive experience for many disabled people with permanent status (Devlin and Pothier, 2011), is hard to enact without formal status and nearly impossible for those not even considered species-members. This cultural context partly accounts for why the informal denial of capacity occurs – and indeed, why it is permitted to occur. These cultural ideologies and conceptions of (in)capacity also shape and are shaped by a neoliberal political economy centred on ableist notions of progress and independence. Research has shown that, while not officially sanctioned, lack of formal recognition continues to shape inter-personal interactions between persons with ID and others; this occurs to such an extent that persons with ID may be denied decision-making power even before their capacity is officially assessed. Unfortunately, the conditions for extra-legal capacity removal are also shaped by social services systems (Joffe, 2010; Joffe and Kerzner, 2008; ARCH, 2014), as we will see in Part II of this study.

Migration, Precarity, and Disability

A lack of recognition before the law shapes a relationship to non-citizenship that is in many ways similar for persons with ID and migrants with disabilities. This means that as a result of capacity laws and immigration systems, both groups can hold formal outsider status. Such problematic social locations have been identified as a major shortcoming of rights-based approaches to social change geared towards disability justice (Sherry, 2014; Meekosha, 2011), and justice for migrants (Banerjee, 2010). Additionally, rights-oriented views of disability (see

for example Rioux, 2003; Rioux and Valentine, 2005) are described by critics as carrying exclusionary effects because their social model premise does not reflect universal understandings of disability, especially those that account for the ways in which impairment is itself a form of injustice (Grech and Soldatic, 2014; Meekosha, 2011). For instance, Meekosha emphasizes the production of impairment through violent processes and atrocities that relate to attempts by the Global North to control resources in the Global South. Addressing such violence includes preventing the production of impairment (p668) – an approach that challenges the social model framing of impairment as 'natural' and disability as its social-relational outcome (i.e. 'disabling conditions'). Failure to address the injustice of impairment-generating processes presents an ethical and practical limitation for rights-based views of disability that are grounded in the social model. Another limitation arises when we consider the many barriers confronting disabled people attempting to make substantive claims to rights. Since they can be located beyond the reach of rights, many persons with ID and migrants with disabilities are unaffected by rights-based gains and continue to face inequitable conditions even after these issues are considered to be resolved by dominant groups. While this study does not seek to contribute to ongoing debates around rights-based approaches to justice, it does document and challenge the role and impact of problematic rights-mediating mechanisms on groups who experience precarious status in Canada.

The precarious status of migrants with disabilities, while perhaps more overt than persons with ID, is also complex and in need of analysis, especially in relation to racially informed colonial processes. In this vein, critical studies of Canada's immigration system show how migrants with disabilities who are racialized and originating from countries in the Global South tend to face particular challenges in obtaining permanent status in Canada, partly resulting from

levels of poverty that make it harder to cover the costs of disability services out of pocket (El-Lahib and Wehbi, 2012; El-Lahib, 2015; Spagnuolo, 2016b). Canadian immigration laws also tend to frame migrants from the Global South as mere labour commodities, as extensions of market-driven needs that can be met on a global scale by drawing upon colonial and neocolonial arrangements that favour countries like Canada. Speaking directly to these trends, critical studies in migration reveal Canada's dehumanizing approach to workers from the Global South who, in the national imaginary, are positioned as less valuable than white migrants and are often situated outside of the national community. This body of research shows strong historic continuities throughout changing immigration policy regimes, and while Canadian immigration law has evolved over time, it has been consistently challenged by critical race and migration scholars for its differential impact on racialized people, especially women of colour (see especially Walker, 2008; Thobani, 2000; 2007; Sharma, 2006; Bakan and Stasiulis, 1994; Tungohan, 2013; Arat-Koç, 1997). Notwithstanding demographic shifts towards higher numbers of migrants who are racialized people who originate from the Global South, which critics of the current system often acknowledge, the ways in which opportunities are structured continue to favour white, Euro-descendent migrants emigrating within the Global North.

There are also noticeable barriers to belonging among migrants with permanent status. Lessard (2010) reports that under the IRPA, and in spite of a certain level of "numerical equality" among marginalized groups, there are rules that contribute to "a gendered and racialized bordering process". Here he signals out sponsorship laws that curtail the use of certain social services (p239). Lessard explains that there are "different levels of membership" that result from this differential access to services (p243). These inequities and more hidden forms of non-citizenship highlight the importance of considering translocal dimensions of transnational

migration experiences. They also challenge the notion that physical presence in a country reflects actual membership and belonging. In the area of migrant labour, which is governed by policies that invite migrants to remain in Canada under work contracts, there have been remarkably fewer opportunities for permanent status for people of colour who predominantly perform this work, and the situation of women of colour is in stark contrast to the recruitment of white women as labourers and domestic servants during earlier decades (Bakan and Stasiulis, 1994; Arat-Koç, 1997; Tungohan, 2013; Spagnuolo, 2018).

The settler colonial roots of these racializing practices have been well documented, including the ways in which immigration law closely parallels practices targeting Indigenous communities (Thobani, 2007). Thobani (2007), for example, has demonstrated how even after the removal of explicitly racist practices coinciding with the introduction of the points-based system in 1967, immigration restrictions and controls continue to be inflected with racially informed knowledge that privileges applicants who are white and Euro-descendent. Referring to the 1976 Act, which was in place until 2002, Thobani argues that these newer examples of racism were enacted through various strategies, including the points-based categories of "personal suitability and independent status", which "reflects the biases of the officers" (p98). While 'personal suitability' was removed from the 2002 Act, this does not eliminate the risk of a racially biased points system, since another factor impacting migration involves the uneven distribution of "resources for immigrant recruitment and processing" between countries in the Global North and South (p97). Thobani concludes that altered laws "maintained the earlier racialized constructs of nation, nationals, and citizenship" (p98), even though Canadian officials accepted that immigration from the Global South was necessary for economic purposes. Along these lines, Dobrowolsky (2017)'s observation that the IRPA, which came into effect in 2002, is

preoccupied with "social cohesion" (p633), might further encourage discrimination against groups who are viewed as being outside dominant constructs of citizenship. Addressing this point in her study on securitization, Ibrahim (2005) illustrates how the IRPA's emphasis on "risk management" frames migrants as threats to a now broadly defined form of human and national security (p179), which also encompasses "a cultural identity" (p170).

'Ablenationalism' and Intersectional Critiques of Development

Racially imbued nationalist ideals are at once "ablenationalist" (Mitchell and Snyder, 2015), in the sense that very often only the 'least' disabled people are deemed worthy of inclusion on account of their ability to assimilate to normative standards (p14). When such ideals are read through this intersectional lens, these citizenship formations can be readily linked to eugenic and (neo)colonial ideologies that denigrate race-based and disability-based forms of difference. Today, through covert as well as overt means, Canadian immigration law continues to deny access to persons with disabilities through excessive demand evaluations, upholding centuries-old traditions of exclusion (Hanes, 2009; Chadha, 2008; Capurri, 2010). Notwithstanding the fact that racialized migrants are also persons with disabilities and that these intersectional identities draw together concerns of race-based and disability discrimination, the roots of what critics refer to as the ableism of the Canadian immigration system are conceptually and historically intertwined with race-based exclusions.

The treatment of migrants from the Global South as labour commodities with few opportunities for permanent membership and the rendering of disabled immigration applicants as inadmissible, are related examples of dehumanization that stem from transnational processes and methods of (de)valuation that are also active translocally. Consider, for example, how the terminology used to exclude migrant groups ('alien', 'inadmissible', 'illegal') reflects the non-

human status accorded to persons with ID ('vegetable', 'defective', 'man-child', 'dead weight'). These discursive constructions are related to the materiality of biocitizenship practices, which extend to the construction and management of identities, spaces, and borders. According to Ahuja (2016), efforts to control the movement of bodies occurs through the cultivation of fear of the non-human. Colonialism thus mobilizes fears of the 'alien' and 'defective' and at the same time, uses it to justify colonizing these 'othered' bodies.

Experiences of displacement and non-citizenship are closely related to bio-management practices that Ahuja characterizes as being directed at "human surplus". This dehumanized surplus is described as, "a population at risk for displacement, dispossession, captivity, and premature death" (xii). Ahuja links these colonial effects to what Mitchell and Snyder (2016) would consider ablenationalist segregationist goals, identifying "an emerging government of species reliant on the segregation of the ill" (p31). Still following Ahuja (2016), these forms of biopower are concerned with "transborder and interspecies entanglement" (p70). In other words, biopower is manifest in the anxiety that surrounds 'alien' migrants with disabilities and 'defective' persons with ID – two communities who have been discursively positioned outside of the human species; this positioning is mirrored in displacing processes that are linked to their non-citizenship status.

Historically, the need to segregate, exclude, and remove persons with ID from the national body overlapped with perceptions of 'foreigners' as being mentally defective or 'feebleminded' (McLaren, 1990; Dowbiggin, 1995; Stephen, 1995; ; Baynton, 2001; Menzies, 2002; Spagnuolo, 2016c; 2018). In Canada, both persons with ID and migrants with disabilities were framed as public health threats – as a direct attack on the nation that needed to be detected, controlled and removed. Moreover, migrants were viewed by eugenic campaigners as being

particularly prone to ‘mental defectiveness’ and were identified as the source of the supposedly growing size of this population (Hincks, 1921). The public health crises that were generated by groups like the Committee for Mental Hygiene, founded by Clarence Hincks, drew upon settler colonial ideas of a white and non-disabled nation. As discussed below and throughout this dissertation, the co-constitution of the threat of disability, race, and foreign status emerges from notions of ‘defective development’. For example, Chen’s (2016) critical analysis of Down’s syndrome and related notion of “slow constitution” suggests “the commingling of racial delay with developmental disability to the point that the two cannot be separated” (p243). Their work shows that ideas about development and delay operate on different scales, including individually and globally. They describe development as “a set of almost homonymous senses that refer to human individual growth on the one hand and economic fate on the other” (p237). Chen also addresses notions of time and “slow constitution”, but I have chosen to extend my study of (in)capacity and (under)development by focusing on their suggestion to “think about developmental time, global economic time, and delay together” (p243). I will do so by considering how hierarchies of (in)capacity are enacted, which also allows me to take up Chen’s invitation “to ask questions about what the legacies are here, to take this kind of thinking as not exceptional even in the present” (p243). Drawing upon Chen’s example, I consider how certain understandings of development take shape individually through assessments of intellectual competence and economically through an imperialist and colonial lens that views nations and racialized people in the Global South as underdeveloped. In these instances, the displacement effects associated with the institutionalization of persons with ID and the deportation of migrants are bolstered by normative views of capacity and development premised on ableist and racist assumptions. Goodey (2016) and Rapley (2004) have each forwarded similar critiques of the ID

label, albeit ones that are quite distinct from Chen (2016) due to their de-emphasis on racial thinking. Nonetheless, these authors argue for the constructivist nature of the ID category as one that is derived from a linear development model and cultural-relational contexts infused with uneven power dynamics.

Returning once more to the co-constitution of disability and race, work by Chen (2016), Erevelles (2014), and others suggest that race-based exclusions interact with disability-related exclusions, to the point that they are "co-constitutive" (Chen, 2016, p235). By extending this theory through comparative analysis, we will see how these exclusions denigrate persons with ID and migrants with disabilities in specific ways. The co-construction of racial and intellectual 'inferiority' does indeed draw upon linear views of development and categorical methods of thinking that hold unique repercussions for persons with ID and migrants with disabilities. Chen's work in exposing the conceptual and material importance of development adds insight to earlier historical findings related to histories of Down's syndrome (such as Kelves, 2004; and Wright, 2004). And while earlier eugenic theories may have changed, it remains true that the perception that medically inadmissible migrants and many persons with ID cannot meet the 'development grade' contribute to their shared experience as outsiders. In this sense, the presence of these communities in Canada is shaped by a lack of legal recognition and precarious access to formal and substantive citizenship. These close parallels serve to emphasize the need for further comparative research into the contemporary situation of persons with ID and migrants with disabilities and the ways in which they are assessed for opportunities for belonging.

Concluding Thoughts

While there are important differences among the communities who make up the focus of this study that cannot be overlooked, this chapter has argued for the importance of viewing the

experiences of persons with ID and migrants with disabilities together. Such an analysis helps illuminate the ways in which dominant understandings of capacity and development operate through the production of non-citizenship to displace members of marginalized communities. Assessment practices geared towards these groups do vary in terms of their stated intent, with testing for persons with ID aimed at offering access to support, and immigration testing blatantly striving to 'protect' health and social services from migrants who are framed as 'undeserving'. However, these practices are historically and conceptually linked to the same eugenic public health campaigns and to similar, more recent expressions of fear surrounding ideas of unproductive and underdeveloped individuals. Communities and individuals captured under these categories are, in essence, framed as social burdens who are not fit for citizenship. With these legacies in mind, we can begin to appreciate how the programs and policies shaping the lives of persons with ID and migrants with disabilities offer a powerful springboard towards a disability framing of displacement.

Part II – Rank, and then File: Developmental Services Ontario, the Supports Intensity Scale, and Ontario's Investment in Psychometric Testing

Section Introduction

This section unpacks assessment processes that target persons with ID by focusing on the MCSS Passport Program and the Supports Intensity Scale (SIS). It aims to situate the SIS within a broader network of assessment practices and policy contexts to consider the shape of the developmental services sector during different policy eras in Ontario. Throughout this analysis, we will see how the conditionality of the 'passport to belonging' – in this case, the Passport funding program – is partly achieved through the implementation of evaluative tools like the SIS, which carry the potential to act as technologies of displacement by regulating access to the conditions that are needed to enact substantive citizenship. These biopolitical tools shape realities of non-citizenship through a feedback loop that creates the conditions by which both access to and presence within the community can be limited or denied. As is often the case, these very same passports also offer the possibility of enhancing mobility and access within community spaces in translocal and transnational contexts; that is, after all, why we continue to apply for them.

Passports, then, present a dual nature, and persons with ID accessing the MCSS Passport program with the hope of receiving funding and supports to facilitate their presence in society can experience displacement both subjectively and spatially. These related experiences of displacement build upon mine and El-Lahib's (in press) reading of Bhabha (1994) and Bakewell (2011) which refers to displacement as the subjective experience of feeling "out of place" (Bakewell, 2011, p23); in discussing these issues in relation to people with ID, we draw upon existing testimonies and scholarship to connect them to "a sense of not being human" (in press). Our understanding of displacement also encompasses spatial dimensions by recognizing the

coerced nature of placements in institutional and residential housing. This dissertation argues that for persons with ID, such experiences are tied to assessment practices that shape their relationship to, as well as the nature of, the services and supports they either receive, do not receive, or are forced to wait for.

The discussion presented over the course of the next two chapters is animated by a concern for the displaced realities of persons with ID "who have not crossed geographic borders" (Spagnuolo and El-Lahib, in press). Additionally, these chapters consider the social positioning of persons with ID as 'species outsiders' who lack capacity, identifying differing notions of (in)capacity within the programs and systems designed to support them. Findings presented within these chapters demonstrate that MCSS continues to emphasize the regulation and monitoring of the imagined deficiencies of persons with ID over actual service provision. This analysis concludes that the evaluative approaches regulating access to the limited services that do exist have the potential to be displacing in that they shape non-citizenship experiences and stratify access to avenues of belonging and opportunities for social presence among persons with ID.

Summary of Chapters

In order to unpack the risk of displacement inherent within the MCSS-managed system, this section is divided into two chapters. Chapter Three – Situating Passport and the SIS: An Overview of Developmental Services in Ontario, takes up the current policy landscape and situates its practices in historical and theoretical context. Chapter Four – Evaluating the SIS, hones in on the ways in which the implementation of the SIS and the Passport Program regulate opportunities for belonging by mobilizing dominant understandings of (in)capacity. Both chapters engage with the MCSS-funded system's view of itself, drawing on official documents

and the perspectives of those who work within MCSS-funded service agencies, including the private non-profit agencies that administer SIS-testing, collectively known as Developmental Services Ontario (DSO), or DSOs. The analytical approach taken throughout both chapters relies on a close reading of legislation, regulations, directives, various policy documents, ministry and agency websites, evaluative forms and manuals, secondary literature, including clinical and historical literature, and interviews with key informants. Some of these materials were obtained through access to information requests (such as expenditures related to the SIS), or provided directly for research purposes, for example, by the American Association on Intellectual and Developmental Disabilities (AAIDD), the company that developed the SIS. Three participant interviews were especially instructive in breaking down how the SIS and related assessment practices fit within the broader developmental services landscape, and how they shape access to the Passport funding program. These include Frank, a former employee of a DSO agency who is now a front-line provider; Carebear, a current DSO employee; and Bill, who manages a service program that DSO clients can access. The names used to refer to these participants are pseudonyms they selected to preserve their own identities. Each of these participants has taken part in SIS assessments as either a service provider or assessor. Their insights are incorporated throughout both chapters of this section to shed light on how Passport funding is regulated.

Chapter Three: Ontario's Passport Program and the SIS: An Overview of Developmental Services

Introduction

The analysis presented in this chapter focuses on MCSS law, regulation, and management of related practices, drawing out similarities between recent and older policy formations that are closely linked to institutionalization, dislocation, and deep forms of segregation. Given that the contemporary developmental services system in Ontario and its associated evaluative tools are severely understudied and that this landscape appears both complex and confusing to many community members and researchers, greater space is reserved in this chapter for demonstrating how services for persons with ID are structured and implemented. The focus throughout this discussion is on the ways in which access to opportunities for belonging are potentially regulated through evaluative technologies such as the SIS, which play a biopolitical function by invoking normative standards and mobilizing hierarchical understandings of (in)capacity. By focusing on the concept of (in)capacity, we will encounter evidence of overlap between current practices and those that characterized earlier and more overtly institutional approaches to ID. We will also see how the historic treatment of people with ID has been shaped by evaluative tools such as the IQ test, and how these legacies remain active today. The SIS and DSOs are at the centre of this discussion, and we will take a closer look at their respective implementation and development in Ontario in order to assess how MCSS currently regulates access to the Passport program and how this carries the potential to displace people with ID. Before turning to these practices, we will briefly review the current policy landscape and Passport program by asking how they measure up to claims around deinstitutionalization and direct funding.

'Policy Assemblages': The SIPDDA and Institutional Carry-Over

The Passport program is a reimbursement program for adults with ID that was created in 2011; it fully replaced the adult stream of Special Services at Home when that program was phased out on April 1st, 2012 (Auditor General, 2011, p291). These changes took place after the Province of Ontario, which had operated large-scale institutions for persons with ID up until 2009 and faced a related class action lawsuit, officially embraced a politics of deinstitutionalization. Leading up to the 2009 institutional closures, MCSS put forth the 2008 Act: Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (SIPDDA). This new act came into play in 2011, replacing the 1974 Social Inclusion Act which, in addition to governing provincially run institutions, is notable for having shifted developmental services from the Ministry of Health to MCSS. The current Act, known simply as the SIPDDA, marks a significant change in that it establishes a de-centralized service landscape where private non-profit service agencies can receive funding to operate MCSS programs, including the Passport program and residential supports. It should be noted that in most cases, these supported housing arrangements consist of the many group homes that replaced the provincially managed institutions. Private, non-profit agencies also oversee eligibility testing for all MCSS-funded programs, including Passport and residential placements.

Currently, the Passport program, which is separate from residential funding, is the only MCSS program that is considered a direct form of funding for people with ID. MCSS explains that "[t]he ministry also provides direct funding to people and families to give them choice in their support arrangements and allow them to select the services and supports they feel best meet their individualized needs" (MCSS, 2017-18 Published Plan). However, it is still the case that Passport money must be received by an agency and cannot be directly given to an individual or a

trusted member of their support network. This simple yet crucial requirement means that Passport does not match the definition of direct funding used by many ID community organizations and advocacy groups, which insists that funding be de-bundled from a service agency and instead flow directly to individuals (for examples of definitions of direct funding, see Stainton, 2013, p9; Stainton and Boyce, 2004). As we will see in Chapter Four, Passport funding decisions and assessment methods – which draw closely on the SIS – are far from individualized. Similarly, on the residential side, individualized and direct funding arrangements are generally not taking place, and all funding is currently required to flow through an agency. The most common practice in Ontario are residential funding agreements made between agencies and MCSS, which offer placements to individuals in a way that is far from individualized – the most common example being the group home model which, as mentioned at the outset of this study, is considered by self-advocate organizations to be an institutional model (see PFC position). While there are some examples of MCCSS supporting individualized funding arrangements that allow an individual to choose where they live and then access personal supports to stay in that home, these are rare examples that have been the exception rather than the rule (Pooran, 17 October 20018, personal communication [cited with permission]). Furthermore, among the individualized residential arrangements that do exist, there are no examples of direct funding not being required to flow through an agency.

According to MCSS, SIPDDA governs community-based services because persons with ID now "live in communities across Ontario" (MCSS, Developmental Services System, Legislation). The Ministry's framing of the Act is consistent with a study that documents shifts in policy discourses around ID, noting the current popularity of the notion of 'social inclusion' (McCauley and Matheson, 2016). However, social inclusion in the developmental services

sector, as McCauley, Matheson, and other critics have found (see also Spagnuolo, 2016a; Spagnuolo and Boulanger 2018), retains many of the tendencies and effects of Ontario's overtly institutional era. This institutional carry-over challenges the Ministry's periodization and any claims to a clear end to institutionalization. Such overlap also points towards what Artiles, Dorn, and Bal (2016), drawing on Ureta (2014), refer to as "policy assemblages". For his part, Ureta (2014) recognizes the work of Deleuze and Guattari (1988) along with more contemporary scholars (see Ureta, 2014, p305), in conceptualizing 'assemblages'. His understanding of policy assemblages is quoted by Aritles, Dorn, and Bal: "policies are never the pure application of rational guidelines or the result of powerful individuals but multifaceted processes in which a multitude of entities, all of them carrying different agencies, intervene and are continually reenacted, changing the policy's outcome in accordance with the presence/absence of certain articulations and practices" (Ureta, 2014, p303, quoted in Artiles, Dorn, and Bal, 2016, pp794-795). As Artiles, Dorn and Bal (2016) explain, policy can indeed contain contradictory views, including the persistence of oppressive ideas about disability that exist alongside more empowering concepts (p794). Other disability scholars have noted similar phenomena. For example, in her work on ID and citizenship, Carey (2009) refers to the co-existence of rights and "contradictory laws and patterns of access" (p7). She highlights the inferior legal status of persons with ID and the persistence of this ascribed identity within a disability rights-oriented society.

Carebear, a study participant who regularly conducts SIS and other eligibility testing for MCSS programs through the DSO, specifically points to "the old way" of thinking and the "institutionalized lifestyle" of the 1920s and 1930s, explaining how this connects to the need for ongoing advocacy so that persons with ID are viewed as complete individuals. Carebear explains

the widespread aversion towards accepting persons with ID as individuals, stating that "even though the individual is looked at in some sectors in the province as an individual, there are a lot of areas where they are still not being looked at as a person". To not be viewed as an individual jeopardizes the identity of a person with an ID as fully human, dislocating them both in terms of their species-membership and as citizens who are members of the nation. Carebear's insights suggest that Carey's (2009) general observations hold true for persons with ID living in Ontario, many of whom are still not viewed as individuals and consequently, are not accepted as full community members. This remains the case despite positive claims made by MCSS about the SIPDDA.

Such considerations set the stage for a nuanced and historical reading of SIPDDA and current MCSS programs, supporting a critical evaluation of the mixed nature of the current policy landscape and its displacing effects. Here we must recall that this landscape is largely controlled by private and not-for-profit agencies that are funded by MCSS. Meanwhile, the carry-over effects of institutionalization can be more clearly understood through a displacement framework that centres experiences of non-citizenship and the role played by impairment hierarchies. More specifically, the concept of a "ladder of development" (see Borthwick, 1996, as cited in Chen, 2016), which promotes the linear ranking of capacity from animals to humans, is instrumental to this critical evaluation of displacement, allowing us to explore two inter-related dimensions of this experience. This ladder also presents intersectional possibilities that are important for critical disability and critical race scholars to consider. As Chen (2016) explains, referring to the work of Borthwick (1996), "even Borthwick notes that the underlying image of the 'ladder of development remains influential, and the conception of disability groups as quasi-races is still a powerful ordering force' (Borthwick 1996: 406)" (p240). One way that we can

begin to address the ideologies that support such hierarchical thinking is by turning our attention to the many displacing processes that disabled people experience.

The first dimension of displacement that is most relevant to people with ID are the many layers of deep segregation and isolation that deny them the supports needed to exercise choice and substantive citizenship and to maintain a meaningful presence in the community. Given that these displacing experiences are structured by MCSS legislation, this form of dislocation is well-aligned with Bakewell's (2011) criteria for displacement as a coerced form of movement that is institutionally managed. Secondly, this chapter puts forth an exploration of how current arrangements and the spatial dislocation they generate through forced or coerced movement into segregated and controlled environments and/or isolation without the supports needed to participate in society and maintain a social presence, are linked to MCSS eligibility requirements and their related implementation of the SIS. These themes emerge through a historically informed reading of current practices that is equally shaped by interviews conducted with those who work in the developmental services sector (i.e. Frank, Bill, and Carebear). Importantly, the same themes are also apparent in interviews conducted with persons with ID and their families, which we will encounter in Chapter Seven. In all cases, we can see how Ontario's implementation of the SIS allows this evaluative technology to potentially shape displacing experiences. The centrality of the SIS in this analysis of displacement requires that we take a closer look at its introduction and implementation in Ontario.

Introducing the Supports Intensity Scale

To begin, the SIS is a clinical tool owned and created by the AAIDD, with the first version, SIS®, appearing in 2004. The tool has been studied and tested by clinicians and found by many to be a valid measure of the "intensity of support needs of individuals with ID currently

receiving services" (Weiss et al., 2009, p939). In Ontario, SIS testing is led by Developmental Services Ontario agencies which, as non-profit private organizations, are directly funded by MCSS and report to that Ministry. In order to implement the SIS, the Ministry of Community and Social Services continues to pay the AAIDD for SIS training while transferring money to DSOs specifically for SIS assessments. In 2017, the Ministry's contract with the AAIDD for quality control totalled $370,000 (MCSS and AAIDD, 1 October 2017, p26). In addition, the Ministry transferred over $14M to the DSO in 2017 alone (Memo, 27 March 2017, p1), with a budget breakdown showing that two of the three funding streams are specifically reserved for SIS assessments (p3). In a sector that is underfunded and that has given rise to interminable waitlists and crises for services, these figures represent significant investments.

Because of its claim to accuracy, bolstered by numerous clinical findings, the SIS carries appeal across many jurisdictions. In Canada and according to the AAIDD, these include the provinces of Ontario and Manitoba. The SIS is also used in British Columbia "on a very small scale with a service provider agency". In Quebec, the SIS has been used for research purposes by one university (Maharaj, personal communication, 14 and 20 August 2018 [cited with permission]). The SIS was previously used in Alberta, but after resistance by a parent-led advocacy movement, was recently dislodged (Inclusion Alberta, 2015). Similarly, a class-action lawsuit led by families in Ontario, certified in 2018 as this dissertation approached completion, suggests a level of discontent with how resources are administered. While it is unclear whether this complaint implicates the SIS, the administrative role that the tool plays certainly leaves open this possibility (see Pooran Law, 21 December 2018). Meanwhile in the United States, where the tool originates, it is used in 24 states. The tool is also used internationally and has been translated into 17 languages and adopted in several countries including Italy, Iceland, Ireland, Latvia,

Netherlands, Taiwan, and Belgium, for purposes ranging from research to service provision (Maharaj, personal communication, 14 and 20 August 2018 [cited with permission]). Weiss et al. (2009), commenting on the rise of the SIS, state that "the SIS is quickly becoming the measure of choice by a number of jurisdictions" (p940).

Positive reception of the SIS is undeniable, and there are now two adult versions of the tool and supplementary materials in circulation. The development of a version targeting children was underway when the 2015 adult version of the SIS was released (SIS-A User's Manual, 2015 p5), and is now available and known as the SIS-C™ (AAIDD, SIS-C). While MCSS has employed an earlier version of the tool (SIS, 2004) to assess adults with ID, it currently uses the latest: the SIS-A, or Supports Intensity Scale – Adult Version, from 2015. However, upon comparing the two versions of the tool (the 2004 SIS and 2015 SIS-A), there is little discernable difference aside from the addition of demographic questions which do not apply in Ontario. A summary of the latest round of changes to the tool shared by Carebear, a study participant who works for a DSO agency, lends a similar impression. Given the strong similarities between these versions of the tool, and even while acknowledging the current use of the SIS-A, the SIS will be discussed in terms of a general approach and methodology by drawing upon different versions, but by simply referring to these as the "SIS".

Looking at the 2004 version (SIS®), at the top of the form itself is a section where "Respondent Name(s)" and their "Relationship to Individual" are listed (SIS, 2004). This section invites others to take part in an interview with a person with ID and is consistent with MCSS' reluctance that persons with ID attend SIS interviews alone. All versions of the SIS consist of a series of questions arranged into different sections that reflect different priority areas. These include Support Needs, Supplemental Protection and Advocacy, and Exceptional Medical and

Behavioural Support Needs. Support Needs is the lengthiest section, taking up approximately half the form. The Support Needs section is further divided into sections corresponding to "six activity domains" (SIS, 2004), including home living activities, community living activities, lifelong learning activities, employment activities, health and safety activities, and social activities. The first two sections employ a five-point scale and instruct assessors to "Identify the Frequency, Daily Support Time, and Type of Support that is reported necessary for the person to be successful in the six activity domains". Assessors must "[c]ircle the appropriate number (0-4) for each measurement". These measurements relate to Frequency, Daily Support Time, and Type of Support. Assessors then "add across each line to obtain the Raw Scores". Notably, assessors are told to circle numbers even when the person with ID is not currently engaging in a given activity (SIS, 2004). Carebear explains that MCSS follows this practice and adds that it is important to ask all the questions contained in the form. The final section of the SIS, Exceptional Medical and Behavioral Support Needs, uses a three-point scale and, as characterized by Weiss et al. (2009), lists "problem behaviors" and "medical conditions" (p935). As previously mentioned, the latest version, the SIS-A, includes new demographic data collection – notably race and IQ – but MCSS, according to Carebear, has instructed assessors to ignore these questions and not to collect this data.

The AAIDD describes the SIS as being distinct from adaptive functioning – a common test used to prove the presence of an ID, firmly stating, "[t]he SIS is not an adaptive behavior instrument and should not be used as one. An adaptive behavior scale measures *skills* whereas SIS measures *support needs* in 85 life activities, and behavior and medical needs areas [emphasis AAIDD's]" (AAIDD, SIS Product Information: FAQs). However, as a more theoretically and historically-informed analysis will soon suggest, this new evaluative tool carries strong

resemblances to adaptive functioning, IQ testing, and other deficiency-oriented measures commonly applied towards persons with ID. Particularly relevant here is the AAIDD's reliance on normative standards in their definition of support needs, which are described as "the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning" (AAIDD, What are support needs?). The claim that measuring support needs through a normative lens is somehow different from measuring skills or deficiencies will be challenged through a historical and theoretical analysis as well as by drawing upon secondary literature and insights gained through interviews with those who work in the developmental sector. Additionally, clinically oriented research by Brown et al. (2009) rejecting the firm distinction between the SIS and adaptative functioning, and which responds to Harries et al.'s (2005) call to explore such relationships (p403), adds a more interdisciplinary perspective to this reading of the SIS. Indeed, Brown et al. (2009) have found that the SIS resembles adaptive functioning testing so closely that clinicians can easily employ the latter for simplicity in data collection. The authors explain, "it should be recognised that current measures of support may, at a basic level, quantify typical performance on everyday activities (i.e. adaptive behaviour)" (p954). These clinical results suggest that in addition to the role the SIS plays in reducing consumer control over the supports people with ID receive – which it does by providing service managers with information that empowers them to make decisions on behalf of their clients – the tool behaves much like other psychometric forms of assessment. As will be argued below, these similarities involve efforts to measure and rank (in)capacity and intelligence and make claims relating to the accuracy and predictive potential of such practices.

A qualitative analysis informed by participant interviews (discussed in Chapter Seven) and that is attentive to the historical and theoretical subtleties of medicalized assessments

suggests that the SIS embodies a form of ranking and prediction that has the potential to generate displaced subjectivities, coercively shaping persons with ID's social location as one that is 'incapable' and 'out of place'. For people with ID, the MCSS-requirement that clients complete a SIS evaluation further threatens what Goodey (2011) refers to as one's "species membership"; it does this by mandating participation in potentially displacing biopolitical processes as a condition of access. As we will see, this approach to access can be deeply pathologizing in the way that it mobilizes hierarchies of (in)capacity, facilitates capacity removal (both formally and informally), and challenges persons with ID' species-membership – an act that is displacing in and of itself. Framing Ontario's use of the SIS in this way helps account for the psychological and subjective dimensions of disability displacement that myself and El-Lahib (in press) introduce through our reading of Bhabha's (1994) work on the colonized subject and Bakewell's (2011) definition of displacement. Extending Bakewell's understanding of displacement, which we summarize as a "subjective state that involves being or feeling out of place" (Spagnuolo and El-Lahib, in press, n.p.), we promote the importance of viewing people with ID who have not crossed borders as 'unsettled' in contexts where their alterity is maintained despite, and even due to, social services systems. MCSS eligibility testing in connection to Passport funding will be looked at in greater detail further on in this chapter through these anti-colonial insights.

For now, it is crucial to recognize that the two dimensions of displacement outlined above are so tightly linked that they may be considered mutually constitutive and inseparable. For example, capacity denial and ranking, and the subsequent shaping of subjectivities that are "out of place" align closely with coerced placements in segregated facilities in that these processes each facilitate and stem from such segregated placements. These dimensions of displacement thus participate in the complex and ongoing feedback loop with non-citizenship

that shapes the lives of persons with ID. Later, we will consider how these experiences can be contrasted with a more relational view of ID that is grounded in the firm recognition of capacity and the right to self-determination. First, we will turn to the broader policy context in which medicalized assessments operate, and the governing legislation – the SIPDDA – that shapes how the SIS and Passport program are implemented.

Paternalistic Treatment and the Access-Control Nexus

SIPDDA, it has been observed, shies away from a rights-based approach to services and supports for persons with ID. Rather than mandating the provision of supports as a right for persons with ID, the Act and its regulations describe how these services can be accessed and funded. In the case of the Passport program, access is regulated through a SIS assessment, which also informs the level of funding that is assigned to an individual. This social services model is closer to the "discretionary social assistance" schemes described by Guest (1997, p116), with rigorous and invasive eligibility and needs-based testing that marks "a serious invasion of personal privacy which precedes the granting of and may even accompany receipt of it" (p61). Social programs that rely on such invasive eligibility and needs-based testing are known to undermine "personal autonomy" not only through their methods of surveillance (p139), but also due to the more discretionary i.e. unreliable, nature of the program. In his historical account of the Canadian welfare apparatus, Guest describes how a more entitlement-based approach can be traced in social insurance programs that are based, for example, on a contributory plan. Unlike the need-based model, entitlement-based programs "transform the citizen from a supplicant to a claimant" by suggesting they have the right to make claims upon the state (p135). In contrast, developmental services are granted based on their availability and only after eligibility is

established through a detailed testing process that is centred on the SIS and that is geared towards assessing the needs of an individual with ID.

Even while the SIPDDA does not guarantee services and supports as a matter of right, such guarantees remain necessary if persons with ID are to make claims upon the state in order to exercise substantive citizenship and be present in the community as meaningful participants. The Passport program directives are equally reluctant to enshrine substantive citizenship, emphasizing instead the precarious and resource-dependent nature of this funding program, as the following statement reveals: "Access to funding under the program is subject to available resources" (MCSS, Passport Guidelines, p5). However, we know that without the right services and supports, persons with ID face spatial segregation, deep isolation, dislocation, and a profound inability to be present in society. By making access to vital developmental supports conditional, the Act and related documents such as the Passport directives, structure the potential non-citizenship of persons with ID and raise the risk of displacement for this community.

All interview participants for this study acknowledged the shortage of services and the lengthy wait lists for existing programs, but in addition to these issues around resource availability, they also described the inappropriate nature of existing resources and methods for resource allocation – a related issue that is linked to an overall lack of consumer-control. Carebear, a SIS assessor and participant who is familiar with the history the Act, explained that MCSS was "putting the cart before the horse" by setting up access and eligibility rules for services and supports that were not yet existent. We will return to this issue later on. For now, it suffices to say that interviews for this study support the Ombudsman's 2016 findings, as well as previous reports that demonstrate a crisis-level shortage of supports in the developmental sector.

Alongside the absence of any right to services within the SIPPDA is evidence of a paternalistic attitude towards persons with ID that takes a protective stance towards services and supports and overlooks the importance of self-determination. The Act appears to substitute self-determination for the goal of 'independence'– a problematic ambition that reinforces the tendency to pathologize the use of disability supports by suggesting that disabled people are naturally 'dependent' and 'burdensome'. Under the current system, persons with ID do not access services as entitled individuals. Instead, they are pathologized and in many ways, infantilized through a legislative framework that presupposes they are 'incapable' subjects who require another party to make decisions on their behalf. Examples of how the system removes decision-making power from persons with ID include the Ministry-funded linking and matching process performed by the DSOs, whereby program administrators can use SIS and other assessment scores to make decisions about funding levels and service appropriateness on behalf of individuals. Even while this top-down linking and matching process can include input from individuals, evidence shared by Bill, a key informant who manages a service program in this sector, suggests that DSO decision-makers can also screen out certain options.

Taking a broader look at current approaches to developmental services, Carey (2009) describes conflicts around choice and control as a trade-off between rights and protections. In this way, persons with ID can be forced to trade their rights as self-directing individuals for certain protections afforded by the state through service provision (p2). We can add to Carey's critique the understanding that without the correct services and supports, persons with ID are not even able to fully access rights. In this way the exchange between choice and support, whether unconscious or not, may be motivated by a desire to obtain much needed access to rights. Given these complexities, it seems clear that the trade-off is not absolute and that in some cases, it can

even lead to greater access to forms of social participation and presence. But regardless of the outcome, the risk of exchanging choice and control for protection and support is built into the structure of the MCSS-run system. And as Carey emphasizes, the reality is that no rights are automatic and all rights must be negotiated, and this makes possible situations where the rights of persons with ID can actually be restricted when accessing services and supports (pp23-24).

Regardless of what previous rights they may be exchanging or what new forms of support and access they may be gaining, some persons with ID experience services as controlling and paternalistic when limitations are placed on their decision-making power or when services do not reflect their own needs, goals, or self-understanding. Without any guarantees around the level of access or nature and adequacy of services and funding levels, there are no safeguards against these harmful experiences. The latest Ombudsman (2016) report also recognizes how this uneven level of access involves supports and services that are of an equally uneven quality, attributing this to the government's devolution of responsibility to private agencies. The report explains, "[w]hile the Ministry of Community and Social Services provides funding, individual services agencies decide on the type and nature of the supports and services they will offer. In this sense, the phrase 'developmental services system' is a bit of a misnomer … Consequently, the access to and availability of services and supports differs across the province" (p17). The report also points to the "individualized visions of hundreds of non-governmental agencies involved in this sector" (p17). Such individualized visions and privatization without consumer control can further account for experiences of displacement and non-citizenship that manifest as coerced spatial segregation and subjective dislocation. Carey's (2009) suggestion that the current service system is structured in such a way that opportunities for choice among persons with ID are severely

restricted (p32), provides a strong impetus for exploring such restrictions in the current Ontario service landscape.

Legal researchers for ARCH Disability Law, an Ontario-based legal clinic for people with disabilities, believe that the SIPDDA actually sets up such limitations through its silence on capacity laws and general failure to ground persons with ID's right to decision-making and self-direction. Joffe (2010) writes, "[s]uch an approach is evident in the provision of the Social Inclusion Act, which assigns decision-making power in particular circumstances to the individual or a person acting on their behalf" (p29). In an earlier study for ARCH, Joffe and Kerzner (2008) explain that the Act "removes the right of mentally capable adults to make their own decisions. It allows for decisions to be made by others on behalf of people with developmental disabilities who have sufficient mental capacity to make their own decisions" (p15). SIPDDA, they point out, also fails to outline the supports that may be needed for an individual to enact decision-making. Decision-making with supports, or supported decision-making, is an important alternative to outright capacity denial (see Browning, Bigby, and Douglas, 2014; Stainton, 2015; CACL, 2014). It is also a framework that incorporates feminist critiques of the binary nature of 'dependency' (see especially Kittay, 1999; 2011), forwarding a vision of decision-making premised on the assumption that everyone, regardless of ID status, engages supports to make decisions. SIPDDA's silence on these issues, which are central to the ID community, among other limitations outlined by ARCH researchers, promotes a taken-for-granted view of adult persons with ID as incapable of exercising control and making choices on their own behalf. Instead, this legislation presents persons with ID as in need of protection and 'management' by other parties. Relatedly, a disability advocacy group known as DANEO,[8] claims that the Act,

[8] In the interest of transparency, I belonged to DANEO's Steering Committee at the time of writing.

"discriminates against people without family or other unpaid supports" (DANEO, Key Shortcomings, para. 6).

A similarly infantilizing view of persons with ID is also evident in the directives provided by MCSS for the SIS and other aspects of eligibility assessment, which state that persons with ID must be assessed with another individual present who knows them well. The directive allows for this rule to be circumvented only in "exceptional circumstances", where such a person is not available or where the person with ID insists on representing themselves ("the interview may be held with the applicant alone if the applicant does not have someone who knows them well for at least the last three months and/or the applicant demonstrates a strong preference to represent him/herself") (MCSS, Policy Directives for Application Entities). The assumption here is that persons with ID do not generally have a "strong preference" for self-representation. Such a view, which reduces persons with ID's ability for self-determination and assumes their disinterest in exercising agency, is dehumanizing in that it condones the general reluctance to view of persons with ID as complete individuals. As Carebear observed, this reluctance to view persons with ID as individuals is a widespread problem in the developmental services sector that is also present within many families. To this end, Carebear shared a critique of parental control that reinforces Carey's (2009) characterization of longstanding tensions between the parent and self-advocacy movement. The parent movement, according to Carey, generally strives for a degree of protection for persons with ID, while the self-advocacy movement insists on the right of persons with ID to self-representation (p158). It must, however, be pointed out that some participants in this study felt they benefitted from having other people present during their assessment (for example, Rocky). The bigger issue, however, is that this form of support is not presented to individuals as an option. Rather, it is mandated by a directive and the preference for self-

representation without support is framed as unusual. Taking into account these shortcomings, we can see that while service shortages displace persons with ID by limiting their presence in society and upholding their segregation and isolation, existing services governed by SIPDDA can also be displacing. This is partly a result of a systemic failure to view individuals with ID as complete persons capable of making decisions on their own behalf, with or without supports.

Spatial Dislocation in Today's Supported Housing Landscape

The failure to recognize persons with ID as complete people is perhaps most apparent in residential services and the predominant MCSS-funded housing model, the group home. There is clear carry-over in the group home model from large-scale custodial models in relation to capacity questions. The similarities between these institutional settings are of course influenced by SIPDDA's approach to questions of agency, decision-making, and choice. As previously explained, the subject position anticipated and shaped through SIPDDA works to deny agency to people with ID. One of the ways in which this policy discourse unfolds in the lives of people with ID includes the lack of control over where they can live. Related to this are coerced and other institutionally structured forms of placement which, to return to Bakewell's (2011) criteria, help link persons with ID to other displaced people.

Commenting on the group home model, other researchers have noted the degree of coercion involved in these spatial arrangements. McCauley and Matheson (2016), following the relocation of institutional survivors done in 2009, found many persons with ID "living in group homes located on the geographic margins of communities" (p5). Observing this situation, they conclude that persons with ID are not "benefitting" from these community placements (p7). The spatial segregation that persons with ID experience in group homes is part of a much broader politics of coercion that effectively reduces choice, as persons living in these environments,

according to McCauley and Matheson, have “limited or no ability to directly influence their living conditions” (p7). McCauley and Matheson’s findings also reflect a study that was lead by a former group home provider in the United States, which caused the group to conclude “that they were oppressing the very people they were there to serve”; they subsequently changed their service model by closing their group homes and are instead supporting persons with ID in their own homes (Goll, 23 May 2018). Myself and Boulanger (2018) came to similar conclusions regarding group homes, while People First of Canada, the largest Canadian self-advocacy organization of persons with ID whose views on the subject ought to count the most, explain in a position statement that group homes are indeed institutions (PFC Position).

Often, the very act of a group home placement is in itself coerced, given that residents are not offered many placement options. In a recent article, I (2016a) promote a definition of transinstitutionalization that includes such forced placements within, as well as forced departures from, group homes. I centre power dynamics between persons with ID and private agencies, showing how neither group home placements nor removals (or evictions) allow for much choice. Other more explicitly institutional arrangements such as nursing homes and hospitals, which continue to house people with ID, are documented in the Ombudsman report from 2016 and have been the focus of many news stories (Ombudsman, 2016; see Spagnuolo, 2016a for a summary). Spatial displacement through institutional housing arrangements, it seems, remains an ongoing problem in the province.

Work by Rimmerman (2018) that looks at global progress towards deinstitutionalization provides further strength to the argument that capacity rights are closely linked to spatial displacement. Rimmerman’s recent book demonstrates that capacity and community presence through deinstitutionalized residential arrangements are two sides of the same coin. This is

because it is challenges for an individual to exercise legal capacity in coercive institutional settings that restrict their choices. Likewise, the exercise of "legal capacity is fundamental for making choices about where and with whom the person wishes to live" (p37). Spatial displacement through institutionalization is thus tied to experiences of non-citizenship that mobilize capacity hierarchies. Within these processes, persons with ID are viewed as legally incapable and denied the supports required to exercise substantive citizenship.

The forms of spatial dislocation evident in (trans)institutional arrangements continue to shape the non-citizenship status of many persons with ID. Some of the effects of (trans)institutionalization have been described as an erosion of the ability to direct one's own life and can thus be further interpreted as generating subjective displacement. Citing a case from Nova Scotia, a recent news story reveals how institutionalized people are subjectively shaped by this (spatially) displacing experience when they begin to lose certain abilities: "Over time, she said she watched as the residents with the legal right to leave lost the ability to function in a community setting, forgetting how to make their own decisions, cook a meal or "do the simplest tasks" for themselves" (Tutton, 14 February 2018, CBC). As we have seen, even community-based housing arrangements, such as group homes, are replete with institutional legacies. These legacies, according to Power, Lord and deFranco (2013), are far too common and, as a consequence of this carry-over, can corrupt the supportive mandate of existing services (p6).

Barriers to participation are equally evident in experiences of spatial isolation and the many restrictions that limit the mobility of people with ID and which characterize institutional-style residential placements. Survivor histories explicitly reveal how individuals were spatially bound to institutions and unable to leave. Carrie Anne Ford (2017) recalls, "I felt like a girl wanting to run away, but no one at Huronia could run" (p18). Ford's account also touches on the

desire to escape articulated by Park (Hutton et al., 2017), and cited in Chapter One. Ford adds that, "What Mrs. G. [Huronia staff member] said always stayed in my head. She said, 'Carrie, you'll never get out of here'. She said that I'm here for life until I die" (p19). As discussed in Chapter One, experiences of (trans)institutionalization among persons with ID can also be conceptualized by applying insights from transnational experiences of displacement. And just as transnational forms of displacement, such as deportation, "tether [..] people to nationally defined territories" (Wright, 2013, p38), (trans)institutionalization locks persons with ID into isolated and segregated environments from which they may feel there is no escape.

Situating the Passport Program within an 'Economics of Uselessness'

Setting spatial segregation aside for a moment, we can consider how the potential for displacement is structured by a political economy that shapes the SIPDDA and manifests itself at all levels across the developmental services sector and within the Passport funding program; this means that an individual does not even have to be forcibly relocated or physically segregated to become displaced. Some of the harmful effects of displacement include restrictions on an individual's decision-making power as well as the loss of other abilities, as the example from Nova Scotia demonstrates. Ford's (2017) statement that "[w]hat Mrs. G. said always stayed in my head" (p19), further links these coercive spatial experiences to the subjective dimension of displacement. On the one hand, persons with ID face restrictions on their mobility by being locked into a place while on the other, as Ford reveals, these experiences of segregation are so profound that they 'stay in your head'. On this subjective and psychological level, "being out of place" (Bakewell, 2011, p23) becomes a defining aspect of the displacement experience. Similarly, the complicity of implementing biopolitical evaluative tools that regulate access to

MCSS-funded services in generating these displaced realities is evident in their conceptual and historical ties to spatial segregation and forced confinement in large-scale institutions.

Addressing the impact of forced confinement on current policy, Ferguson (2004) outlines three inheritances from overtly custodial treatment models that allow us to situate experiences of displacement in a political economy of medical decision-making. Ferguson considers the legacies of almshouses, where a diverse range of poor and marginalized people could be found, and shows a continuation in "concept and practice" all the way through to asylums that were specifically designed for persons with ID (p56). These almshouse inheritances can be used to analyze both the "soft law" (see Sossin and Pottie, 2005) that involves frontline sorting practices and the implementation of clinical evaluative tools such as the SIS, as well as the hard law from which they flow. Such continuities, as described by Ferguson (2004), include the "[c]ontradictory purposes" (p56) around the aims of certain practices – an observation that accounts for the 'policy assemblages' that characterize the MCSS-run system.

According to Ferguson, the concept of chronicity is another enduring idea that speaks directly to the position of people with ID within an "economics of uselessness" (p58), as well as the perceived inherent incapacity of certain persons with ID. The inter-related notion of chronic 'uselessness' adds further nuance to Goodey's (2011) ladder of nature and to the stratification of services for persons with ID based perceived levels of (in)capacity and relationships to productivity. Lastly, Ferguson (2004) points to historical practices of custodialism as the preferred form of treatment for those deemed 'incurable' or more 'profoundly' disabled – an approach that is most evident in Ontario's specialized services network, the Community Networks of Specialized Care, designed for persons with ID who are thought to have complex

needs or dual diagnoses, including what are perceived as behavioural issues. We will return to this segregated network towards the end of this chapter.

With this service landscape in mind, an 'economics of uselessness' helps capture how linear views of (in)capacity can pathologize any perceived failure to be independent and structure access to services according to this judgment. The concepts of independence and autonomy thus provide an important point of entry into challenging the problematic regulation of services. Scholars concerned with how state responses to demands for the deinstitutionalization of persons with ID compare to deinstitutionalization work led by other disability groups often employ a disability feminist theory of inter-dependency to challenge the very possibility of an autonomous subject. Kittay (2001), for example, explores the mutual dependency of persons with ID and those in caregiving roles, promoting an alternative to social contract theories that demand an autonomous citizenry. Her work suggests how service segregation on the basis of the presumed incapacity of persons with ID can be productively challenged through a rethinking of the dependence/independence binary. Kelly's (2016) work on Independent Living provides another strong example of this approach, offering a clear window for viewing how a binary understanding of capacity structures differential treatment towards persons with ID that segregates them not only from the broader community, but also from other disability communities.

As Kelly has shown, the deinstitutionalization movement led by people with physical impairments and/or disabilities often takes the form of Independent Living through direct funding. Unfortunately, however, direct funding has not been the model of choice for people with ID in Ontario and is at times even conflated with individualized funding (see Lord and Hutchinson, 2008, p45), even though it is possible to have one without the other. The reluctance

to implement direct funding can be contrasted with research by Stainton, et al. (2009) reporting on practices in Wales which carry encouraging results related to budgetary concerns. Stainton et al. show that "if implemented effectively, [direct funding] need not be any more costly than traditional services and may over time prove to be less costly" (p171). Stainton, Asgarova and Feduck (2013) arrived at similar conclusions related to cost-effectiveness in a study specifically focused on direct funding for people with ID in British Columbia (p7). Despite such evidence, direct funding and consumer control is by no means the favoured approach taken towards persons with ID.

In Ontario as in most other places, Passport, which MCSS considers a direct form of funding for community participation for persons with ID and respite services for their guardians, merely approximates direct funding. This is because the program requires funding to be attached to and administered by an agency. In other words, Passport funding is not provided directly to recipients. Instead, it is directed to agencies who must then reimburse recipients for eligible service costs. In terms of residential support, there is in fact no money set aside for arrangements that would provide funding directly to individuals and their support network. Just like individualized funding (Pooran, 17 October 20018, personal communication [cited with permission]), direct funding for residential supports remains the exception, not the rule, even while it is possible that there may be some experiments in this area. Along these lines, the advocacy group DANEO states, "There is no provision for direct funding to allow people with intellectual disabilities to make their own choices on where to live and with whom" (DANEO, Key Shortcomings, para. 1). And while the Passport program can certainly be framed as supporting deinstitutionalization, upon closer inspection the program falls short of the empowering promise of Independent Living. Instead, the version of direct funding aimed at

people with ID poses so many restrictions to the exercise of choice that it presents a clash between community understandings of direct-funding and those held by MCSS. Before we can enter into a program-specific critique of direct funding, we must review the Independent Living philosophy of self-managing funds. We will then be equipped to examine how MCSS positions persons with ID within a political economy of 'uselessness' that centres their presumed incapacity for self-management by seeking to supplement these supposed deficiencies.

Returning to the roots of the direct funding movement, Independent Living was born out of a desire to prevent institutional placements by providing individuals with physical impairments and/or disabilities with the means by which they could access and control the supports they required to live in the community. Importantly, direct funding through Independent Living places the disabled person in charge of their own funding and supports – including human supports. But as Kelly (2016) has argued, this direct funding model has generally excluded persons with ID under the reasoning that members of this community do not have the capacity to manage their own support systems. This argument is reflective of several trends that are also apparent in the MCSS-run system and which relate to an "economics of uselessness" (Ferguson, 2004) that organizes access according to perceived (in)capacity. These trends include an obsession with the supposed incapacity and dependency of persons with ID. Complementary to this is the valorization of independence as well as the tendency to stratify persons with ID according to categories that align with their supposed (in)capacity for independence in different areas of life.

We can see this valorization of independence at play in the Passport funding program's stated mandate to "*[f]oster independence* [emphasis added] by building on individuals' abilities and developing community participation, social and daily living skills" (MCSS, Passport

Guidelines). This framing of independence as an unquestioned goal, coupled with a belief in the inherent incapacity of persons with ID promotes an 'economy of uselessness' wherein individuals are ranked according to their in/ability to model forms of independence that dominant groups (specifically, those without an ID) identify as useful. The Passport program and its use of the SIS, as we will see, mark a continuation of this ranking practice in that it is oriented towards a hierarchy of capacity and productivity, even while claiming to offer a version of direct funding. The distinction between what is commonly defined as direct funding and the MCSS Passport program turns on the degree of consumer control that is denied persons with ID. Through a detailed analysis of the SIS and related assessment practices that govern access to Passport, we can begin to see the roots of this struggle for control and self-determination, which echo older policy eras where overt institutionalization was officially condoned.

At the same time, and like most other forms of continuity, these connections are far from straightforward and new ideas about ID are apparent within the Passport literature and the broader sector surrounding the program. And while there are many policy continuities that carry negative consequences, there have also been positive changes. Accounting for such complexities supports a more balanced reading of Passport by acknowledging positive efforts and signs of change. At the same time, this reading is admittedly more concerned with the displacing effects and institutional carry-over manifest in the program, given that these consequences can amount to profound forms of non-citizenship and yet remain both under-theorized and unrecognized. Furthermore, these negative continuities exist in tension with the positive potential that Passport creates for many individuals. Author and disability scholar Newman-Stille articulates this tension nicely by applying the passport metaphor towards accommodation letters in educational settings. Newman-Stille (5 June 2017) describes how mediation by a medico-legal system exposes

disabled people as outsiders until they are granted entry: "I likened the accommodation letter to a passport, allowing us into a space that we are considered unwelcome in and a space where we can have our rights withdrawn at any time" (Able-Bodied People Speaking About Disabled People).

Newman-Stille's account also reflects critiques of postsecondary policies towards disabled students and the systemic modes of exclusion they generate (see for example Hibbs and Pothier, 2005). Connecting Newman-Stille's 'passport' to the MCSS program are eligibility requirements that establish a biomedical foundation for granting access and membership. This foundation frames persons with ID as already-outsiders, as sub-humans who can be situated in Ahuja's (2016) "zones of exclusion". This stigmatized social location is framed as an acceptable position, as there are no guaranteed rights that would allow people with ID to access the supports needed to remove them from here. Worse, the supports that are available and which might facilitate this positive movement are actually premised on an acceptance of their inferior social position. This paradox speaks to Newman-Stille's (5 June 2017) point that disabled people are not welcome and Titchkosky's (2011) observation that their presence is something always unexpected and unanticipated. A perpetual outsider status also informs a key dimension of displacement in colonial contexts and transnational interactions, as Ahuja (2016) and Bhabha (1994) both suggest. It becomes evident, then, that people with ID must negotiate service systems that risk undermining their species-membership. Almost always, these systems use the perceived incapacity of recipients as a justification for the removal or attempted reduction of their right to self-direction.

Evaluative practices and forms of resource-allocation centred on the SIS, whose implementation informs access to Passport, are coercive in the sense that they reduce an

individual's right to make choices about disability supports, replacing this almost entirely with a linking and matching system that assigns funding levels based on the categorical sorting of the (in)capacities of persons with ID. The same system also matches individuals to services by drawing upon the results of these sorting exercises, albeit with more potential for input from the individuals themselves. A detailed discussion of these practices and sorting exercises is presented in Chapter Four.

In their previously-cited article, Artiles, Dorn and Bal (2016) provide a powerful critique of eligibility policies that can help us interpret some of the complexities of the Passport program and its implementation of the SIS. Taking up the issue of educative access for students with disabilities, they find that these students "remain … part of objectified routines" (p797), despite the adoption of rights-based ideas in these settings. The authors account for the ongoing impact of older ideas by identifying entrenched institutional structures and in particular, the development of an "industry of testing" (p787). This industry, according to them, applies diagnostic tools and seeks to enhance administrative authority, and it is through these practices that poor and racialized students are more likely to end up segregated in special education settings (p797). The relationship between racial discrimination, segregation, and testing described throughout Artiles, Dorn, and Bal's account of special education provides valuable insight into how persons with ID can end up in segregative and institutional settings through routines that objectify their identity through clinical methods. Notably, these processes continue to occur despite the official adoption of a deinstitutionalization agenda by Ontario and despite rights-based discourses that attempt to de-medicalize disability. Deinstitutionalization, however, has also been characterized by a devolution of government responsibility and the growth of private non-profit agencies – a trend that we will consider in the next section.

Launching Developmental Services Ontario and the Search for Objectivity and Standardization

As part of the trend towards devolving government responsibility for social services to private agencies, SIPDDA states that "application entities" will be responsible for assessing eligibility for MCSS services and determining an individual's need for services and supports (SIPDDA 14 and 17). These entities are known as DSOs, or developmental services offices. As mentioned earlier, the DSO is made up non-profit private agencies, or application entities, spread across different regions. The DSO was specifically founded with the mandate to regulate access to MCSS services across the province by managing assessment processes and coordinating access to services; DSO agencies are directly funded by MCSS and report to that Ministry. The DSO officially launched in 2011, the same year that SIPDDA took effect. Leading up to this, payment transfers to DSO regional offices and internal memos show that the "phased implementation" of DSO assessments was taking place and included payments to DSOs ("future application entities") in the years leading up to 2011, in order to "build the assessment capacity" of these entities. In June 2010, for example, approximately $1,000,000 in funding was transferred to support the work of assessors (Memo, 12 January 2011). The year prior, 1,300,000 was allocated to DSOs for "the implementation of the Supports Intensity Scale" (Memo, 25 May 2009).

Carebear is familiar with the history of developmental services and explained that planning for the DSO coincided with planning for the Passport program and the introduction of the SIS. Importantly, the SIS was proposed as an evaluative tool along with another standardized tool intended as a supplement, known as the Application for Developmental Services (ADSS). The architects of these programs included service agencies that came together with MCSS

beginning around 2003 and 2006. Notably, and according to Carebear, self-advocacy and family organizations were not involved in this process. The exclusion of these major stakeholders both reflects and helps account for the lack of consumer control within the current system. Between 2007 to 2011, Carebear explained that the architects of the new system live-tested the SIS and ADSS on individuals. The SIS and ADSS are both named in MCSS policy directives and the SIPDDA refers to these directives whenever eligibility and service prioritization are mentioned. As previously explained, policy directives require that all SIS assessors undergo AAIDD training every 18 months. Information obtained through an access to information request reveals that the cost of this training is $1600 per review in addition to "service provider expenses". In 2017 the total contract amount was for up to $370,000 (MCSS and AAIDD, 1 October 2017, p26). Under the current service delivery model and with the number of assessors and clients in the developmental sector growing, we can only expect these costs to rise.

As previously mentioned, MCSS evaluative tools and related programs are all managed and implemented by DSOs. DSOs assess individuals for eligibility and also play a linking and matching role between these clients and provider agencies, but they use only SIS data and information about "caregiver concerns" and "current services and supports" derived from the ADSS to determine Passport funding levels (MCSS, Passport Program Mapping Tool; ADSS Version 3, 2018). As we will see below, four of the five categories that are inputted into the algorithm that determines Passport funding levels that can be accessed by individuals with ID (through the Community Participation Supports) are directly taken from SIS scores, and only one category is based on ADSS information gathered about current supports. The use of standardized forms to determine funding levels is consistent with how Carebear explains the overarching goal in founding the DSO as "a central intake piece"; this is also consistent with how the DSO is

presented in official website materials (DSO, DSO Overview). However, far from forming a straightforward access point, the MCSS-funded service landscape remains confusing to many individuals and families.

The Ombudsman reported in 2016 on how chaotic the situation really is (p17), reinforcing complaints shared during a family forum led by DANEO, where participants reported confusion around how the developmental services system works (DANEO, 27 March 2018 [cited with permission]).[9] The DSO does indeed present a complicated system: it operates through nine regional offices within Ontario and each office receives an annual funding agreement with MCSS. But what is referred to as the DSO Program involves nine different agencies that "provide DSO services in the nine regions" (DSO Toronto Region); these are referred to as "Developmental Services Ontario agencies" (DSO, DSO Overview). However, this description only seems to reflect the role these agencies play in relation to DSO services, and it should be noted that most do not exclusively provide these services. This study, then, refers to the various offices, agencies and actors involved in implementing the DSO Program as DSO or DSOs. Regardless of the arrangement in a particular region, it is DSO administrators who always conduct eligibility assessments for MCSS-funded services.

Adding a further layer of division and decision-making, DSO assessors such as Carebear are often not the same staff who conduct the linking and matching process that shapes service assignments and residential placements. There is thus even further separation between DSO assessors and those who determine Passport funding amounts for individuals. One can detect from this arrangement an attempt at creating an objective process through the separation of powers and processes – an effort that aligns well with the clinical claim to accuracy related to the

[9] While I was a member of DANEO at the time, I did not take part in the forum.

evaluative work performed by assessors. Yet, the practical consequence of this bureaucratization is a deep disconnect between decision-makers and the persons with ID who are affected by their choices, as we will see later on.

A quick scan of this policy landscape lends the impression that there is indeed a deep disconnect around the community's actual needs and the services on offer, and a severe imbalance in how decision-making authority is distributed within the MCSS-managed system. As several informants have complained, funding that goes towards bureaucratic management can impact what is available for direct client services (see also DANEO, Key Shortcomings, para. 3). Frank and Bill both draw attention this problem throughout their interviews. Bill, a manager for a service program, poignantly asked, "how many people do we have doing assessments and coordinating what is essentially no services, there's nothing available, there's nothing to coordinate". He followed up with another question that directly challenges MCSS funding decisions: "why are we spending all this money coordinating and assessing?" Some of the expenditures that Bill refers to include the over $14,000,000 transferred to DSOs in 2017 (Memo, 27 March 2017, p1) with designated amounts for SIS assessments, and the $370, 000 contract with the AAIDD for assessor training from the same year (MCSS and AAIDD, 1 October 2017, p26).

Carebear, who unlike Bill works for and is highly supportive of the DSO and feels that the role played by these agencies are positive, nevertheless described similar issues related to the availability of services. In Carebear's words, MCSS was "putting the cart before the horse" by developing the DSO system before creating the services that they coordinate. The impact observed by Carebear is that DSO administrators are often forced to share "heartbreaking" news with persons with ID and families who approach them hoping for "their big break", only to be

waitlisted for funding and services following their assessment. The focus at MCSS is indeed on regulating rather than enabling access. The failure of assessments to meet the needs of persons with ID will be addressed briefly in this chapter and explored in more detail in Chapter Seven, through an analysis of interviews with persons with ID and their families.

As documented above, part of Ontario's investment in service regulation involves purchasing the SIS from AAIDD, the American-based company who developed and own the tool. It also involves coordinating training for DSO assessors according to AAIDD standards and by contracting AAIDD staff. This training is part of the stated effort to ensure consistency across the province and is mandated to take place every 18 months (MCSS, Directive). However, a clinically oriented study by Brown et al. (2009) suggests that one of the problems in administering the SIS relates to the time required to apply tool – including "the extensive training required of interviewers" (p954). At the start of their careers, all DSO assessors must pass an initial certification program managed by MCSS (MCSS, Directive). Carebear explains that the MCSS trainer is someone who directly works for the AAIDD, and that DSO assessors also undergo regular assessments by the same organization. Carebear's description is consistent with the budget information cited throughout this chapter. As mentioned earlier, contracts between MCSS and the AAIDD, obtained through an access to information request, show that the regular reviews that follow the initial training, referred to as the "SIS interview reliability and qualifications review", cost $16, 000 per review, in addition to AAIDD fees for "service provider expenses"; the total costs of this review process are reflected in a contract between the AAIDD and MCSS for up to $370,000 in 2017 (MCSS and AAIDD, 1 October 2017, p26). Individual reviews occur "at various locations within the province" (p24) and involve "a comprehensive discussion/debrief with the trainee". The AAIDD is also contracted to report to the DSO and

MCSS with the results, noting "any assessors who do not reach Status" (p25). This approach to implementation suggests that overall, the evaluative process is treated as an objective practice that can be perfected through training and then measured for accuracy. After all, assessors are shadowed by an MCSS SIS-trainer and their results are scrutinized for accuracy. Yet, as we will see, the objectivity of the SIS and the decisions that are based on the clinical claims of this tool can and ought to be challenged through a qualitative analysis that is attentive to lived experiences of disability displacement.

As previously explained, by turning the responsibility for assessments and service matching over to the DSOs, Ontario has moved access to services and funding into the area of "soft law", where it becomes much harder to challenge wrongful decision-making. We should recall here that "soft law", according to Sossin and Pottie (2005), encompasses how the manuals, directives, and other documents not commonly considered as legal work to regulate resource provision. The authors outline the challenges that soft law has posed in efforts to attain justice, emphasizing that while it remains integral to forms of decision-making in social service provision, it is typically viewed as existing beyond the scope of the justice system, thus undermining any recourse recipients may have when problems arise. Again, this gap between problem and remedy is part of the devolution of government responsibility and further indicates SIPPDA's failure to ground the supports needed for substantive citizenship in actual rights.

Documenting Intellectual Disability – A Three-Pronged Assessment Process

We can approach some of the limitations in current approaches to ID by taking a ground-level view of how access to developmental services works and then linking these processes to certain ideological investments made by the province. When someone approaches a DSO to access MCSS-funded services, they must demonstrate that they have an ID. SIPPDA defines ID

as “limitations in cognitive functioning *and* adaptive functioning” that are likely to be permanent, impact the ability for independence, and began before the age of 18 (SIPPDA, 3(1)). This definition is similar to the AAIDD’s definition of ID as “a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills… [and] originates before the age of 18” (AAIDD, Definition). By referencing childhood onset (“before the age of 18”), the AAIDD is appealing to the idea of chronicity, or permanency, of the impairment. Furthermore, to satisfy the eligibility requirement set out in the SIPPDA, persons with ID must demonstrate their incapacity through either an IQ test – “an overall score of two standard deviations below the mean, plus or minus standard error measurement” either on “a standardized intelligence test” or, “in two or more subscales on a standardized intelligence test” coupled with “a history of requiring habilitative supports” (Regulation 276/10, 2.1); a determination of “signification limitations in cognitive functioning” coupled with use of habilitative supports; or through a standardized adaptive behaviour test where they score “at least two standard deviations below the mean, plus or minus standard error measurement, in at least one of the areas of conceptual skills, social skills, or practical skills” (Regulation 276/10, 3). All tests must be performed by a psychologist or psychological associate. An individual must also demonstrate their age and proof of Ontario residency. Individuals need to be at least 16 years of age to access the DSO, but at least 18 years of age to access Passport and other MCSS-funded services. As mentioned, these programs can only be accessed after a SIS evaluation and ADSS are completed. To summarize, in addition to proof of age and residency, all MCSS funded programs, including Passport, require a three-pronged assessment that includes: an IQ test or similar proof of “significant limitations in

cognitive functioning" i.e. an adaptive behaviour/functioning test, a SIS evaluation, and an ADSS.

Even though IQ and adaptive functioning tests are both listed in the SIPDDA and associated regulations as a means of demonstrating ID, in practice IQ testing remains a relied-upon measure. Yet, the American Psychological Association (APA) indicates a major shift away from IQ and towards adaptative functioning (Tassé, 2016) beginning with the DSM-5, explaining that while IQ testing is still used to diagnose ID it is not mandatory and should be used in conjunction with adaptive functioning testing (APA, 2017). The APA's definition of adaptative functioning (2017) is similar to the AAIDD's, which states that it "covers many everyday social and practical skills" (AAIDD, Definition of ID). The AAIDD claims that "[s]tandardized tests can also determine limitations in adaptive behavior" (Ibid.) The AAIDD and APA's understanding of the role of IQ testing should nevertheless be contrasted with Rapley's (2004) finding, drawing directly on Greenspan (1994), of the potential that IQ has maintained its influence as a "dominant, if silent partner in the 'diagnosis' of ID" (Rapley, 2004, p48). These insights are supported by the APA's suggestion that IQ ("intellectual functioning") and adaptative functioning tests "complement each other", but his findings do not sit well with the organization's claim that the tests involve "two separate and distinct constructs" (Tassé, 2016). Approaching ID through the broader notion of (in)capacity or incompetency helps account for the relationship between IQ and adaptative behaviour. Rapley's research suggests that impaired 'competence' encompasses the possibility of intellectual 'deficiency' (p48), as well as supposed deficiencies in adaptive abilities related to '"conceptual skills"' that are linked to intelligence (p40). Helpfully, he quotes Das, Neglieri and Kirby (1994), who argue that adaptive functioning

stems from competence, which "is another name for cognitive functioning or ability" (pp143-144, quoted in Rapley, 2004, p48).

These findings are further supported by the fact that the alternative to IQ testing, an adaptive behaviour or functioning test, is not mentioned by any of the participants interviewed for this study. In fact, Frank and Carebear specifically refer to IQ scores as being collected by DSOs and as the standard used to decide whether an individual is eligible for MCSS-funded services. Furthermore, there is arguably little difference in providing the DSO with results from an IQ test, which asks about intellectual capacity, or an adaptive functioning test, which looks at competency, as both of these requirements participate in the same deficiency-oriented approach to ID that continues to define persons with ID as having a disorder in thinking (see Rapley, 2004, p48). Furthering this point, my reading of Rapley (2004) suggests that adaptive behaviour and/or functioning and other new testing methods are akin to IQ testing in the sense that their focus remains fixed on issues of intelligence and capacity, even while they present the claim that it is an individual's 'competency' that is being measured. The difference between testing for intelligence and testing for adaptability is a slim one in this regard. As Rapley's discussion, drawing on several other authors, suggests, 'defective' intelligence is often inferred from 'defective' adaptive abilities associated with competencies, and vice versa (p48).

The two tests for ID also share a common lineage: adaptive functioning and behaviour tests evolved from other normative measures, such as the IQ, by incorporating newer normative measures focused on specific aspects of daily living. Stephen (2007) indicates a similar shift during the 1940s, when the mental hygiene movement began to consider "the conditions' of 'normal' personality development" (p75), all with the aim to "better understand mental abilities" (p78). Importantly, and recalling the previous discussion of Rapley (2004), areas of daily living

outlined in adaptive functioning tests can still fit under the umbrella-concept of competency, which is closely related to capacity and encompasses the idea of intellectual 'deficiency'. According to Das, Naglieri, and Kirby (1994), as quoted in Rapley (2004, p48), competency is partly what constitutes adaptive behaviour (Das, Naglieri, and Kirby, 1994, pp143-144). We must recall here as well that Rapley, referring to Greenspan (1994), points out that IQ potentially remains present and more influential than incompetency, as a "dominant, if silent partner" (Rapley, 2004, p48). This claim is reflected in Carebear and Frank's insights around the importance of IQ testing, as well as in the definition of adaptive functioning presented in the Ministry's own regulations (Regulation), reviewed earlier. IQ testing, then, can be read as both a dominant eligibility requirement in Ontario, and a dominant concept that shapes alternative methods of testing such as adaptive functioning.

Given earlier observations by the Ontario Ombudsman (2016) that the nature and quality of developmental services varies widely across the province, it appears that one of the only guaranteed standards in Ontario is a reliance on standardized tools such as IQ tests, adaptive functioning, and the SIS. The emphasis on consistency in testing reflects the broader tendency to put resource management ahead of resource-creation and, along with this, the monitoring of marginalized people ahead of efforts to support them. Yet these evaluative standards, as suggested earlier, are far from objective and reliable. Rapley's (2004) research speaks directly to this point and provides a rare opening into the under-studied world of professional interactions with persons with ID, presenting a careful analysis of encounters between individuals and their support staff and assessors. His findings cast doubt on claims to fairness and accuracy in testing and help call into question both IQ and adaptative functioning criteria. Applying a theory of governmentality largely derived from Rose's critique of the psy-complex, Rapley draws attention

to the relational contexts in which tests for ID occur, exposing the uneven power dynamics that structure these encounters and the ways these shape the "interactional production of competence" (p5). Rapley supports the claim that since ID is relationally produced, its defining characteristic – incompetency – cannot be detected through positivist testing methods. His research further demonstrates that even while testing environments are "artificial", they generate claims about how persons with ID exist in the world on a daily basis. In his words, "the asking of bizarre, unoccasioned, questions" (p29), that are often used in testing contexts can facilitate the outsider status of persons with ID, leading to their "disqualification … as human agents" (p29). His explanation of the "distorting account" (p50) that is produced through psychometric testing further suggests how these experiences can shape displaced subjectivities by undermining the human status of persons with ID.

Measurements of intelligence based on IQ testing, which informants suggest have superseded other forms of proof of ID status in the MCSS funded system, remain controversial tools with biopolitical ramifications. This is because the very practice of measuring IQ is linked to the modern idea that intelligence is a mark of membership in the human species. As Goodey (2016) puts it, intelligence is the "*core definition of the human species as a whole* [emphasis Goodey's]" (p13). Goodey further describes how "human self-representation" (p28) is often based on claims to intelligence even while intelligence remains a murky social construct, "an unstable, already political concept at root" (p36). He contends that intelligence and IQ are in fact unmeasurable, and that efforts to create impairment categories based on such measures stem from preconceived negative perceptions held by assessors about individuals labelled with ID. Along these lines, intelligence testing assumes the *a priori* existence of an intellectual deficiency and then sets out to prove this supposition by identifying individuals who 'actually' have

intellectual deficiencies. Goodey frames this process as being oriented towards efforts to expose deficiency, stating "[t]hese tests' ultimate task … was to expose ('help') the deficient" (p57).

Goodey's critique, much like Rapley's (2004), throws into question dominant definitions of ID that draw upon notions of (in)capacity. Perhaps more forcefully than Rapley, Goodey (2016) emphasizes the ways in which intelligence, as a definitive species-marker, has been used to undermine the human status of persons with ID. At this point it is helpful to recall that in Ontario, as in most other places in Canada, one of the ethical and practical consequences of labelling someone as 'deficient' in their ability to think and reason includes the legal and extralegal removal of their ability to be formally recognized before the law. Having their capacity-recognition and legal status stripped from them positions persons with ID as non-citizens who are denied the right to make decisions about their own lives. The legacy and legitimacy of this deficiency-oriented approach to testing must be explored and then linked to newer testing methods in order to fully appreciate its relationship to displacement. The ways in which the SIS and the immigration medical exam participate in the logic exhibited by earlier deficiency-oriented approaches to disability are among the questions that will be addressed in this chapter and the next through the inter-related concepts of (in)capacity and (under)development.

It seems clear then that intelligence, or more accurately, intellectual deficiency, remains the definitive characteristic of ID. As previously demonstrated, IQ testing is set out in SIPDDA and appears throughout policy directives that establish eligibility testing for MCSS-funded services. Even though the law allows for adaptive functioning testing, my reading of Rapley (2004) has argued that such measures simply mark a continuation of IQ-oriented thinking about ID in that they maintain an interest in detecting a form of incompetency that is co-constitutive

with intellectual incapacity. Yet, MCSS' description of SIPDDA misses this crucial link to traditional and derogatory definitions of ID, claiming instead that the Act adopts an updated understanding of ID. MCSS draws attention to this supposedly new conceptualization in the following statement: "The new definition of developmental disability is not based strictly on IQ. It also considers how a person handles common demands in life and how independent they are compared to others of a similar age and background" (MCSS, Legislation). Yet there is nothing radical in the approach reflected in MCSS legislation and practices, since ID is still characterized in comparative terms that focus on an individual's ability or failure to 'handle' aspects of daily living that are considered "common". Consequently, this claim to a "new definition", which follows the APA and AAIDD's inclusion of adaptative functioning testing, conveys a profound misrecognition of deficiency-oriented thinking about persons with ID as one of the underlying factors shaping the forms of exclusion and displacement confronting this community. The ability for MCSS to guide dignified service provision is undermined when deficiency-oriented views of ID confront individuals the moment they approach service agencies and challenge the capacity of these intended clients. This undermining is facilitated by the implementation of evaluative methods and requirements that entrench the controversial IQ measure, albeit alongside other related measures of normativity.

Earlier, we saw that before a person with an ID can apply for MCSS-funded services and undergo the evaluative process that includes the SIS and the ADSS, they must provide proof to the DSO of an external psychological examination that demonstrates a level of incapacity. Relatedly, deficiency-oriented views of persons with ID that stem from IQ testing spill over into the evaluative tools implemented by the DSOs. Yet, IQ testing is a problematic practice both in methodological and historical terms, as the next section of this chapter addresses in more detail,

posing ethical and practical challenges that carryover into other interactions between the DSO and persons with ID.

In terms of the ways in which IQ requirements disqualify individuals for support, Frank and Carebear, who both have experience working for a DSO agency, refer to issues surrounding the rule that an individual's IQ must fall a certain level below the 'norm' – a criteria specified in the Act's regulations (Regulation 276/10, s.2).[10] On a practical level, this requirement is restrictive since it denies access to individuals who perform 'too well' on IQ tests, but who may nevertheless require certain supports for daily living. Frank and Carebear both recall that the actual level of IQ that is accepted by the DSO as proof of an ID has changed over time, which is suggestive of the subjective nature of this criteria. When asked about IQ-based service exclusions and specifically about individuals with Fetal Alcohol Spectrum Disorder who are known to seek developmental services (see DANEO, Key Shortcomings, para. 2), Carebear agreed that certain individuals can indeed be excluded and expressed concern about the consequences, stating "I am afraid to find out where those people end up". When individuals do meet the burden of proof and can demonstrate their ID status, they proceed to the next phase of the assessment process, which we will now consider through a brief look at the history of IQ testing.

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[10] Regulation 276/10, s.2: Significant limitations in cognitive functioning:
2. (1) For the purposes of subsection 3 (1) of the Act, a person has significant limitations in cognitive functioning if the person meets one of the following criteria:
1. The person has an overall score of two standard deviations below the mean, plus or minus standard error measurement, on a standardized intelligence test.
2. The person has a score of two standard deviations below the mean in two or more subscales on a standardized intelligence test and the person has a history of requiring habilitative support.
3. On the basis of a clinical determination made by a psychologist or a psychological associate, the person demonstrates significant limitations in cognitive functioning and the person has a history of requiring habilitative support.

A Governmentality of Incapacity: From IQ Testing Onwards

As the previous section suggests, one of the consequences of entrenching IQ-related testing in the SIPDDA and within DSO practices is the shaping of a broader assessment culture that focuses on the incapacity of persons with ID. This is a culture that reinforces dehumanizing assumptions around the competency and ability of persons with ID to make decisions about their own lives. Implementation of key assessment and eligibility tools established in MCSS regulations and directives – the IQ test, adaptive functioning test, and the SIS – can be framed as participating in a governmentality of (in)capacity that potentially shapes displacement experiences through a reliance on normative standards and relatedly, the *a priori* assumption that intelligence and a capacity for independence are measurable. Also related to MCSS criteria is the conceptual premise, mentioned earlier, that persons with ID are incapable of fully exercising their capacity for decision-making. Importantly, this is a premise that challenges the species-membership of people with ID at the very outset of their encounter with the service system.

From this assumption of incapacity flows the many processes that require individuals to be tested according to normative measures and slotted into categories that determine their Passport funding level and potential access to any available, pre-designed services that are intended to facilitate their social participation. Failure to fit into these service categories, to obtain adequate supports through an assigned funding level, or to meet the criteria set out by providers, can result in profound segregation through a lack of access to substantive rights and a limited ability to be present in the community. In some cases, as will be discussed towards the end of this chapter, the inability to meet the expectations of service providers can lead to a further degree of segregation within the developmental services system, such as being assigned to a special category of support administered through the Community Networks for Specialized

Care. Because persons with ID are already positioned as potential members of "zones of exclusion", to borrow Ahuja's (2016) term, that risk keeping them apart from the human species on the basis of their supposedly impaired capacity, this taxonomical and deeply stratifying approach to evaluating individuals for services and funding is viewed by some stakeholders as being helpful. Meanwhile, the potentially displacing effects of these systems are not readily grasped. To appreciate the problematic nature of these service arrangements we must return to the history of the still-dominant test for ID – the intelligence quotient.

IQ testing has served a largely disciplinary function towards persons with ID as well as towards other marginalized communities and racialized communities in particular (see for example Singham, 2001; Mensch and Mensch, 1991). Historical research also shows how testing for sub-normal intelligence has guided the eugenic violence of forced confinement, forced sterilization, and deportation. Carrie Anne Ford (2017), in her reflections on Huronia, describes being assessed at the very beginning of her custodial career, "to see where I would be put" (p15). Her history speaks to the influential role of assessment practices in shaping experiences of non-citizenship through spatial displacement and in Ford's case, forced confinement. The various iterations and roles played by IQ testing in Canada have been detailed by historians of education (see Ellis, 2018) and the welfare state (Stephen, 2007) and will not be discussed in great detail here. Importantly, however, Stephen (2007) demonstrates that IQ testing became integral to social planning following WWII, establishing the role of psychological expertise within an atmosphere where regulating 'the norm' was treated as a pressing priority.

Equally important to the present discussion is how findings from this body of research link IQ testing to cultural norms that punish Indigenous people, racialized people, migrants, and poor people, as well as disability communities. As Chen's (2016) work suggests, linear views of

individual development shape intersectional forms of oppression because they are simultaneously applied on a broader scale that looks at race-membership. This view of intellectual development is conducive to an analysis of (neo)colonial processes impacting transnational migration and settler colonial immigration systems that employ medical testing, as discussed in Chapters Five and Six. Importantly, Chen's conceptualization of ID as bound up with racist assumptions reveals a linear ranking system similar to Goodey's "ladder of nature" (2011), Ferguson's "economics of uselessness" (2004), and the questionable practice of IQ testing that reinforces perceptions of individuals with ID as sub-human.

Gould's (1996) famous account of the development of the intelligence quotient challenges the very accuracy and usefulness of the practice of measuring intellectual capacity in scientific and methodological terms that support Goodey's (2016) critique of the quantification of intelligence. In Gould's (1996) effort to disprove white supremacist claims that racialized people are intellectually inferior, he outlines two fallacies that are apparent in any attempt to measure human intellect. The first involves the reification of the concept of intelligence while the second addresses the reductionist practice of numerical linear ranking ("ordering complex variation as a gradual ascending scale"), that arrives at "an objective number" (p56). There is an important lesson to learn from Gould's history of IQ and his identification of related scientific fallacies. Such lessons can be applied towards MCSS' implementation of the SIS and other management tools and practices that aim to facilitate community inclusion. Similarly, and as Gould explains, the goal of developing IQ measures was not inherently oppressive. In fact, American medical practitioners like Goddard altered one of the original founder's (Binet's) motivation in developing IQ testing, which was to "identify in order to help" (p189). Conversely, Goddard and others wanted to "identify in order to recognize limits, segregate, and curtail

breeding", in the name of protecting "an endangered American stock" (p189). We can easily see how related work would try to promote a white and non-disabled dominant society free of supposed defects.

Much like the IQ test, the SIS appears to encompass mixed motives as well as effects. In addition to its similarities to adaptive functioning testing (Brown et al., 2009), the SIS can also be viewed as an out-growth of the IQ model as a result of its participation in the reductionist tendencies outlined by Gould (1996) and its related concern with an individual's capacity for independence. Some of the underlying aims of the tool certainly reflect a genuine desire to help and support individuals, as Carebear has described. These can be traced in the way results assist providers in matching individuals to what DSO administrators consider to be appropriate funding levels and services. At the same time, this matching process can carry displacing effects that stem from the deficiency-oriented view of persons with ID that is embedded within the biopolitical implementation of the SIS. As previously explained, a deficiency-oriented perspective is suggested by the AAIDD's framing of support needs as those required to meet normative standards. The biopolitical potential of the SIS is arguably reflected in the ways in which the tool promotes stratification based on assumed needs and simultaneously the way its implementation in Ontario limits individual options through the assignment of related documentary identities.

Likewise, the SIS applies a linear ranking model and relies on the reification of multiple actions and embodied experiences, indirectly asking about the (in)capacity of persons with ID for independence across different life domains. Perhaps not surprisingly, DSO administrators, front-line service providers, persons with ID and families interviewed for this study disagreed on the benefits of the MCSS evaluative processes. While Carebear, a current DSO assessor, finds the

SIS useful, Frank, who formerly worked for a DSO agency and who is now a front-line provider, and Bill, who runs a service program that DSO links clients to, are highly critical of the tool. Furthermore, none of the persons with ID or relatives who took part in this study described their experience with the SIS as helpful and most found the assessment experience to be quite difficult. These participant narratives will be explored in detail in Chapter Seven and we will see how, similar to Bill and Frank, much of the feedback received from those experiencing assessments is negative and suggests that current evaluative processes can carry displacing effects. Any benefits that arise from 'accurate' matching to services and funding are thus reliant on sorting and assessment practices that also carry the potential to generate harmful repercussions as a result of their pretense to objectivity, their attempt to both quantify and order complex forms of human difference, and the premise that intellectual deficiency or ID is a measurable entity in the first place.

As previously mentioned, the SIS is implemented through a linking process that is used to match persons with ID for all MCSS funded services and determine Passport funding levels. And while the concept of IQ and 'adaptability' play a key gate-keeping function for MCSS-related services, these are not methods of evaluation that Ontario invests in or oversees, since DSOs do not directly perform IQ or adaptive behaviour testing. Rather, the agencies require that individuals provide proof of ID and then proceed to refine their understanding of an individual's supposedly impaired capacity for independence through the SIS. MCSS is open about the fact that it uses the SIS to evaluate the support needs of persons with ID in terms of their capacity to be independent. But the extent to which these evaluations differ from IQ or, as Brown et al. (2009) claim, adaptive functioning tests, may be challenged through Rapley's insights (2004). Along with MCSS and the DSOs that implement the SIS, the developer and owner of the tool,

the AAIDD, has not drawn such connections. As we have seen, the AAIDD frames the SIS as being distinct from adaptive functioning tests.

Nevertheless, a historically informed analysis that is attentive to a governmentality of (in)capacity shows that Ontario's implementation of the SIS assessment resembles Gould's (1996) description of "the ladder of progress as a model for organizing life" (p348). Accordingly, the SIS can be viewed as performing this organizing work through what Gould describes as "the reification of some abstract quality", using abstraction as "a criterion for ranking" (p348). Within the structure of the SIS, these abstract qualities are the capacity for independence across different life domains – framed as the supports needed for normative functioning, as the next chapter will explain. For now, it should be emphasized that what distinguishes the SIS from earlier evaluative methods and adaptative behaviour tests in particular is its interest in documenting the frequency and degree of support needs. At the same time, however, the AAIDD is clear that these needs can be understood in relation to normative expectations. In this sense, and by applying a critical disability lens, support needs may be understood as the outcome of specific disability-related 'deficiencies'.

It is also important to note that the AAIDD intended for the SIS to inform decision-making and to be applied alongside "person-centred planning" (SIS User's Manual, 2015, p1). In practice, however, Ontario uses SIS scores to determine funding amounts, priorities for services, and to match individuals with specific services – an exercise that requires DSO administrators to limit the scope of services and dollar amounts that persons with ID can access. Narratives shared by participants involved in this study suggest that some of these decisions are partly based on a DSO administrator's view of what constitutes a good match, as well as their interpretation of SIS interviews and ADSS results. Passport funding, however, is largely determined by the entry of

SIS results into a standardized scoring tool, the Passport Program Mapping Tool, which will be analyzed in the next chapter.

The way in which MCSS implements the SIS as a resource management tool can be treated on a continuum with earlier forms of ranking that were applied in institutional contexts, including asylums, and that resulted in differential treatment within these environments (see Ferguson, 2004; Dwyer, 2004). All of these methods reflect what Gould (1996) refers to as "unilinear ranking by implied worth" (p348), given that they assign resources based on evaluative results that stratify the ID population. To this point, Dwyer (2004) exposes how in institutional contexts, several categories were drawn around the perceived degree of intellectual impairment and used to determine ward placements, the degree of punitive treatment received, and other aspects of daily living. From this account we can see how the ordering principles that shaped who ended up where within the asylum hierarchy are readily linked to Ferguson's "economics of uselessness" (1994; 2004), and perceptions of an individual's (in)capacity for productivity. Such economic thinking is active across different policy eras and areas (see for example Posner, 1973). We will see in Chapters Five and Six how the same logic shapes transnational resource allocation and observe striking similarities in the ways that migrants are assessed and granted differing levels of access and 'presence' based on their predicted use of health and social services and the imagined contributions they will make to Canada's development.

MCSS-mandated DSO assessment practices also mobilize an "economics of uselessness" by suggesting that certain individuals are not the appropriate recipients of certain resources. The hidden rationale is that they are either undeserving or incapable of using those resources. This notion of (in)capacity and (un)deservedness can be linked to clinical evaluations that rely upon

and reinforce a hierarchy of impairment wherein persons with ID are situated at the lowest level as a result of their perceived connection to dependency. Even further stratification occurs among those who are placed at the bottom of the ladder of development that informs this low-ranking form of impairment, as work by Ferguson (see especially 2014), Dwyer (2004), and Goodey (2016) all demonstrate. Ferguson (1994; 2004; 2014), for example, has argued that some persons with ID are viewed as "chronic" and "incurable" cases. It was thought that these individuals were "therapeutic failure[s]", immune to the benefits of supportive resources such as education (2014, p47). As a result, they were placed in what Ferguson refers to as the "back wards", or "institutions within institutions" (p57). Due to their lowly status, these supposedly chronic cases were banished to "those out-of-sight hellholes where the inmates with the most significant disabilities, the most challenging behaviors, the most hopeless of prognoses were abandoned" (p46).

Some of the dangers of scoring low in a linear-based system, as Dwyer (2004) shows, include receiving fewer supports and worse forms of treatment. Dwyer's research is especially concerned with the historical treatment of persons with ID with multiple impairments who were confined in Craig Colony, New York. However, individual IQ scores and assumptions that the supposed deficiencies of persons with ID are chronic or permanent continue to justify decisions about the services and funding they can access. For example, in defining ID, SIPDDA outlines that the condition must be permanent, i.e. "life-long in nature" (SIPDDA, Definitions, 3(b)). Such static views of human need invoke the concept of 'chronicity' and often fail to capture the fluid and relational nature of the ID experiences. In the next chapter, we will take a closer look at how DSOs are active in regulating the potential for (non)citizenship and displacement based the

view that support needs are both static and predictable and that ID realities can be accurately captured by assessment tools.

Concluding Thoughts

This chapter has reviewed dominant framings of ID and MCSS' implementation of assessment tools in order to situate them within legacies of institutionalization. It has done so by focusing on the production of knowledge about (in)capacity and the related practice of establishing hierarchies around this concept. Over the course of this discussion, we have seen that many of the assumptions supporting institutionalization can be detected in newer policies and in current laws that structure the developmental services sector. These assumptions rely on problematic views of (in)capacity as measurable and the pathologization of 'dependency'.

The displacing effects of these dominant views of ID and the processes that stem from and shape them are both spatial and subjective and relate to the role of ID as a potential marker of sub-human status. The adoption of the SIS as an assessment tool by MCSS is implicated in these trends, and its implementation has also taken place through the delegation of government responsibility into the private non-profit sector. Similarly, access to the disability services and supports required for individuals with ID to exercise substantive citizenship have been placed in the realm of "soft law", posing significant barriers to justice. Overall, this chapter has provided a portrait of the developmental services sector as disempowering, confusing, and both decentralized and top-down, wherein policies are carried out by private agencies through a paternalistic model of service delivery regulated by standardized testing. In the next chapter, we will consider how these specific characteristics shape the implementation of SIS assessments in relation to Passport funding decisions and support the potential displacement of people with ID.

Chapter Four: Evaluating Access to Developmental Services in Ontario

Introduction

In the previous chapter, we saw how the legislation that governs developmental services in Ontario reflects notions of (in)capacity that reinforce binary views of independence and problematic constructs such as the intelligence quotient (IQ). In this chapter, we will take a closer look at how the SIS, the key evaluative tool implemented under MCSS directives, reflects hierarchies that are built around these dominant and historic understandings of (in)capacity. We will see how certain views of people with ID shape front-line interactions and decision-making in ways that deeply impact their opportunities for enacting substantive citizenship, to be present in the community in meaningful ways, to shape their self-understanding, and to maintain a degree of control over their own lives. These impacts will be explored in relation to the Passport funding program and to a lesser extent, through the linking and matching role played by the DSOs. Broader questions around whether resource allocation and decision-making are individualized and reflective of an individual's reality will be addressed throughout this discussion in relation to the displacing potential of evaluative practices that reinforce medicalized views of (in)capacity.

Medicalized evaluative techniques can include practices developed by clinicians and that extend beyond the examining room. This is certainly the case in Ontario's developmental services sector where the SIS is applied by non-clinicians such as Carebear, a participant in this study who currently works for a DSO agency. The resulting SIS scores, according to the AAIDD (SIS User's Manual, 2015), can assist in resource allocation when combined with some additional questions about the individual (p90), and "used in conjunction with person-centred planning" (p1). Accordingly, the DSO employs SIS scores to make decisions about Passport

funding levels. The results, used in conjunction with data gathered through the ADSS, also influence decisions around other MCSS-funded services. The fact that medical practitioners are neither responsible for SIS-testing nor funding decisions does not, however, belie the biopolitical dimensions of the tool. Nor does it diminish its ability to regulate and shape individual relationships to (non)citizenship by drawing on normative and medicalized understandings of perceived (in)capacities. If anything, the application of SIS testing by a non-clinical bureaucracy speaks to the pervasive influence of medical thinking in our society that extends from the asylum-era and is evident in IQ testing.

Eugenic concerns from the asylum-era shaped the mental hygiene movement so that an early focus on IQ testing and the detection of intellectual 'deficiency' was eventually broadened to encompass other dimensions of (in)capacity. Relatedly, Stephen (2007) identifies a major shift that occurred during the 1940s when the belief in "the full range of human capacities as quantifiable" supported the desire to test for more than simply IQ (p85). This early trend finds a close echo in Rapley's (2004) references to adaptative functioning and other forms of assessment as performing a similar function as IQ testing. Similarly, this chapter presents a critical reading of Ontario's implementation of the SIS that suggests that by assessing support needs, the tool also ranks individuals according to their failure to exercise a capacity for independence in daily living, as reflected in coded understandings of normalcy that permeate the developmental sector. At the same time, this reading of the SIS shows how applications of the tool can participate in the production of knowledge about what a 'capacity for independence' should look like, setting out a new "grid of intelligibility" (Foucault, 1990, p93). This grid, of course, is informed by pathologizing assumptions about the perceived 'dependencies' and 'incapacities' of people with ID.

Shaping Opportunities for 'Meaningful Belonging' – The Supports Intensity Scale in Context and Practice

An interpretation of Ontario's application of the SIS as contributing to a grid of intelligibility based on capacity hierarchies is strengthened by earlier critiques shared by community members. For example, Inclusion Alberta, a parent-led advocacy organization that pushed for the removal of the SIS as a testing tool within that province, accused the SIS of "categoriz[ing] people on the basis of their disability, with no demonstrated benefit to individuals and their families" (Inclusion Alberta, 2015). Advocates suggested that Alberta's use of the SIS failed to support a model of individualized funding because it framed individual needs through categories rather than responding to and accurately capturing specific circumstances. In Ontario, DANEO recommends that MCSS "***c****ollaborate with Disabled People to Revise the Needs Assessment Process* [sic; emphasis DANEO's] to make it accessible and respectful of people's ability to know best what supports they need and their right to decide (DANEO, Recommendations, 2). At the same time, proponents of the SIS argue the exact opposite, describing the tool as a way of supporting individualized funding when used in combination with other intake processes. In Ontario, the DSO does incorporate a second intake form, the ADSS, but as will be demonstrated, SIS results far outweigh those achieved through this second tool and remain the more influential source of information shaping the decision-making process when it comes to Passport funding.

A close-reading of the SIS also shows how implementation of the tool upholds discourses around normalcy that risk displacing persons with ID, suggesting a deficit-oriented view of ID that is akin to understandings set out in the SIPPDA. The AAIDD SIS User's Manual (2015) articulates such deficit-oriented thinking, describing an overall approach to ID in a statement that

defines persons with ID as being 'delayed' in their learning and development. The Manual states, "[t]raditionally, people with IDD have been understood by the extent of their deficits and diagnoses on the basis of significant limitations in intelligence and adaptive behaviour. This is because limitations are manifested in people's lives by *delays in learning and development* [emphasis added]" (p2).

Even though the SIS does not directly name incapacity, the tool presents a linear ranking method related to the supports that are needed for independence. In this way, it generates numerical values aligned with different support levels that inherently depend upon the classification of perceived deviations from an imagined norm. This approach is closely underpinned by a deficit-oriented view of persons with ID that projects onto them the idea of 'delayed development', suggesting that it is these individuals who must modify their way of living to 'keep up' with current social arrangements. The fact that the AAIDD manual refers to persons with ID's supports as "extraordinary," stating that the SIS can help "identify people's extraordinary support needs" (p2), is further suggestive of an outlook that pathologizes and frames support needs as resulting from an inability to live according to normative standards of independence which. Recalling Wendell (1996), however, such standards are neither possible nor desirable for all disabled people (p56).

Even while the SIS is a relatively recent tool, designing disability supports according to a paradigm of independence is not. On the contrary, such an approach fits the long-standing fascination and clinical interest in ordering persons with ID according to their perceived degree of incapacity. Thinking back on institutional contexts, Radford (1991) explains that the marginalization of the ID community has had more to do with the notion that they are incapable. He explains how, "[m]ental defectives were not put away because of a medical condition or

educational failure, but because they could not fit with our highly organized modern world" (p456). In other words, the spatial displacement of persons with ID was never exclusively based on any objective measure of their ascribed pathology, as justified by low IQ scores. Rather, their displacement was defended on the basis that they somehow deviated from established social norms. In the case of the SIS, we can see how these norms shape the belief that disability supports ought to align to the degree of (in)dependency or (in)capacity experienced by a person with an ID.

Through this model of service assessment, autonomy and independence are promoted as a criterion of citizenship and belonging. Of course, the process of identifying an individual's support needs does not amount to an inherent condemnation of their capacity for citizenship, and as previously mentioned, good intentions likely motivate such assessments. The issue, rather, is around how support needs are identified and interpreted, and the degree to which the person with the disability retains control over defining their reality and potential needs. Rather than asking adults with ID to identify their own support needs, the SIS encourages assessors to rank these individuals according to pre-conceived categories. This is most evident in directives given to assessors instructing them to ask all the questions on the evaluation form. This requirement means that regardless of whether an individual feels they require support in a certain area, they are nevertheless asked about their ability to perform that activity (without support), so that the results can be factored into their overall SIS score.

Far from a consumer-led approach to identifying support needs, the SIS can be situated alongside older medicalized techniques, such as adaptive functioning and the IQ test, that have been used to rank and order disabled people according to normative and largely non-disabled perceptions of reality that valorize independence. One of the most pervasive examples of this

impulse to organize disabled lives according to the paradigm of independence can be seen in the drive to 'cure' disability-related impairments and 'disorderly bodies'. Wendell's (1996) intervention into the struggle over 'disorderly bodies' applies a feminist disability lens to draw attention to disciplinary practices (p88) related to "the widespread myth that the body can be controlled" (p93). This myth supports rehabilitative strategies that aim to cure disabled people of their perceived dependency. While acknowledging that the mandate to cure holds positive effects for some disabled people (p11), Wendell takes issue with its broad application, arguing that "neither independence nor integration is always an appropriate goal" (p56). As an example, she points to material "limitations" that accompany some – but importantly, not all – forms of impairment, and which cannot be changed (p45).

As Kittay (2001) has argued, an overriding preoccupation with independence is typical of citizenship cultures derived from a liberalist social contract theory. Reflecting on the experiences of her daughter, who is a person with an ID, Kittay promotes an alternative to this autonomy-centred model. She criticizes the model of "community placement" for persons with ID because it "has as its goal the independence and productivity of the disabled" (p569). In Ontario, the types of "community placement" described by Kittay shape the aims of the MCSS-funded system. Under this model, the goal of supporting independence co-exists alongside intentions to include persons with ID in the community – despite the fact that these individuals have been clinically-defined in opposition to dominant standards of independence as well as by their perceived lack of autonomy. This contradictory imperative to 'include' persons with ID while seeking to improve or alter their perceived qualities suggests a very limited form of acceptance marked by ongoing discrimination against this group – a problem that recalls Mitchell and Snyder's (2015) warning about ablenationalism. Quite similarly, Carey (2009) observes that

disability rights movements and the changes they have generated do not necessarily challenge the basis by which disabled people are excluded. Instead, these movements often adopt and reinforce dominant values. It is "far more revolutionary", in Carey's opinion, to attempt to subvert these standards altogether (p17). In the case of the SIS, we find alongside the intention to support and bring about inclusion yet another example of the tendency to uphold dominant values such as 'autonomy' to the potential detriment of persons with ID who are defined in opposition to this standard.

Because the SIS is based on normative measures that rank the degree of support needed to attain a given activity or level of functioning according to frequency, type, and duration, it can be seen as reflecting the general scientific trend towards refining or re-inventing testing methods based on a desire for 'correct' depictions of the reality of intellectual deficiency and incapacity. As Dwyer (2004) shows, at one point IQ testing combined the Binet-Simmon model with the Yerkes-Bridge model in an attempt to achieve greater accuracy. The change was justified because "a point scale … measured mental abilities more accurately than did the Binet-age scale" (pp262-263). In a similar way, the SIS can be seen as a refinement of older testing methods that allows for the continuation of institutional-era approaches towards persons with ID. Inclusion Alberta's description of the purpose of the SIS might be interpreted in this regard. The group claims that "[i]nstruments, such as SIS, serve the interests of systems not individuals and families, draining precious resources in money and time" (Inclusion Alberta, 2015). By considering Inclusion Alberta's claim that the SIS centres the interests of the system and not persons with ID, we can begin to critically asses the biopolitical aspects of the tool. Specifically, this analysis considers how implementation of the SIS in Ontario might participate in a governmentality of (in)capacity that can carry displacing consequences for persons with ID. To

approach this question, we must review some of the chief claims that the AAIDD, MCSS, and DSO uphold. These include the belief that the SIS is both useful to service providers and accurate.

Accuracy is indeed the chief claim of the AAIDD and other SIS supporters. Upholding these claims are many clinical studies (see for example Weiss, et al., 2008; Shogren et al., 2017) as well as the training exercises that DSO assessors undergo, all of which are geared towards attaining a level of accuracy in assessing and ranking persons with ID according to a complex grid of needs. In describing the MCSS-managed SIS training, Carebear stated that assessors are required to obtain a certain score and level of accuracy in practice tests "to be qualified by the Ministry person" after they are tested by this trainer. Prior to this testing, DSO assessors "go for a full week training, then from there, you must shadow a qualified assessor". As we saw earlier, ongoing training has also been important in implementing the SIS in Ontario. Referring to the SIS interview reliability and qualifications review, which costs MCSS $16,000 a session in addition to AAIDD provider expenses, Carebear explains that every year, "th[e] Ministry trainer must sit with every SIS assessor in Ontario at least once and review that they're still applying the tool to their qualifying standards". Accuracy in testing is thus a major point of investment for MCSS.

As mentioned above, as part of its effort to objectively measure support needs, the AAIDD advises SIS testers to ask all the questions presented on the form. Carebear agrees with this practice and attests to its relevancy in providing a full picture of an individual's potential needs. Nevertheless, it is easy to see how this mandatory questioning about support needs can potentially work backwards from the needs and priorities of the individual. Rather than allowing persons with ID to discuss their own needs and priorities and frame these according to their own

values, the SIS behaves as so many standardized tools do and assesses these individuals for the needs that clinicians, situated within a network of 'expertise', consider to be valuable. Inclusion Alberta is critical of such an approach and contrasts it with "a values-based person centered planning, with supports and funding to be provided accordingly" (Inclusion Alberta, 2009). However, the creators of the SIS are careful to acknowledge the tool's limitations in this context, explaining that it is not intended to replace person-centred approaches, but instead to inform them (Manual, 2015, p1). It is nevertheless questionable whether Ontario has implemented the SIS in this way. We may further question whether an individualized funding model based on person-centred approaches can be achieved through the combined use of a technology that facilitates standardized (i.e. non-individualized) testing methods, and it is unclear why such a combined approach would ever be desired.

What is clear in MCSS's application of the SIS is that the evaluative results it generates are indeed informing what those within the system refer to as individualized, person-centred planning – although there are good reasons to resist such a characterization of the developmental services system. According to documents reviewed for this study, the SIS shapes MCSS planning in such a way that decisions about resource allocation and specifically around Passport funding are made almost exclusively on the basis of SIS scores, with only some input related to an individual's current support system. Meanwhile, a crisis-driven prioritization process continues to operate in the background to determine when individuals will actually receive the services they qualify for through their DSO assessment. The negative experiences of persons with ID and families interviewed for this study reinforce Inclusion Alberta's belief that this implementation of the SIS can benefit the system and not its clients, suggesting that if person-centred decision planning and decision-making were actually occurring – and again, evidence

from this study suggests that they are not – they are being overshadowed by forms of decision-making that are overly reliant on a standardized evaluative tool.

One of the reasons that the SIS continues to be a favoured assessment tool in Ontario is that the supposed benefits of this method include the ability to provide administrators and service providers with accurate measures of the level of need presented by a person with an ID. This perception of course is based on the supports that 'experts' deem relevant for social participation. However, the result of an assessment can also be read as generating a static picture of an individual's perceived degree of disability and their position on a ladder of (under)development – a rating that can then be used to assign funding levels, match them for services (which may or may not exist), and where necessary, segregate them in an 'exceptional needs' category based on perceived or actual issues of behavioural and/or medical needs. As we will learn from participants, and particularly Frank and Bill's feedback, it seems that not everyone in the service sector and DSO agrees that the SIS has been useful in working with clients with ID.

There is also evidence suggesting that Ontario's implementation of the SIS participates in MCSS' systemic failure to recognize people with ID as experts in their own lives. SIS scores are based on interviews, but they also allow for a standardized tool to represent individual needs. This is so that decision-making about services and supports can be made by DSO administrators in a more 'efficient' manner. Rather than an individualized approach to resource allocation based on the expressed desires of persons with ID, MCSS promotes a top-down style of management that restricts and organizes expressions of need according to SIS scores and, to a lesser extent as we will soon see, scores derived from the MCSS-developed tool known as the ADSS. As previously explained, the AAIDD claims that the SIS is not measuring adaptive functioning because it asks instead about "practical support requirements" of persons with ID (AAIDD, SIS-

A: Overview). The SIS has largely been received by clinicians as achieving these aims and has been described as being distinct from other evaluative tools. For example, Weiss et al. (2009), in their Ontario-based study of the tool, explain that, "[t]he SIS differs from other measures of adaptive behaviour in that it assesses the frequency, type, and duration of supports that a person needs to perform activities successfully and not merely what a person typically does independently" (p933).

The primary claim made by the AAIDD is that the SIS provides greater 'accuracy' – yet as we have seen, this accuracy is largely concerned with clinically-derived measures that reflect certain normative standards and implicate dominant conceptions of (in)capacity. Rather than asking about 'deficiency', however, the SIS asks about an individual's support needs with the overarching aim of producing an image of those needs that may be valid for up to five years (MCSS Directive). In Ontario, this image, or documentary identity, also reifies the (in)capacities of that individual and allows for decisions to be made about the funding and services they require. The imagined legitimacy of these scores support their use in algorithmic decision-making processes that are used by MCSS to determine an individual's level of Passport funding. These decisions are structured by the Passport Mapping Tool, and we will turn to these processes shortly. First, however, we will consider how the SIS interacts with another MCSS evaluative tool: the ADSS.

Ontario Embraces the Supports Intensity Scale and Introduces the Application for Development Services and Supports

Given the above questions, we may wonder how the SIS came to serve as a source of data for algorithmic decision-making. Returning to the roots of the SIS and the DSO, Carebear explained that the tool was among different methods originating from Australia, the US, and

other countries, that were considered by the architects of the new system. Frank worked at a DSO agency at the time the SIS was introduced and he recalls much excitement around the tool, stating that, "it was something everybody was touting as a great assessment that was efficient and would be easily installed here in Ontario". Participants in this study suggest that as a highly anticipated assessment tool, the groundwork for the introduction of the SIS in Ontario took place not long after the tool was developed by the AAIDD. According to Carebear, the SIS was live-tested by the Province between 2007-2011, three years after it was launched by the AAIDD. Ontario planners appreciated the SIS, but they still felt "that there were still a few things missing". As Carebear explained, "[f]or this reason, they developed ADSS as a complementary evaluative tool". The ADSS was developed in 2006, and Carebear emphasized that it is so closely wed to the SIS that one does not even take precedence over the other. In other words, Carebear feels it would be impossible to simply rely on the ADSS or the SIS. Yet, as we will see, Passport funding decisions are mostly drawn from SIS scores that are manipulated through pre-set algorithms.

To summarize, the ADSS is a tool that collects basic biographical information about an individual, asking questions about where they currently live, with whom, and what forms of support they currently receive. The form itself is divided into seven sections: Intake Process ("preliminary information … to begin the eligibility and assessment processes"), About the Individual ("preliminary descriptive information"), Getting to Know You ("an opportunity to gather information that helps to understand things that are important to the individual's current needs and plans"), Services and Supports ("information on current services and supports" and the ones being requests), Additional Medical and Behavioural Support Needs ("The assessor completes this section with the SIS-A and requests additional information on the Behavioural

and Medical areas of the SIS-A"), Care Concerns ("care concerns for the individual") and Unpaid Primary Caregiver Concerns ("care concerns for unpaid primary caregivers") (ADSS Version 3, 2018). When asked about the information that the ADSS is intended to cover that is not captured by the SIS, Carebear described "tombstone information", including "the people i.e. respondents that come with the individual, their relationship to that individual and contact information of the family… physical elements of hearing, vision, expressive communication …. their living environment i.e. their living style at that point in time …. the mobility requirements … the supports and services that they are receiving form not just MCSS but also Ministry of Health, Education, also at the other ministries or any other support networks out there, natural support networks… physician's name and address… requests for services i.e. what they want". In this way, the ADSS enhances the data collection method laid out in the SIS, especially the Interview and Profile Form and Exceptional Medical and Behavioural Needs, also elaborating on the SIS process with further biographical questions.

Above all, it was felt that the SIS did not collect enough information about an individual's current context and the ADSS was developed to compensate for this gap. The ADSS, therefore, may be treated as a regional adaptation of the SIS-oriented assessment process overseen by MCSS. Since it asks mostly basic biographical questions, the ADSS can be viewed as an extension of the first page of the SIS. Only section three of the ADSS, Getting to Know You, referred to by Carebear as the "what they want" portion of the evaluation, stands out as a taking a different approach to testing and assessing service needs. This section promises a level of individuation and the chance for persons with ID to express their own desires, and it is Carebear's favourite part of the ADSS form: "a whole section dedicated to a person directed plan where it's the All About Me package". Carebear stated "I like to paint that as a painted picture of

the individual's wants… because it's the individual and their respondent talking to me and giving me their wants". However, the potential for this more personalized and interactive section of the ADSS to impact DSO decision-making has been called into question by Frank. While not directly referring to the ADSS, Frank suggested that within the DSO assessment context, concerns for "what they want" are somewhat tokenistic and provide "only general illusions to the things they're interested in". He characterized the responses generated by these types of questions as "facile observations" and offered, "so-and-so likes horse-back riding" as an example.

In addition to Frank's critique, a closer look at the Passport Mapping Tool, which uses SIS results and some data collected from the ADSS to assign funding levels, shows that SIS scores far outweigh ADSS results. In addition, caregiver availability is factored into the assessment and impacts funding decisions, demonstrating yet again that policy directed at people with ID is linked to their assumed 'dependency', the existence of family units, and the (unpaid) support work of relatives. To begin, there are two sections in the Passport Mapping Tool that DSO administrators complete to determine how much funding an individual will receive, up to a maximum of $35,000, which can be used for community participation and respite services. The first part relates to one component of this funding, which is a maximum of $25,000 for Community Participation Supports. This the largest portion of the Passport funding pot and the only portion that may be accessed by persons with ID. Funding for this section is determined through an algorithm that seeks input into five categories, four of which directly request SIS scores; the fifth category asks about current service-usage and is likely drawn from the ADSS (but referred to as the ICE Record in the Mapping Tool). The second part of the Passport funding stream is for Respite services, and allows a maximum of $10,000 to caregivers; this amount is

for ‘breaks’ from caring for a person with an ID and this portion of funding is thus not available to self-advocates with ID and does not impact those who do not have caregivers or legal guardians.

The only ADSS results that are considered in funding decisions relate to “current services and supports” and “caregiver concerns” (discussed in sections seven and eight of the form), which include the potential for an individual’s current ‘caregiver’ to continue in their unpaid role. By pointing out the presumed presence of an unpaid caregiver I do not intend to dismiss the potential desire for these relationships on the part of people with ID, but instead to highlight the assumption that people with ID have families who are available for this unpaid work, and that both parties desire such a relationship. Such assumptions reflect broader trends observed by Saaltnink and Ouellette-Kuntz (2014) around parent labour and its importance in accessing developmental services in Ontario. My analysis of the Passport Funding tool expands on the authors’ conclusion that parents “do work that seems to affect who gets services” (p53), by showing how this reliance revolves around a much deeper failure to accept people with ID as individuals and to instead view them within dyadic ‘caregiver-dependent’ relationships. Conversely, viewing people with ID as complete people would require the state to enable their access to services regardless of whether they are paired with a relative. In keeping with this trend, “what they want” never factors into Passport funding decisions – and there is simply no mechanism by which the preferences of people with ID can be included in the algorithm that determines funding levels. Again, this failure to incorporate person-centred assessment methods, despite the AAIDD’s intent for the SIS to be paired with these processes (SIS User’s Manual, 2015, p1), suggests MCSS’s reliance on categorical thinking about persons with ID. It also points to the influence of related deficit-oriented views of ID as articulated within the SIPPDA

and the SIS – an assessment tool which, according to this critical re-reading, is grounded in a framework that measures persons with ID's support needs against normative standards that reinforce capacity hierarchies.

At the same time, these normative standards are not simply restricted to the SIPPDA and SIS: they are part of dominant social systems and cultural values. In this sense, we can interpret Carebear's description of the approach taken by both the SIS and ADSS as a comparative one that invokes the notion of normalcy: "the SIS and ADSS support the understanding to the service providers of what level of service they are going to require to be successful in their community. *Comparing them to the average person in their society* [emphasis added]". The SIS and ADSS are however described differently by Carebear, with the SIS being "more aligned to a clinical style questionnaire", and the ADDS as "just a nice relaxing conversation about getting to know the person". Here, Carebear's experience with the SIS implies that the interview may be 'unrelaxing', recalling Bill and Frank's characterization of the assessment process as well as those forwarded by other participants (see Chapter Seven). These comments challenge the claim that the SIS involves "*a positive* [emphasis added] and thorough interview process"(AAIDD, SIS-A: Overview). Frank agreed that the SIS is a 'clinical' experience, but then took issue with the assessment process, describing it as being too "mechanical" and medicalized: "it was extremely frustrating because it was very much a mechanical, medical model type of assessment".

Most aspects of the ADSS do indeed resemble a questionnaire aimed at collecting basic information such as supports currently being used, medical needs, impairments related to mobility, communication, and other areas, including biographical factors (ADSS Version 3, 2018). It is only the Getting to Know You Portion of the ADSS that aligns with a less clinical

style of assessment, as Carebear pointed out. It is thus important to emphasize how the more unstructured and person-centred Getting to Know You portion of the ADSS differs from a clinical-style assessment. Contrasting how different these conversations are when compared with other aspects of the assessment process, Carebear mentioned how uncomfortable certain aspects of the SIS can be for persons with ID. Importantly, Carebear noted how a concern for the comfort of clients shapes the additional work DSO assessors must put into preparing them for what are "very very private conversations". To help prepare persons with ID for these difficult aspects of the SIS, Carebear will "rhyme off the five that seem to be the five most embarrassing to ask, and then I say to them, 'When we get to that question, I will give you a signal, like Oh here we go! Here's the big – you know -question". Participants are then offered the opportunity to continue the interview along with Carebear or leave the room and have someone else answer on their behalf. These difficulties and the need for persons with ID to possibly remove themselves from the discussion on account the discomfort generated by the testing context suggest deep problems with the accessibility of the tool and the expectation that persons with ID can participate.

The ability of the target population to comfortably participate in the SIS, regardless of whether the questions posed during this process are deeply embarrassing ones, is undermined by several participant narratives. Carebear's comment that the SIS interview "is a little bit too boring and clinical" was followed by the acknowledgement that "yes, people will need to check out at points in time". Bill, who took part in a SIS when he was asked to accompany a person with an ID to the assessment, is much harsher, calling the process "meaningless" for persons with ID. Frank, who has attended many SIS assessments, explained that he has never witnessed one where a person with an ID attended alone. Based on these accounts, the SIS does not appear

to be an accessible process for persons with ID and assessors like Carebear must perform additional work to make the tool more useable. This barrier may have been anticipated by the AAIDD and MCSS, and Carebear's comments help show how the MCSS directive that requires persons with ID to attend a SIS interview with another person works in action.

These built-in barriers, however, suggest an inherent bias towards persons with ID as incapable of fully representing themselves. Along these lines, the SIS interview may be read as potentially inaccessible and uncomfortable for people with ID, as well as challenging their ability to make decisions and present their own needs without the involvement of third parities. While support in decision-making may be helpful to many individuals, it should not be a requirement for all individuals as this risks undermining the agency of those who do not desire or require such support. Commenting on the situation of self-advocates who choose to represent themselves, Frank feels there is no recognition of this preference. He stated, "the system is blind to their existence on a level". In fact, the AAIDD discourages participation by self-advocates alone (SIS User's Manual, 2015). In a list of assessor "dos and don'ts", the manual advises assessors not to, "interview just one person to complete the *SIS-A*, even if the one person is a self-advocate" (p7). At the same time, the manual states that that persons with ID ought to be included in their own assessment, suggesting it might "yield valuable insights" and serve as "an empowering experience for the person" (p6). Unfortunately, personal narratives related to developmental services addressed in Chapter Seven, suggest that these assessment experiences are not always empowering.

From general problems related to a lack of individualized and accessible discussions about support needs stem some of the potentially harmful effects of the MCSS-managed system, including spatial and subjective displacement. As we have seen throughout this study, these two

forms of displacement are inter-related and mutually constituting, and it is not necessary for spatial displacement to occur for evaluative processes to generate displaced subjectivities. And yet spatial displacement arises when individuals end up in institutional or deeply segregative contexts as a result of their support and funding needs not being met. The assessments processes and forms of decision-making that land them there and the very experience of not being present in the community, are subjectively displacing. They can include a misrecognition of support needs and individual abilities as well as mandatory exposure to forms of moral judgment that pathologize and degrade persons with ID's embodied differences. This means that on a psychological and deeply personal level, the identities and actions of persons with ID can be coercively shaped through evaluative processes and the relationships to funding and services that they structure, as the next section of this chapter will illustrate.

Evaluating Incapacity: Moral Judgments and Truth Claims

The SIS evaluative process relies on a disaggregated view of persons with ID that seeks to measure their disability-related needs and inadvertently, levels of (in)dependence, through a categorical break-down of certain life activities. The accuracy and thus the very utility of this method in an Ontario-context depends on how well the SIS supports the process of linking persons with ID to the services and funding levels they require to enact substantive citizenship. Many of the narratives shared by participants in this study who experienced developmental services challenge MCSS' use of the SIS by questioning the possibility that a disaggregated framing of daily living can accurately reflect and fully equip providers to respond to individual realities. Tensions between reality and assumptions about support needs appear to shape concerns on both sides of the assessment process: relatives of people with ID describe not identifying with their SIS results (as will be discussed in Chapter Seven), while there is strong

reason to believe that non-clinical front-line providers may not find SIS results all that useful or accurate, as Bill's narrative suggests.

Interestingly, the SIS-A user manual acknowledges some of these potential tensions from a practitioner's perspective. The manual raises the question, "How do planning teams distinguish supports that a person truly needs from those that a person may want?", drawing a distinction between "items that are important *to* a person and items that are important *for* a person [emphasis added]" (p73). Such distinctions could however encourage assessors to pass judgement on persons with ID's claims by comparing the validity of their stated needs against different categories of needs ("important to" and "important for"). In this sense, these guidelines can be read as promoting a best-interest approach to decision-making, supporting interactions and decision-making processes that could potentially undermine persons with ID's expressed needs. While those who implement assessments are likely aware that there is a struggle around disabled people defining their own support needs, and while they may wish to promote dignified interactions, there is also a risk that that will end up participating in efforts to wrest this definitional control away from the individuals they are assessing. Such struggles may be conducted with the belief that definitional control is necessary in order for assessors to perform their jobs well.

As we have seen, not all front-line providers are supportive of the SIS. Bill explained that he receives many SIS results through his work as a manager for a service program, and he observed that only about 20 per cent of that information is useful to him. He further explained that the results do not communicate the complete realities of many of his clients: "I don't think you can put knowing everything about an individual into a document. I don't think that will ever be the same as actually knowing the individual and knowing what has to happen". Addressing

the fluid and holistic nature of support needs, Bill challenged the very possibility of numerically assigning scores to certain aspects of daily living and critiques the SIS as an exercise in quantification: "I mean, one level four might be different from another, because there are infinite levels of support you might need". He added that support needs are "situational": "there are infinite levels of support, it's so situational. I mean, dressing yourself when you're wet after swimming is so different than dressing yourself when you get up in the morning. And an assessor has no idea which of those two needs to be considered by a service provider". It is worth noting that while clinical studies have celebrated the accuracy of the SIS, some of these studies have also relied on disaggregated views of individuals with ID that clash with Bill's understanding of support, using "protypes for each level of need", and asking "what a typical level of need would look like based on clients seen in the past", and whether SIS results reflect other clinical findings (Weiss et al., 2009, p936). It is thus important to expand the evidence-basis for the SIS by taking into account non-clinical perspectives such as Bill's and the perspectives of others who work in front-line service positions and in particular, the perspectives of persons with ID who undergo SIS evaluations.

In the previous chapter, Gould (1996) and Goodey's (2013; 2016) critique of the quantification of abstract concepts such as IQ allowed us to challenge MCSS eligibility standards that are based on a deficit-framing of ID. Analyzing participant experiences with the SIS through a similar analytical framework, which challenges positivist claims, gives rise to a clearer appreciation of how complex exercises in disaggregation and quantification risk not only falling short of reality, but can carry displacing effects that can exclude individuals from opportunities to be present in the community as substantive citizens. While the SIS is one of the most influential evaluative tools in relation to Passport funding levels, participants suggests that it is

also used by DSOs when linking and matching individuals to services. Rather than simply using ADSS results as one might expect, participant narratives show that SIS results are also used in determining program placements, for example.

As a service provider, Bill explained that he receives anonymized SIS results from the DSO as part of the file of the person being considered for the program he manages. Recalling the SIS results, he described a "cumbersome" level of "detail and documentation and paperwork". This complaint reinforces some of the concerns shared by Brown et al. (2009) related to problems in administering the SIS (p954). Going beyond these challenges in implementation and returning the lived effects of the tool, Bill shared that he had encountered examples of assessments that have justified the exclusion of persons with ID from his program. He described how the DSO plays a gatekeeping role when it uses assessment results that include SIS scores to decide whether or not to refer an individual to his program. He recalled a specific example where an individual wanted to join his program, but was denied this opportunity based on their assessment. In the following statement, he suggests that it is likely that similar forms of decision-making occur elsewhere through pre-screening by the DSOs: "I know a certain amount are not screened in and referred based on the information provided in their DSO assessment". Conversely, Bill described receiving descriptive, written information – likely derived from the ADSS – in much more positive terms. This information includes "so-and-so likes this, this is how they are", and he explained that these summaries are much more helpful to him.

Keeping with his preference for more individualized approaches while taking aim at the screening role performed by the DSO, Bill said he would much rather meet the individual personally and allow them to try out his services to see if they are a good fit. In his words, "actually knowing and understanding if that link makes sense is something that needs to be done

in the community and not in an office". Throughout his reflections on the DSO, Bill suggested a form of knowledge usurpation similar to what Frank, who formerly worked at a DSO agency, has more explicitly linked to the rise of certain assessment practices. As described below, Frank is pointedly critical of the SIS because he feels it displaces local knowledges and more intimate interactions between frontline staff and DSO case managers, whom Frank frames as playing a supportive frontline role.

Bill and Frank are suggesting that through the introduction of standardized evaluative tools, frontline relationships have been replaced with knowledge derived from assessments and more clinical relationships. Referring to the changes that took place after the SIS was introduced Frank recalled, "suddenly what happened was that all the common knowledge that was case-manager based or based in the community was suddenly usurped by this entity that came in and this process of assessment that was met with real horror by a lot of those who had been in the community". The "horror" that he recounts was apparently a shared reaction by those who worked in the community upon being confronted by a standardized and depersonalized process for determining service allocation. Frank was unambiguous in dismissing the SIS – at least as it is applied in Ontario – as unhelpful, reinforcing parts of Bill's critique by stating, "it doesn't really tell us anything about the person themselves or the context of their families". The loss of individual context described in this quote can be related to the disaggregated framing of persons with ID and the displacement of local and experiential knowledge based in the community, as explained by Frank. At the same time, these issues can also be interpreted as a potential outcome of an evaluative process that relies on abstraction and quantification. The effects that Frank noted are similar to some of the issues observed by Bill and include inappropriate referrals. In his words, "it would be kind of a joke as to the things that they were referring them to, because they

had no hands-on experiences with these resources". Frank contrasted the role of assessors with that of case managers and suspected that the latter is being phased out: "I think ultimately they want to eliminate case managers, because of course that's another expense and it's not as efficient on the system side." In his view, replacing case management with an assessment role is linked to the issue of potential misreferrals: "my understanding is they eliminate the case managers and make SIS assessors navigators, whatever that means. So they would have a list of resources and while they are doing the assessment they can refer the families to them immediately. But what we found is that it would be kind of a joke as to the things that they were referring them to, because they had no hands-on experiences with these resources." Here, Frank is centering experiential knowledge as a way of better supporting persons with ID by helping identify the services they actually want and need. Bill agreed that it is important for persons with ID and frontline providers to work out solutions together, and declared "let the people that provide the services in consultation with the individual and their family, figure out exactly what's needed".

The dynamics described by Bill and Frank are structured by MCSS and suggest a disconnection that carries specific consequences for persons with ID as a result of the historic undermining of their human status. At the same time, this disconnect is in no way unique to the developmental services sector. Sossin and Pottie (2005), for example, detail how welfare services tend to be shaped by decisions that are disconnected from the reality of the front-lines. The authors suggest that this separation in knowledge is a broad-sweeping issue and observe "the degree to which applicable doctrines have originated from settings far removed from the distinctive realities of social welfare decision-making" (p150). As a document that originates in the United States and was developed by clinicians, Frank and Bill's critique of the SIS reflects

Sossin and Pottie's concerns in that they describe assessment results as being removed from the local reality of many persons with ID and the front-line staff who support them. The link between local knowledge and displacement is also true at an individual level. We can see this when a person with an ID's actual support needs are not reflected in recommendations informed by SIS scores, as Chapter Seven will discuss, or when they are denied a service they may wish to access, as Bill has explained.

Interviews conducted with persons with ID and their relatives, analyzed in Chapter Seven, suggest that as a result of MCSS decision-making, individuals may be barred access to opportunities to be present in the community similar to what Bill described. Persons with ID may face barriers in accessing appropriate MCSS-funded supports and funding levels due to matching and linking decisions related to their assessment results, even when not exclusively drawn from them. But regardless of the structures and tools shaping the DSO's work, the effects associated with MCSS placing certain funding and service decisions in the hands of administrators rather than persons with ID reflects a reduction of consumer control. This tension around control is closely related to the persistence of a paternalistic and all-too-familiar 'best interest' approach to persons with ID. Best interest treatment is, after all, based on an inherent belief in the incapacity of persons with ID that challenges their species-membership and works to deny them decision-making power. These assumptions work to reinforce the dynamic described by Carey (2009), whereby rights (such as the right to choose where one lives) may be traded for services and supports (p32).

Limiting Front-Line Advocacy and Enacting Ineligibility/Illegibility

The search for accurate ways of representing the needs of persons with ID and the use of disaggregated techniques to achieve this goal carry other potentially exclusionary effects. These

effects can include undermining the desire of front-line providers to support communities in need. Touching on this issue, Frank described how service exclusions can also result from medically-oriented requirements such as IQ testing and the strict definitional criteria used by MCSS to demarcate the ID community. This aspect of standardization, Frank claimed, has led to the exclusion of "street-oriented" individuals. He further explained that these are "people who I could barely reach or be in touch or didn't want to be part of any structured thing." The effects of standardization and the adoption of standardized assessments by MCSS on this street-oriented population are profound, according to Frank: "instead of having a case manager go out and meet them at the corner of wherever, there's now a requirement for them to attend a formalized meeting. And if they don't want to, they're kinda shunted [sic] to the back of the line or off to no-man's land". Frank's description of what happens to those who do not want to take part in a formalized assessment allows us to contrast the disciplinary, gate-keeping function of eligibility testing with what may be viewed as the supportive role of DSO case managers.

At the same time, speaking with Carebear shows that DSO assessors can also be motivated by a desire to support and advocate for persons with ID. Specifically, Carebear referred to issues around capacity laws and to the need to be careful when claims are made by others on behalf of persons with ID. Carebear explained that unless "that individual has his own right to sign a document, unless you show me a physical POI or guardianship that indicates not". Carebear also expressed, "I would like to see a lot more advocacy, and advocacy for the individual, right". As these statements reveal, Carebear is interested in supporting persons with ID to achieve greater capacity-recognition. This desire to be supportive can help explain why some persons with ID and family members interviewed for this study provided positive feedback about DSO assessors as individuals, while at the same time describing the DSO assessment

process in strongly negative and displacing terms. But as positive as some of this feedback may be, it must also be acknowledged that the disconnect described by Frank could severely restrict an assessor's potential advocacy role.

Frank argued that the distance that exists between assessors and persons with ID is based on the fact that they only meet once or twice in their lives, and only for the purpose of conducting the SIS and ADSS assessments. In practice, he feels that this short-term relationship leads to "no culpability" or connection between assessors and the effects of their work: "there's no culpability because they go and meet with families once or twice and that's it. And some will consult with the case manager but they've actually been discouraged from doing that." Frank stated that persons with ID are therefore forced to be, "reliant on someone who barely knows the family". Along these lines Carebear, explained that there is almost no chance for follow-up by assessors with the persons with ID they encounter, as this is not how the developmental services sector is structured. This disconnect can certainly impede any potential desire to advocate for persons with ID.

What is clear is that the ambiguities between the DSO's assigned gate-keeping function and the potential advocacy role that DSO staff may play are reflective of the thin line, suggested by Rose (2007), between helping and judging (p40). These complexities further suggest that it is the structural context and not necessarily the individuals who occupy them that account for negative experiences with the DSO and that shape the potentially displacing effects observed in this study. By considering the various motivations and discourses that surround and are contained within assessment regimes and the biopolitical dimensions of tools such as the SIS, we can see how the intent to empower persons with ID can exist within 'policy assemblages' that also give rise to restrictive practices. At times, these positive goals can be attributed to individual

agency, such as Carebear's desire to be supportive, and an overall system-level intention to support people with ID. But regardless of positive intentions, participant experiences suggest that MCSS assessment processes can be included among the many structural forces that potentially shape displacing processes and outcomes. Focusing on the thin line between helping and judging also relates practices that officially seek to support persons with ID with immigration testing for excessive demand – an assessment regime that promotes a more blatant form of moral judgment, as discussed in the next two chapters. Complex interactions between individual and structural forces, positive motivations, unintended consequences, and overlapping policy discourses further attest to the wide network that Goldring and Landolt (2013) claim is key to negotiating (non)citizenship. At the same time, these dynamics continue to demonstrate Carey's (2009) point that access to rights can also be experienced as a form of control (p32).

Even from a system-oriented view of the MCSS-managed system, we can see how attempts to access the supports needed to enact substantive citizenship, such as Passport funding and other services, subject persons with ID to potentially displacing processes that involve the coercive shaping of their subjective realities. We have already seen how street-oriented persons with ID who do not agree to take part in a formalized process are denied recognition and along with this, supports for substantive citizenship and opportunities for being present in the community. This means that individuals who agree to participate in the DSO evaluation may be forced to change their behaviour to fit the system's processes and to submit themselves to certain documentation techniques. Such disciplinarily and displacing effects go beyond the problem of objectification. As Day (2014) explains, and touching on the issue of displaced realities introduced earlier, documentary practices also shape individual subjectivities. Day describes how documentation places individuals on a "journey of consciousness" that goes beyond the

mediation of their reality. According to him the subject, through documentary tools, "is shaped in its very social and personal identity" (p4). The example provided by Frank of street-oriented people confronting evaluative practices shows how resistance to being documented – or illegibility – literally displaces persons with ID from the service sector, shaping an experience of non-citizenship through service ineligibility and denial. These individuals encounter forms of spatial displacement related to being on the street in a zone of exclusion that is deeply stigmatized. Simultaneously, they are subjectively displaced by being formally judged as being 'out of place' and not fit for service provision, and consequently are officially unrecognized by the system.

In more subtle ways still, persons with ID who participate in the shaping of new documentary identities through assessments are at risk of displacement. This is true both spatially through the potentially limiting decisions that are made about their opportunities to be present in society. It is also true subjectively, as is the case when individual needs and realities are interpreted, objectified, ranked, and then actively shaped through the act of re-interpretation. Interviews with persons with ID and their families suggest that the risk of displacement is a broad phenomenon present in Ontario's developmental services sector, evaluative processes, and implementation of the SIS in particular; this allows us to characterize Ontario's implementation of the SIS as a biopolitical technology that ought to be analyzed in relation to potentially displacing processes in translocal contexts. The forms of decision-making that flow from SIS assessments can therefore be situated within the legacy of positivist medical knowledge that claims the authority to accurately predict and subsequently shape individual actions and potentials. Histories of IQ testing that result in spatial displacement come to mind here and as always, by drawing out these implications we can see the degree to which the SIS represents an

evaluative tool that can be placed on a continuum with IQ, as well as with adaptive functioning testing (see for example Brown, et al., 2009). The possible role that SIS scores play in predicting and then potentially shaping and displacing the subjectivity of persons with ID in Ontario informs the next section of this chapter.

Algorithmic Decision-Making, Predictive Practices, and the Shaping of Displaced Subjectivities

Existing research shows that a reliance on predictive psychometric techniques can be deeply reflective of eugenic theories, their moral imperatives, and their employment of biological determinism. Gould (1996) details how such deterministic thinking strives to shape future action, writing that "[b]iological determinism is, in its essence, a theory of limits. It takes the current status of groups as a measure of where they should and must be" (p60). In similar ways, psychometric assessment practices such as the SIS can shape the social positioning of persons with ID by assigning them to different categories of need that are directly based on normative ideas of how 'healthy' and non-disabled individuals 'should be'. These assignments rely upon a process of objectification enacted through disaggregated and static views of given aspects of daily living that are exposed to evaluation.

Often, to render individual needs static is to objectify them. Using SIS scores as an example, we can see how this objectifying process is focused on fitting individuals into pre-determined categories of need based on their perceived level of (in)dependence. This exercise in the objectification and categorization of persons with ID is part of a broader industry of testing, described by Artiles, Dorn, and Bal (2016), which at one point justified itself as a form of "accountability", but over time simply moved towards the goal of "sorting" (p787). In this broader context, the emphasis on sorting over accountability is consistent with the cart-before-

the-horse approach taken by MCSS which, rather than investing in appropriate resources, launched the DSO to monitor and manage the allocation of inadequate supports and funding levels. One consequence of this top-down approach is that persons with ID can be sorted into pre-determined categories while many of their real needs remain unmet. As a result, individuals are both at risk of being indirectly prevented from exercising substantive citizenship and can face pressure to conform to the expectations that come along with their new documentary identities.

To appreciate how deterministic thinking and prediction shape individual subjectivities, we must return to the regulation of the Passport funding program. As previously explained, several standardized tools work together to determine how much Passport funding an individual is eligible to receive. As mentioned earlier, MCSS employs a Passport Mapping Tool that uses pre-set algorithms to translate assessment data into funding levels. SIS scores and to a lesser extent, ADSS data are fed into the mapping tool which then, through numerical manipulation, produces a final score that aligns with funding categories to ultimately determine resource allocation. As already mentioned, this process only determines which resources an individual will receive when those resources become available, while processes for determining priorities for service allocation are separate and beyond the scope of this study.

Within the algorithm set out by the Passport Mapping Tool, there are 73 funding categories related to the Communication Participation Portion of Passport funding (the $25,000 maximum that is available to persons with ID), and 35 funding categories for the Respite funding portion (the $10,000 maximum that is only available to caregivers). It is unclear how these funding categories were devised and how the corresponding scores were then assigned to them. For example, an individual score of 13 leads to $3020 in funding, while a score of 26, which doubles that amount, leads to $5490, which is not equal to $3020 times two. Meanwhile, the

difference between a three ($1200) and a four ($1380) is $185, while the difference between a 25 ($5300) and a 26 ($5490) is $740, and a 29 ($6060) and a 30 ($6250) is only $190. The scale appears almost random. What is apparent, however, is that the higher the score, the more the funding an individual receives, while the logic behind these funding increases remains hidden and not readily available to the public.

Passport funding categories thus appear arbitrary and categorically-based rather than individualized and shaped through real service needs. Similarly, the process of numerical manipulation used to match individuals to funding levels is an exercise in prediction grounded in assumptions rather than reality. Consider, for example, how a Passport score is arrived at: SIS scores and select results relating to caregiver needs and current service-usage that are gathered from the ADDS are inputted into the tool and undergo manipulation through a pre-set formula. The assumption is that SIS scores and information about an individual's present relationship to a 'caregiving network' and 'current services', as represented in an ADSS score, accurately reflect their reality and can predict their present and future needs. There are several flaws with this approach. The first is that two individuals with the same score in one SIS area may not, for example, have support needs that cost the same. Furthermore, the overall Passport score may be arrived at as a result of aggregate scores that resemble each other for very different reasons. Yet, as a result of their shared Passport score, different persons with ID will end up in the same funding category.

Feedback from participants explored in Chapter Seven support discussion results from a family forum held in Ottawa where participants, mostly parents of persons with ID, complained that Passport funding amounts are simply insufficient and fall short of the actual monetary costs of the supports they need (DANEO, Family Forum Minutes, 24 March 2018 [cited with

permission]). While they are derived from individual assessment scores, funding categories just as equally assume that individuals can be grouped together based on similar scores and that they have support needs that will cost the same. Such thinking participates in the move towards algorithmic decision-making, which is perhaps more evident in immigration policy and will be discussed in the next section of this study.

Potential problems stemming from assumptions around support needs provide another example of how standardization and the use of algorithmic representation can fail to capture individual realities. In fact, interpreting potentially inaccurate representations as the complete expression of individual needs can displace their subjective realities by depriving them of the resources they require to exercise citizenship and be present in the community. We can detect similar problems in the rules that govern Passport spending: a $25,000 maximum for community supports and a $10,000 maximum for respite services. These figures are severely limiting in that they suggest that the needs of some persons with ID will simply be beyond what is considered 'reasonable' to provide. Once again, there are strong parallels between this logic and the logic that governs immigration testing. Additionally, this approach to equality, while striving for positivist neutrality, allows for persons with ID with the same score to receive the same dollar funding while in practice, some of these individuals will get less than they need, while others may receive more than they require (although this last occurrence seems less likely and is much less problematic). What appears to be taking place throughout the MCSS-run system is that the services and funding amounts that are needed are not always provided and instead, persons with ID are being fit into pre-designed services and funding categories.

By assigning fixed funding amounts based on categorical thinking about persons with ID that potentially disregards their actual support needs, the Passport Mapping Tool makes it clear

that an individualized approach to resource allocation is not happening. The service landscape described by the Ombudsman (2016), participants in this study, and participants in the Family Forum referenced earlier, show that persons with ID can either be forced to accept inadequate funding and services or go without support. According to these sources, these are services that were designed by an array of private agencies and that quite often, rather than reflecting individual needs, may compel persons with ID to fit into existing services and make do with pre-set funding levels and limits. The standardized processes used to match individuals to funding levels and services rely largely on SIS results that were arrived at through a standardized assessment method and then inputted into a mapping tool that is categorical and de-individualizing. The linking and matching role that the DSO is mandated to play and the Passport Mapping work they perform may be read as exercises in forecasting that rely on the creation – and potential imposition – of documentary identities derived from typologies of ID and disaggregated categories. We can link the creation of these identities to many of the consequences observed within the developmental services sector, the most important of which are the unmet needs of many individuals with ID.

Day's (2014) observation that potentially false needs are created through documentation processes that relate to consumerist goals helps account for some of the consequences observed above. Day suggests that as a result of these processes and the imposition of consumerist goals, real needs get ignored. He refers to '"objectivized' personhood" (p70) as one of the outputs of a system oriented towards these processes. He explains that this form of objectification is closely linked to typological and predictive thinking, to "algorithms and indexes that construct and link information according to needs that are predicted as attributes of subjects" (p69). Similarly, in Ontario, the prediction of persons with ID's support needs is arrived at through documentation

techniques that use mathematical indexing. Quite dangerously, the 'personhood' that is shaped through these processes can involve displacing the very subjectivity or self-knowledge of persons with ID. Day, referring to Althusser (2001), describes this as "the displacement of the personal psychological self (understood as a toolbox of hypothetical *potentials* [emphasis Day's])" (p82).

To have one's potential actions shaped or limited through documentary processes can be a form of subjective displacement, if we consider Day's formulation. Returning to the SIS, the risk that this tool and its implementation by MCSS may not always capture the complete realities of persons with ID and facilitate their presence in society coincides with the 'false' or imposed opportunities for belonging that can be presented to these clients and which do not necessarily reflect 'what they want'. The potential imposition of these opportunities aligns with documentary methods that seek to predict the future possibilities of persons with ID, closing a circle that includes documentation, moral judgment, prediction, and the potential shaping and displacement of subjectivity. As we have seen, the opportunities offered to persons with ID through predictive techniques can take the form of the often-inadequate Passport funding levels and services that are neither individualized nor empowering due to their preconstructed nature. In reality, and still according to Day, the fake opportunities offered through documentary techniques actually relay ideological constraints (p131). In the case of MCSS-funded services, these constraints are premised on the assumed incapacity of persons with ID, the lack of needs-based and individualized service planning, and an absence of direct funding.

As repeated throughout this chapter, the emphasis on sorting real or perceived impairment-related (in)capacities is connected to the presumed incapacity of persons with ID. The relationship between ID and incapacity is also a legacy of the institutional model described

earlier, which stratifies persons with ID based on their perceived deficiencies within an 'economy of uselessness'. In addition to other equity-related concerns, these forms of stratification can be displacing when persons with ID do not recognize the categories they are being fitted into and when these categories are allowed to inform decision-making that bars access to, or reduces their presence in, certain areas of society by offering them constraining opportunities. In very concrete ways then, evaluative practices that include these documentation techniques can also lead to insufficient funding amounts that prevent opportunities for exercising substantive citizenship. We have seen some of these effects in the algorithmic decision-making structured by the Passport program, which assigns differing levels of funding based mostly on SIS results and with some input from the ADSS. Because the Passport program uses a formal mapping tool, it provides a concrete example that allows us to identify the rationale employed by the MCSS-run system, which invokes a hierarchy of (in)capacity that is somewhat more difficult to detect in other areas as a result of conflicting claims and "policy assemblages" (Artiles, Dorn and Bal, 2016; Ureta, 2014).

Subjective Displacement and the Transformative Potential of the Supports Intensity Scale

Passport decision-making is still but one example of how a governmentality of (in)capacity operates and generates potentially displacing effects. The relationship between SIS scores and decision-making around Passport funding also exemplifies the power dynamics that are involved when predictive claims are made about an individual's (in)capacity and their potential support needs. For Day (2004), predictive matrices are laden with accuracy claims (pp132-133), and through their supposed connection to truth, they are empowered to shape an individual's social position. The problem with prediction in the context of disability support needs is that its power to shape reality is often stronger than its ability to actually reflect an

individual's situation. As Frank has suggested, a key shortcoming in how Ontario applies the SIS relates to a reliance on its predictive capacity, which is potentially flawed as a result of an assessment model that presents an individual's life out of context. Frank related these issues to the question of identity: "it doesn't cover a spectrum of reality, so there's no individual identity of that sort of thing". In the following quote, he suggests that the tool's inability to fully capture reality can cause individuals to feel surprised by their SIS results: "so many families would say, I don't recognize what you've written in these". The possibility that DSO assessment results can describe individuals in ways that do not match their self-understanding has the potential to shape the very subjectivity of persons with ID along coercive lines when these results are treated as factual. We will explore these processes more fully in Chapter Seven by considering interviews held with persons with ID and their relatives.

As we will soon see, the criticism of the SIS forwarded by many participants is closely reflective of feminist disability critiques of medicalized knowledge production. Wendell (1996), for instance, describes how medical authority alienates persons with disabilities from their own embodied realities, associating this alienation with broader cultural tends towards "bodily perfection[ism]" (p119). Quite similarly, the paradigm of independence, which has been forcefully rejected by some feminist disability scholars due to its detrimental impact on persons with ID (see Carey, 2009; Kittay, 2001; Kelly, 2016), manifests itself in the normative orientation of the SIS. The use of normative standards in decision-making around disability can potentially alienate individuals from their own subjective realities, positing new subjectivities in their place. These examples reveal Day's (2014) argument that individuals are both objects and subjects "of representation by documents" (p39), meaning that there is a feedback process that shapes individual actions once they are objectified (p137). This feedback loop helps account for

how displaced realities can be shaped through assessment and decision-making processes aimed at people with ID.

Day does not downplay the possibility that documentation techniques hold such a transformative potential for individual subjects. He writes that these approaches can, "transform the possibility of identity into the empirical reality of … facts" (p3). For persons with ID, this transformation is most noticeable when claims about an individual's (in)capacity and related needs are interpreted or re-created through assessments. These interpretative and forecasting exercises can set in motion a process that risks objectifying persons with ID through quantification techniques that simultaneously compel them to conform to the conclusions suggested by a given evaluation. In this way, we can see how governmentality operates in the developmental services sector through a linear view of support needs, underlined by a hierarchy of (in)capacity. In the context of Ontario, the assessment tools involved in this process can be characterized as a biopolitical apparatus that measures deviations from the norm, documents these deviations, and then potentially shapes individual behaviour based on these measurements by informing decisions about services and funding levels.

By mobilizing hierarchies of (in)capacity, assessments perform important identity-shaping work that can further alienate persons with ID, who are already defined as species-outsiders on the basis of their presumed incapacity. As Day suggests, prediction through the use of matrixes and other research techniques are never objective but are always imbued with moral judgment (p50). The potential role that moral judgment plays in this process helps question positivist claims that medicalized assessments can be fair and objective. Commenting on assessment results, for instance, Frank suggested that objectivity is lacking and described being, "astounded by the judgment that's inserted into these pieces". Again, and as we will see in

Chapter Seven, many persons with ID and their families shared a similar feeling upon viewing their assessment results. These reactions may be read by contextualizing the nature of decision-making around developmental services through dominant and hierarchical understandings of incapacity and dependency. Viewed in this way, community-based service solutions can be placed on a continuum with older methods. After all, as Rapley (2004)'s findings suggest, even newer approaches are still about the "management of [people with ID's] (in)capacities and (in)capabilities" (p1).

Most importantly, criticism shared by front-line workers, persons with ID, and families interviewed for this study allow us to question clinical findings and official claims about the validity and utility of the SIS. As Bill observed, "I don't sense a great deal of satisfaction from the community that requires these services with the process". Conversely, the study by Weiss et al. (2009) referenced earlier specifically set out to assess the predictive potential of the SIS and their findings were quite favourable (p939). Yet, when viewed through a critical disability lens, these predictive exercises represent inherent moral judgments about (in)capacity that carry the potential to shape the subjectivity of persons with ID along normative lines. And it is this very shaping of individual subjectivity through the linear ranking of (in)capacity – a species-defining quality – that can contribute to a form of subjective displacement. This is on account of the potential ability of this model to move persons with ID into "zones of exclusion" (Ahuja, 2016) that are situated beyond what is considered 'normal' and human, as well as beyond the qualities required for active citizenship.

Colonial Legacies of Quarantine and the Segregation of the 'Most Disabled'

Meanwhile, MCSS continues to expand and celebrate the Passport funding program as a form of direct funding, invoking the consumer-controlled Independent Living arrangements

created and accessed by people with physical impairments and/or disabilities through its use of this term. MCSS describes Passport as being intended to allow greater individual choice, stating that "[w]ith the right services and supports, [persons with ID] can participate fully in community life and feel that they truly belong" (MCSS, Developmental Services System – Legislation). To make sense of the official narratives that surround Passport and the SIS and that present these as positive opportunities for the ID community despite striking examples of displacement linked to this system, we can turn to Ahuja's (2016) study of technological interventions in colonial contexts. In arguing for connections between predictive clinical practices to spatial segregation and confinement, Ahuja provides further support for Day's (2014) insights into documentary identities. Ahuja's (2016) research also illuminates how (in)capacity hierarchies can contribute to persons with ID's moral status as outsiders, while helping to account for why these potential consequences may remain invisible to system administrators and key decision-makers.

In exploring how colonial power channels fears of racialized and colonized subjects into harmful policies, Ahuja found that many of these individuals were confined in quarantined zones after being assessed as potential "disease carrier[s]", even while most were in fact not. Such acts of confinement even occurred in contexts where the feared disease was not considered contagious. The prediction that racialized people could potentially be affected by a disease and present the "endangerment of able-bodied whiteness" (p33) was based on a racially-motivated moral judgment that resulted in their incarceration under imperialist control. Ahuja explains that the prospect of a cure or improvement to the (non)condition represented by racialized bodies was sometimes held out as a source of justification for their segregation and custodial treatment. The face of this cure, offered in the segregated "zones of exclusion" where supposedly infected

colonized people were sent, is linked to biomedical monitoring and involved close medical surveillance as well as medical acts of violence.

The ongoing surveillance and violence enacted against colonized people can account for the other dimension of support offered to persons with ID, which is also evident in the early asylum-era's mandate to confine and cure the 'feebleminded'. When weighed against their impacts, such imperatives suggest how protective goals relate to the desire to 'save' a non-disabled and white public from the eugenic threat of those deemed mentally incapable. Because of perceptions of their reduced capacity, persons with ID reflect the threat of the non-human to the rest of the species, just as Ahuja's colonized subjects, framed as "living embodiments of the apparent degeneration of human form" (p39), threatened the health of a profit-oriented imperial white society. In turn, these marginalized individuals were subject to dehumanizing policies, even while the optimistic and seemingly positive discourse of a 'cure' was held out as justification for their treatment. In such contexts, and within the developmental services sector, positive goals can be underpinned by discriminatory views that both justify and erase the displacing and harmful effects generated by the treatment of these segregated subjects.

Within the current MCSS-managed system, the starkest example of quarantine that stems from the fear of perceived degeneracy derived from an individual's supposed (in)capacity involves the segregation of individuals who fall under what Ferguson (2004) refers to as the category of "chronicity". By 'chronic' cases, Ferguson (2014) has in mind those persons with ID who are viewed as being most profoundly disabled and as "having the most challenging behaviours" and who are thus likely to occupy the "back wards" (p46). In Ontario, the most 'chronic' cases fall into the Community Networks of Specialized Care referenced earlier. These networks are geared towards persons with ID with dual diagnosis and/or "challenging

behaviours". According to the Ombudsman (2016), the networks "pool their expertise to treat and support adults who have developmental disabilities, mental health needs and/or challenging behaviours" (p96); they are directed by private agencies, as are most other MCSS-funded services. Access to one of these networks is potentially informed by the final section of the SIS, which asks about 'exceptional' medical and behavioural needs. The SIS manual specifically refers to "13 problem behaviors" (SIS User's Manual, 2015, p1). Far from an afterthought, then, planning for this further level of segregation directed at 'exceptional' and 'problem' people is made possible during the initial assessment process, revealing how Ferguson's (2004) "economics of uselessness" expresses itself through the category of chronicity.

Whereas the manifestation of this ideology in an asylum context took the form of abandonment, in contemporary society, chronicity tends to result in special medicalized interventions and coordinated forms of segregation. The Networks of Specialized Care thus assume the existence of a group of persons with ID whose incapacity is so 'profound' that they are beyond the scope of even the segregated services offered by the MCSS-run system. A special category is devised for their care and this treatment, unlike the style of abandonment described by Ferguson during earlier historic periods (1994; 2004; 2014), is explicitly geared towards rehabilitation through medical services. This extra step is needed because this category of persons with ID are supposedly not ready for inclusion. While a closer look into these networks is required before any arguments can be made about the quality or benefits of the services they provide, the very existence of the networks and the potential they create for service differentials may nevertheless be critically considered. This analysis may begin by considering how segregation operates through the hierarchical ordering of impairments that is informed by perceptions of (in)capacity. Such a critical reading of the specialized networks is bolstered by

recent predictions made by Australian scholars (Bigby, et al., 2014) that the group home model will persist due the view that it presents the best option for people with profound ID, even while individuals with 'less severe' ID are transitioning towards more individualized housing options.

Earlier research by Albrecht (1992) provides reason to believe that stratification, which is part of the production of disability, is linked to "a larger exploitation process in which disabilities are produced and treated at a profit in a society" (p244). This is due to several observable dynamics within the rehabilitation industry which may apply in the case of ID as well. As Albrecht explains, services seek to intervene to "improve the functional level of independence for persons with disabilities" (p223). Accordingly, we might expect that individuals who are thought to come much closer to normative standards, possibly as a result of the 'milder' nature of their impairments, will be prioritized by service industries that are oriented towards this paradigm of independence. This observation is in keeping with Ferguson's concept of 'chronicity' (1994; 2004) and his related notion of the "back ward" as "a physical location and conceptual justification for those whom professional seem unable to help" (2014, pp58-59). Thus individuals who may be thought to possess a greater rehabilitative potential, may be privileged when services are being designed. As a result, they could be expected to have access to a better quality and broader range of services. As a result, more 'mainstream' developmental services that are oriented towards enhancing capacities for independence among people with ID may target those who fall outside the specialized networks of care. The reasons for which the quality and variety of these mainstream services may be better, extrapolating from Albrecht's observations (1992), could be related to the imagined cost benefits of serving these more 'integratable' individuals. In Albrecht's words, "it is less expensive to bring individuals back to their highest level of function, given moderate intervention, than to provide support services for

dependent individuals for life" (p224). Conversely, those who are considered to have a lower rehabilitative potential may be denied access to certain services and relegated to specialized or more segregated forms of treatment. However, rather than being "largely forgotten", as was the case in some of the earlier versions of 'back wards' described in Ferguson's study (2014, p46), these individuals could have access to a different, more specialized, and possibly more segregated stream of services. The difference between abandonment and specialized care may however be accounted for through Ferguson's discussion of 'back wards' in relation to a continuum of services that can be distinguished by the level of segregation experienced.

Just as Ferguson's chronic cases were defined by medicalized and individualized views of perceived problems, the exclusion and challenges faced by persons with ID who are identified as having exceptional behavioural or psychiatric needs are not often viewed through a structural lens that takes into account the whole of a disabling society. Neither do these views reflect a complete understanding of individual realities, circumstances, and preferences. Instead, individual problems are medicalized and individualized based on an initial assessment that presents an incomplete view of the person. Persons with ID with a dual diagnosis – in other words, with a psychiatric as well as an intellectual disability – can be viewed as 'doubly' disabled and their segregation within developmental as well as other service areas, such as health, can be justified on the grounds that their 'condition' is a complex one.

The Ombudsman report (2016) shares the Community Networks of Specialized Care's claim that the individuals they work to connect to specialized services are at risk of incarceration "in shelters, or in forensic psychiatric facilities" (p96). Needless to say, persons with ID who fall into the category of dual diagnosis and/or challenging behaviours, may be among the most marginalized in this community. As a result, persons with ID with these higher support needs can

remain more hidden and segregated within an already-segregated sector, echoing Dwyer's (2004) fear that the consequence of scoring low in an evaluation of incapacity and having multiple disabilities includes different forms of treatment. In Ontario, individuals accessing the Community Networks of Specialized Care may, for example, be placed in a group home that specializes in behavioural issues, while being denied entry into day programs and other spaces that are not specifically designed for their level of need.

The needs of these individuals are presented in official discourses as 'specialized' and 'exceptional' – terms that help expose the level of pathologization that shapes their treatment. The existence of this special category further demonstrates how linear assessment processes such as the SIS set up an excluding formula by allowing for the existence of a low-ranking category. As Goodey (2016) argues, such an approach is problematic, "because it opens up the possibility of an ultimate or extreme outsider whose needs cannot be met" (p56). Within the deeply stratified MCSS-run system, those with 'challenging behaviours' or more profound disabilities who are grouped together in specialized congregate care environments represent one of the farthest zones of exclusion.

Concluding Thoughts

The evidence presented in this section raises questions around MCSS' description of a "fair and consistent way" of resource allocation that will "make it easier for adults with developmental disabilities and their families to apply for supports" (MCSS, A New Way to Apply). Relatedly, this section has presented a critical reading of the Passport funding program and assessment and decision-making processes that allocate scarce funding through the DSOs. Above all, this analysis draws on participant interviews to question whether current assessments and decision-making accurately reflect and respond to the needs of persons with ID. Further

research around the potential benefits of current practices to the ID community in Ontario, especially from non-clinical perspectives, would help justify their cost and provide a clearer image of this ten-year-old system. Existing clinical validity studies do not appear to answer the many questions that participant interviews have opened up around the SIS and more interdisciplinary research into lived experiences with this assessment tool would certainly be beneficial.

Meanwhile, a critical reading of how Ontario implements the SIS – including the experience of being assessed, the (in)adequacy of funding decisions based on assessment results, and the (in)appropriateness of the supports offered to those being assessed – suggests that these practices have the potential to shape displaced realities and negative experiences. By situating broader assessment and decision-making practices in a historical and theoretically-informed context, we have seen how hierarchical understandings of (in)capacity allow for people with ID to be ranked according to normative standards that reinforce exclusionary citizenship regimes and potentially undermine both their personhood and their agency. Alternative approaches suggested in this section require us to recognize the values that risk rendering people with ID species-outsiders. Possible ways forward require a greater respect for the potential for people with ID to define their own subjectivities and more individualized ways of meeting their self-described needs. These solutions involve funding more direct front-line support and along with this, allowing greater consumer-control for persons with ID and where appropriate, their families, so that they can be play a role in designing services.

Supporting the agency of people with ID also involves placing them in a position to select the services they feel they need and even trying them out, as Bill suggested, by meeting with providers and making those decisions together. Carey (2009) describes what this new

system might look like when she points out that a paradigm shift would "render meaningless professional judgment regarding who should and should not receive services and rights" (p104). Overhauling the current system by shifting greater control to persons with ID to articulate their support needs and inform service design in a way that will meaningfully impact their lives requires MCSS to shift its investment focus away from monitoring and regulation and towards the creation of services that respond to individual demands. This could include, for example, instituting a direct and individualized service and funding model that shifts the balance of power.

Lastly, it may be observed that the potential shortcomings of dominant assessment practices relate to the paradox posed by their claim to support persons with ID while testing them according to the same values that are used to exclude them. As already noted, the use of normative measures of (in)capacity and (in)dependence and the often-hidden but inseparable notions of intelligence and intellectual deficiency, reflect a degree of carry-over from earlier eugenic practices. The persistence of these ideologies, which centre capacity and the possibility of independence and productivity as requisite markers of citizenship, can subsequently be linked to a broader failure to challenge how we define citizenship (Carey, 2009, p7). There is however, an imagined incentive in retaining these exclusionary values that can help explain their persistence and along with this, MCSS' decision to centre regulation over service provision. As Kittay (2001) explains, there are perceived cost savings associated with an independent citizenry. For this reason, she argues that service provision for persons with ID can only be justified within the dominant culture as advancing independence. When supports advance independence, they are thought to be worthwhile investments. However, when it is impossible for persons with ID to attain independence, investment in services that support self-determination – and thus access to citizenship – may never materialize. As Kittay writes, "when it is not cost effective to promote

'independence' and 'productivity'– if it would be more costly to promote these than to continue state support – then a way of life that is more self-determining, even when it is desired by the individual and recommended by state-appointed professionals, can be scrapped" (p569). Bringing this decision-making lens into focus allows us to account for why an inability to perceive many persons with ID as independent may result in a failure to invest in their needs. The position of people with ID who are labelled as dual diagnosis and who are prone to further segregation through the Community Networks of Specialized Care raises further concerns around how the 'most disabled' are being treated.

The experiences of migrants with disabilities help draw these economic links into even sharper relief. An analysis that centres both transnational and translocal experiences reveals how Canadian government decisions around who will be admitted into the citizen body are largely informed by medicalized economic calculations and notions of (in)dependence and (in)capacity. The next two chapters address how the immigration medical exam regulates permanent residency status in Canada through the excessive demand provision of the immigration act, drawing insights and comparisons from Ontario's developmental services system and the governmentality of (in)capacity described so far. Specifically, this analysis applies an ID lens to consider how (in)capacity and (under)development are assessed in transnational contexts and under legislation governed by Immigration, Refugees and Citizenship Canada. By focusing on evaluative tools and regulatory mechanisms across different jurisdictions where persons with ID and migrants with disabilities live their lives, we can better appreciate Carey's (2009) point that the problem of exclusion relates to broader issues such as "the way in which we allocate rights" (p2). The next section takes up this problem by turning to immigration policy and practice.

Part III – Migration and Displacement: Reading Excessive Demand Screening Through an Intellectual Disability Lens

Section Introduction

This section is concerned with the particular barriers faced by migrants with disabilities seeking permanent status in Canada. The two chapters that follow address these issues by comparing the ways in which Immigration, Refugees and Citizenship Canada (IRCC) conceptualizes disability to the differential impact of the Immigration and Refugee Protection Act (IRPA) on migrants with ID and people of colour moving to Canada from the Global South. The imagined fairness of Canada's immigration system is certainly important to its reputation (Satzewich, 2015, p35). However, advocacy and research cited throughout this study that centres immigration discrimination and prejudice against disabled people, people of colour, women, and other groups challenges this imagined reputation in important ways. The two chapters featured in this section reflect such critical traditions by expanding on the argument that the Canadian immigration system does indeed discriminate against disabled applicants. In extending this argument and adding to existing critiques, these chapters demonstrate that immigration discrimination is best understand along intersectional lines that develop the conceptual power of ID as way of interpreting linear ranking systems and screening tools.

In Chapter Five, the 2001 IRPA, which came into force in 2002, will be placed in historical perspective through a discussion of policy reform efforts leading up to 2017. The post-2002 policy era will then shape the focus of Chapter Six and inform an in-depth analysis of a recent Parliamentary Committee study on immigration in addition to the specific medical screening tools that are enacted under the IRPA. The focus throughout both chapters is the legislative provision within the IRPA which requires that visa and medical officers employed by

the IRCC and the panel physicians who report to them, screen applicants for 'excessive demand'. The excessive demand criteria remains but one dimension of the category of medical inadmissibility – a category that also targets certain risks to public health and safety through Sections 38(1)(a) and (b). And while this dissertation will only focus on excessive demand assessments legislated by Section 38(1)(c), there is nevertheless important overlap between these categories.

The legislative basis for these screening practices can be found in Section 38(1)(c) of the IRPA, introduced at the start of this dissertation, which states that

> 38 (1) A foreign national is inadmissible on health grounds if their health condition
> (a) is likely to be a danger to public health;
> (b) is likely to be a danger to public safety; or
> (c) might reasonably be expected to cause excessive demand on health or social services
> (Immigration and Refugee Protection Act, SC 2001, C.27)

The provision applies to and mostly effects economic class migrants and their families, including investors, skilled workers, live in caregivers, temporary residents, and students (CIMM, 2017, p12 and p27). By recent count, the majority of excessive demand determinations (78 per cent) relate to applications for permanent residency (p26). IRCC reports 900-1000 cases a year, which does not include individuals who never apply or who withdraw their applications (CIMM, 2017, p11). Exceptions to this provision are also set out in the legislation and include "a foreign national who":

> (a) has been determined to be a member of the family class and to be the spouse, common-law partner or child of a sponsor within the meaning of the regulations;
> (b) has applied for a permanent resident visa as a Convention refugee or a person in similar circumstances;
> (c) is a protected person; or
> (d) is, where prescribed by the regulations, the spouse, common-law partner, child or other family member of a foreign national referred to in any of paragraphs (a) to (c)
> (Immigration and Refugee Protection Act, SC 2001, C.27)

At the start of this dissertation it was explained that excessive demand involves a cost evaluation that takes into account an applicant's prospective use of health and social services as well as how this may impact current wait times for services in Canada. IRCC officials compare these projected costs to a "Canadian average", defining excessive demand in the following way:

> *excessive demand* means
> (a) a demand on health services or social services for which the anticipated costs would likely exceed average Canadian per capita health services and social services costs over a period of five consecutive years immediately following the most recent medical examination required under paragraph 16(2)(b) of the Act, unless there is evidence that significant costs are likely to be incurred beyond that period, in which case the period is no more than 10 consecutive years; or
> (b) a demand on health services or social services that would add to existing waiting lists and would increase the rate of mortality and morbidity in Canada as a result of an inability to provide timely services to Canadian citizens or permanent residents. (Immigration and Refugee Protection Regulations, 1.1, S.O. R/2002-227).

According to IRPA Regulations, the health services that are currently subject to this provision include:

> "any health services for which the majority of the funds are contributed by governments, including the services of family physicians, medical specialists, nurses, chiropractors and physiotherapists, laboratory services and the supply of pharmaceutical or hospital care."

Social services include:

> "any social services, such as home care, specialized residence and residential services, special education services, social and vocational rehabilitation services, personal support services and the provision of devices related to those services,
> (a) that are intended to assist a person in functioning physically, emotionally, socially, psychologically or vocationally; and
> (b) for which the majority of the funding, including funding that provides direct or indirect financial support to an assisted person, is contributed by governments, either directly or through publicly-funded agencies" (Immigration and Refugee Protection Regulations, 1.1, S.O. R/2002-227).

Following reforms announced by the IRCC in April 2018, "special education services, social and vocational rehabilitation services, and personal support services" will be removed as the basis for excessive demand cost evaluations (IRCC, 2018a). Another important change that

occurred in 2018 was to the cost threshold used to determine which demands may be 'excessive'; that amount was raised from $6604 to $19,965. As previously explained, these announced amendments to the definition of excessive demand were offered in place of a full repeal. The Minister of Immigration, Ahmed Hussen, accounted for this decision by explaining that while there is a need for change, the IRCC wishes to lead further consultations before pursuing a repeal. Meanwhile critics argue that delaying the repeal even while presenting it as a future possibility, "amount[s] to discrimination despite the 'vague assurances' from the minister that the policy eventually will be fully rescinded" (Harris, CBC News, 16 April 2018).

Summary of Chapters

Taking into account the results of the 2018 decision by the IRCC, the chapters in this section ask why a full repeal was not considered possible at the time. This section situates this question within a history of resistance to the excessive demand provision that culminated in the 2017 Parliamentary Review. To approach these issues, we must first step away from the legislation and look at its historical, conceptual, and political background. The overall goal of this section is therefore to present a theoretically-rich and historically-informed analysis of how medical assessments mobilize capacity hierarchies to shape experiences of non-citizenship and displacement among migrants with disabilities. This will help situate the lived experiences recounted by participants (which will be explored in Chapter Seven) within a displacement framework that is centred on the concept of ID. This approach also allows us to read these narratives through transnational and translocal contexts, as well as alongside the experiences of Canadian citizens with ID. In this way, findings from this section add a layer of nuance to, while also moving beyond, existing claims that the IRPA simply discriminates against disabled migrants by framing their disability-related needs as a potential burden to Canadian health and

social services. These two chapters unpack specific biopolitical tools enacted under the IRPA's excessive demand provision, grouped under the immigration medical exam. This close-reading demonstrates the relationship between assessment tools and experiences of disability displacement through an analysis that is centred on forms of screening related to ID. As this section develops, we will see that intersectional and linear understandings of (in)capacity and (under)development form the ideological basis upon which the 'burden narrative' of disability has been permitted to flourish.

First, Chapter Five presents an historical exploration of excessive demand that situates the provision within settler colonial legacies. This discussion sets the stage for Chapter Six, which addresses recent advocacy around the provision, forwarding one of the first critical discussions of excessive demand in light of the 2017 Parliamentary Review and related changes announced by the IRCC in April 2018. Chapters Five and Six each build upon the small body of extant research on the excessive demand provision, contributing an up-to-date analysis as well as a more focused discussion of the immigration medical exam and specific medical assessment tools. A sample of these assessment tools will be considered in detail in Chapter Six, which presents an analysis of their application and impact from a critical disability perspective. Chapter Six also brings to light the many dimensions of displacement that are shaped by these tools and which go beyond, while still interacting with, deportation and other forms of spatial displacement.

Chapter Five: Risk, Regulation, and Reform: Negotiating Inadmissibility Through Capacity Hierarchies

Introduction – Deepening Existing Critiques Around Disabled Migrants and the 'Burden Narrative'

To set the stage for an in-depth analysis of the recent CIMM review, this chapter draws upon existing research to outline the broader history as well as law and policy reform efforts associated with Canada's excessive demand provision. To this end, this chapter engages research by civil society groups to provide a clearer picture of how the provision has been applied; it argues that certain groups, and namely migrants with ID and racialized migrants, are affected by the provision in unique ways as a result of how the IRPA conceptualizes and evaluates (in)capacity. The formal exclusion of migrants with disabilities can thus be placed on a continuum with experiences of non-citizenship that shape the lives of people with ID who currently hold permanent status. At root here are the medical screening tools that enact Section 38(1)(c). But before we can assess these tools, we must refine our understanding of (in)capacity by considering intersectional and historical connections related to how people with ID, racialized, and colonized people are conceptualized. The first part of this chapter thus seeks to elaborate important links between (in)capacity, racism, and xenophobia – a potent example of prejudice that will help account for the seemingly permanent and undoubtedly persistent nature of Canada's excessive demand regime. Throughout this discussion, the notion of (under)development is invoked as a close corollary to (in)capacity which, when viewed through an intersectional lens that is attentive to race and disability, can help us appreciate the ways in which migration and mobility are regulated and shaped by economic interests and a governmentality of (in)capacity. Addressing histories of resistance to excessive demand screening, this chapter then engages established critiques around the regime which question the presumption that disabled people pose a 'burden' to Canadian society. This discussion views the

history of immigration law and policy reform through the notion of (in)capacity as a force that has been active in shaping citizenship cultures and formal criteria around 'who belongs'. In doing so, it sets the stage for experiences of displacement enacted under the excessive demand provision. Throughout, the analytical framing of these issues helps promote an intersectional approach that is attentive to notions of 'development' on both individual and global scales, foregrounding Chen's (2016) intersectional formulation of capacity.

While the notion of (under)development has not yet been addressed in critical research around the IRPA, much attention has been directed at the broader ableist assumptions underpinning the legislation. Academic research related to the IRPA and disability has been somewhat limited (for important exceptions see Dowbiggin, 1995; Chadha, 2008; Hanes, 2009; Capurri, 2010; Wong, 2012; El-Lahib and Wehbi, 2012; Reaume 2014; Joseph, 2015; El-Lahib, 2015; 2016a; 2016b; Spagnuolo, 2016b; 2016c; 2018). Alongside existing research, media coverage and work by civil society groups – especially surrounding the CIMM review – support the establishment of powerful counter-discourses highlighting the ableist dimensions of Canada's immigration law. As previously suggested, these challenges to ableism work to undermine the 'burden narrative' associated with disability and locate this narrative within the IRPA's excessive demand provision. For this reason, it is now much less surprising to encounter claims that immigration policy discriminates against disabled people.

Perhaps one of the most representative as well as influential critiques of the regime was articulated in a 2009 research paper on excessive demand by Bakerlaw, commissioned by the Council of Canadians with Disabilities (CCD).[11] In their report, Bakerlaw (2009) claims that

[11] Once again, in the interest of transparency, I should share that at the time of writing, I served on CCD's Social Policy Committee, National Council of Representatives (Board of Directors), and had been involved with the organization in other ways.

excessive demand "is not based on a cost comparison from one child to another, but based on the fact that the cost created by one child is considered and the other is not". The report continues, "[t]he objective of the legislation then cannot reasonably be said to avoid excessive demands or costs to the government" (pp27-28). Bakerlaw is forwarding the claim that testing for excessive demand is based on a value judgment about which costs are beneficial to society. This is because it allows for costs associated with supporting persons with disabilities to be placed beyond the vision of what is viewed as an acceptable investment in socio-economic terms. Excessive demand assessments, according to this critique and the above quote, do not take into consideration the costs incurred by supporting a non-disabled child, but instead focus only on the costs incurred by supporting disabled children. The flipside of this approach to assessment is that excessive demand "excludes the benefit to Canadian society brought by people with disabilities" (p28). As we will see, elements of Bakerlaw's critique and namely the exclusion of disabled people's contributions and the assumption that they pose a burden, recur throughout the history of resistance to the provision. This idea can be traced in the comments shared by the many civil society groups, researchers, lawyers, migrants, and other stakeholders who participated in the 2017 CIMM review, as well as in the many struggles leading up to this Parliamentary study.

Ultimately, the Parliamentary Committee recommended a number of strategies for mitigating the adverse effects of the excessive demand provision, but their top recommendation was for a full repeal of 38(1)(c). As we saw earlier, IRCC responded to the recommendations by reforming rather than ending the practice, raising the cost threshold used to evaluate excessive demand and altering which services fall under the scope of the provision. To better appreciate why the IRCC chose to keep the controversial provision in place amidst widespread criticism, we can work backwards from the CIMM review to address the limitations of earlier challenges to

the regime. The following sections centre a critical reading of immigration law and policy, reinforcing the claim that under the excessive demand provision of the IRPA, the immigration medical exam – a biopolitical technology of the Canadian state – carries displacing effects for migrants with disabilities as well as for disabled people who hold formal permanent status. These displacing processes shape disability relationships to non-citizenship along spatial, subjective, and substantive lines.

So far, the criticism that disabled people pose a 'burden' to society has been well articulated by critics. However, this 'burden narrative' requires further exposition to clarify the importance of the inter-related concepts of (under)development and (in)capacity. As we will see, the immigration medical exam and associated screening tools are more productively situated within a framework that acknowledges the importance of ID as both concept and cornerstone of ideologies shaped by a faith in predictive medical technologies. Such thinking supports the hierarchical ranking of human capacity and development and shapes disability displacement along intersectional lines within both translocal and transnational contexts. By focusing on hierarchies derived from ID-related concepts, we can draw a clearer picture of the political economy of medical decision-making that serves to justify excessive demand screening. For these reasons, the notion of ID as an impairment category characterized by the inter-related concept of (in)capacity and (under)development is invaluable to a critical analysis of excessive demand practices.

Historicizing Excessive Demand as 'Defective' Development

While ID has been associated with both incapacity and underdevelopment (or 'halted development') in biomedical terms, in some contexts, and especially in relation to immigration restriction, ID and development are more helpfully conceptualized in relation to race. For this

reason, we may consider the excessive demand provision through a theoretical framework that incorporates an intersectional knowledge of ID and that draws direct attention to its racial dimensions. While the general systems that support spatial displacement are the focus of this chapter, a discussion of (under)development and (in)capacity will also equip us to analyze the specific mechanisms that are at play in shaping excessive demand determinations, which will be unpacked in Chapter Six. Along with immigration exclusion and deportation, this discussion also relates complex forms of subjective and translocal experiences of displacement that are central in shaping non-citizenship for both migrants with disabilities and Canadian citizens with ID. Before unpacking this framework, a brief overview of immigration exclusion as a process shaping spatial displacement is required.

The regulation of mobility, which can be enacted through the denial of permanent status, migrant detention, and deportation, is a more readily traceable form of spatial displacement, and immigration law serves as one of its most obvious manifestations. Canadian histories of migration, with the important exceptions outlined earlier, have nevertheless tended to overlook the fact that disabled migrants have been targeted by restrictionist policies and formally excluded from settling in Canada with permanent status. Even fewer researchers tend to acknowledge how this exclusion is bound up with racist ideologies that privilege white settlers and denigrate people of colour. A fuller historiographical discussion of these points was presented in Part I, and while a detailed history of immigration law remains beyond the scope of this analysis, a thematic and historically-informed overview is nevertheless helpful at this stage. Evidence presented by Hanes (2009) and Chadha (2008), for example, show that disability has always been a category of exclusion. Race, while removed in the 1967 Regulations (Department of Justice, 2015), continues to be an implicit one, especially when viewed alongside disability exclusion and

analyzed through an intersectional lens. Work by El-Lahib and Wehbi (2012), Wong (2012), El-Lahib (2016a; 2016b; 2015), Joseph (2015), and myself (Spagnuolo, 2016b; 2018) is notable for beginning to address these intersections from a Canadian immigration perspective. However, we have yet to unpack how the view of disability dependency expressed in IRPA Section 38(1)(c), embodies normative constructs of ID and the inter-related concepts of capacity and development. And while existing research into the history of disability and migration in Canada and the United States (see for example Spagnuolo, 2016c; Baynton, 2016), address the imagined link between disability and dependency and its role in shaping screening and deportation practices, it does not provide a critical assessment of how immigration policy has framed (in)capacity and (under)development. Before addressing these relationships and developing this layer of analysis, we should recall that most disability histories of immigration restrictions tend to centre 'dependency' as a disqualifying feature. The association between incapacity, underdevelopment, and dependency means that such critiques are highly relevant to an ID-centred framework. Further exposition of these findings will support a critical analysis of how reform efforts have addressed or failed to address the underlying concept of (in)capacity and its intersectional possibilities.

In one of the earliest studies of Canada's excessive demand provision, Hanes (2009) dates discussions of dependency and disability to Canada's first Immigration Act of 1869. Although Hanes' discussion does not name the white settler population as an object of protection, he describes how the Act sought to protect "the general populace" from contagious diseases and from those who might have required what was referred to as charitable relief. The 1910 Act then established the category of "Prohibited Classes", which clearly listed disability as grounds for exclusion. Hanes explains, however, that at this stage Canada did not deny disabled

migrants entry under absolute terms. Instead, the legislation intended that disabled people who could support themselves (i.e. who did not 'burden' the public system) would be allowed entry. In Hanes' words, these are important exceptions: "[t]he historical record shows there were restrictions but the record also indicates that allowances were made. And these allowances were made with the belief that individuals, no matter their status, would be able to provide for themselves". Omitted from Hanes' survey are the ways in which dependency and contagion – especially from a medicalized colonial perspective – are racially imbued categories, as Ahuja (2016) has shown. El-Lahib (2016a) also draws attention to this oversight in Hanes (2009), arguing that the issue of racism as a mode of immigration exclusion ought not be considered a closed question. Nevertheless, Hanes notes that while the 1967 points system initiated many changes, including the removal of race as an explicit category of exclusion, it left disability exclusions in place as a "prohibited category". That category was not removed until the 1976 Act, but even then it was only replaced by the category of "Inadmissible Classes."

The terminology around medical inadmissibility that is currently present in the IRPA can indeed be traced to the previous Act. However, in suggesting that this updated terminology marks a fairly insignificant change, Hanes claims, "the language changed but the consequences of the legislation for people with disabilities and their families remained the same". His dismissal of these changes is further supported by the fact that up until 1991, the Act actually referenced disabled people within the excessive demand clause. According to CCD, this reference was only removed as a result of the organization's own advocacy efforts. Notably, since 1984, CCD (which at the time was known as the Coalition of Provincial Organizations of the Handicapped) has been pushing for the complete removal of disability as grounds for inadmissibility and for higher rates of admission for refugees with disabilities (CCD, Immigration). As we will see

below, CCD has also been involved in many court challenges around the excessive demand provision.

Conceptualizing Immigration Screening Through an Intersectional Understanding of Intellectual Disability

Underlying these histories of Canadian immigration restriction dotted by reform campaigns is a political economy of medical decision-making. This economy carries problematic understandings of capacity and competency that resemble those explored in the previous chapter's discussion of ID and the governmentality of (in)capacity in Ontario. Through an analysis that is attentive to the political economic dimensions of these ID-related concepts, we will see that knowledge-claims about who constitutes a 'burden' can be based on the identification of an individual's capacity to contribute to Canada's socio-economic development. In this sense, capacity and development are related pillars of both individual and broader national progress, normatively defined. In fact, Russell (1998) specifically links dominant views of progress and "economic growth" to the marginalization of disabled people (p126), centring these consequences in her call for alternative cultural and economic arrangements (p143). Understanding how connections between capacity and development surface in biomedical and rights-based framings of disability is of paramount importance in assessing current immigration reform efforts. Often viewed in economic terms through the lens of 'employability' (see, for example Stephen, 2007), capacity is, at the same time, defined in opposition to people with ID. As Chapters Three and Four have argued, ID remains the quintessential condition of 'defective' or 'halted' development. Following Chen's thinking (2016), inter-related notions of capacity and development can be applied towards individuals and entire communities, affecting global

processes and giving rise to expectations around both individual and economic capacity for development (p237).

A closer look at the burden narrative that is so frequently centred in disability-informed critiques of Canadian immigration law also suggests the importance of focusing on conceptions of ID. So, while people with ID constitute one of the smallest impairment categories in Canada, making up less than one per cent of the population (Statistics Canada, 2017, p8, Table 3), the relationship between this community and provincial approaches to developmental services remain important to understanding much broader modes of exclusion, including the excessive demand regime. Consider for instance how the ascription of ID and related categories to racialized groups is a medical form of labelling that has been used to justified racist policies (see for example Mensch and Mensch, 1991). Quoting de Lone (1977) who wrote about, "the systematic misclassification of black children as retarded" (Mensch and Mensch, 1991, p61, quoting de Lone, 1979, p71), Mensch and Mensch (1991) suggest this was closely related to inherent biases within psychometric practices resulting in segregation within the school system (p61-62). Such ascriptions are but one example of the potency of the intersectional links described in this section.

The ways in which migrants with disabilities access and enact permanent residency status, citizenship, and associated rights are part of complex legacies of discrimination against people with ID and racialized communities. Indeed, the intersectional nature of these forms of displacement draw together racist and ableist thinking around development, presenting a view of (in)capacity that is inseparable from predictions of individual and economic growth and development. Recalling that ideas about development have been shaped by scientific racism and histories of violence against people with ID, we can take up Chen's (2016) suggestion to "pause

here and think about the relationship between biopolitics … and the transnational biologisation of governance" (p246). Such an approach will only deepen our understanding of how the excessive demand provision regulates belonging by ranking human capacity and the potential for human and economic progress. Chen's ideas will be referenced throughout this discussion to inform our understanding of the links between ID, race, and colonialism as they unfold through the history of the excessive demand regime.

Excessive Demand: 'Out of Step' with Canadian Values?

The ongoing outsider status and non-citizenship experienced by people with ID who hold formal permanent status in Canada provides a window into viewing the persistence of the excessive demand regime. Conversely, the continuation of this regime may be hard to appreciate when its reasoning is only assessed in economic, anti-discrimination, or human rights terms. Challenges to the imagined cost savings and rights violations associated with excessive demand screening have, after all, been well articulated (see especially the 2017 CIMM report), and yet have failed to dislodge the provision. As previously explained, the changes announced by the IRCC in April 2018 do not alter the legislation but aim instead to refine its mechanisms by updating the cost threshold and the services that fall under this benchmark. While a repeal may eventually take place and has been alluded to by the Minister of Immigration (Harris, CBC News, 16 April 2018), this is not a guaranteed outcome and it remains important to understand why the provision has not yet been removed.

Focusing on ID in the context of excessive demand screening reveals why existing economic, anti-discrimination, and rights-based arguments do not completely account for the underlying barriers to belonging faced by migrant with disabilities and their families. Such a critical reading of the updated inadmissibility regime challenges official claims by the IRCC that

the changes bring the policy "in line with inclusivity for persons with disabilities" (IRCC, 2018a). Equally important is how the reading presented in this section challenges the narrative forwarded in the review presented by CIMM to the House of Commons on 13 December 2017, which curates the various strategies taken up by civil society groups, lawyers, and migrant and disability advocates in their call for a full repeal. The report states that medical inadmissibility is "out of touch" with Canadian values (CIMM, p1). Similarly, Bakerlaw's report (2009) to CCD contains the claim that "it is quite ironic that the items ["specialized disability services"] that make Canada more accessible for current residents make it less accessible to prospective immigrants" (p28). This chapter and the next argue that far from being ironic and out of touch, immigration screening is closely reflective of domestic approaches to disability and to ID in particular, that relate to a governmentality of (in)capacity. The medical screening practices that constitute excessive demand testing can thus be situated within dominant understandings of (in)capacity and all its intersectional possibilities.

The official response by the Minister of Immigration to claims that the excessive demand provision contradicts domestic approaches to disability was to aim to "make the excessive demand policy more fair and inclusive of persons with disabilities, while also protecting publicly-funded health and social services" (Government Response, 2018). Of course, the view that excessive demand can be rendered 'fair', especially when coupled with an insistence on protecting services, does not adequately respond to the argument that the very existence of the provision is unjust and the protection of certain services discriminatory (CIMM, 2017). The IRCC's response may be viewed as an impartial rhetorical appropriation of the general critique and push to update the IRPA to bring it in line with 'current thinking' around disability. The problem of course is that 'current thinking' around disability remains problematic, especially

when viewed through an ID lens that centres intersectionality. To understand why economic, anti-discrimination, and rights-based claims failed to trigger a full repeal of the excessive demand provision and why CIMM recommendations permit the continuation of these practices even while acknowledging their unlawfulness, we must consider such policy reform efforts through the lens of ID, incapacity, and underdevelopment.

Notably, the IRCC reported that the excessive demand regime costs an estimated $800,000 to $1,100, 000 annually (CIMM, 2017, p15). However, reflecting on historical immigration practices, Joseph (2015) has found that the economic motivation for welcoming migrants was often trumped by greater eugenic concerns (p105). While these eugenic motives reflect the fear that disabled people pose a burden, the financial credibility of this narrative was recently called into question and does not fully account for why the excessive demand regime persists. As previously mentioned, the entrenchment of these practices can be better accounted for when viewed alongside provincial disability systems and specifically developmental services systems. A careful and comparative reading of immigration medical exam screening tools that takes into account how provincial disability services as exemplified by developmental services are structured, suggests a more nuanced picture. Specifically, we will see that Canadian citizenship culture continues to conceptualize disability through a hierarchical ordering of (in)capacity and, importantly for this study, that it does so in a way that legitimizes IRCC laws and practices. Particularly important to this discussion is how medical inadmissibility criteria shapes non-citizenship by denying migrants with disabilities formal permanent status.

These detrimental framings of disability fit the ablenationalist pattern of welcoming the 'least disabled' and investing in forms of participation that do not challenge dominant social relations and structures or compel them to change in any way (Mitchell and Snyder, 2015, p14).

The power dynamics that can be detected in broader social structures mirror developmental services systems in the sense that they organize opportunities along a continuum of (in)capacity and (under)development, allowing for groups to be assessed, ranked, and documented as more or less 'capable'. Going beyond the general association between disability, dependency, and undesirability makes visible a radical fear of incapacity. This helps us push past the basic recognition that the medical screening practices which are associated with Canada's excessive demand criteria discriminate against disabled people. It also allows us to move beyond the argument that these practices are discriminatory because they frame the services disabled migrants may use as imposing a potential 'burden' and fail to recognize the potential contributions and value of disabled people. Consistent with prior historical research that I conducted around immigration screening (Spagnuolo, 2016b), the following sections will demonstrate that a fear of people with ID is embedded within medical inadmissibility testing practices. Perhaps even more surprisingly, this fear inadvertently structures existing economic, anti-discrimination, and human rights-based arguments against the excessive demand regime, as we will see below. Without confronting the underlying stigma of incapacity and underdevelopment, the possibility of ranking and ascribing certain groups according to these categories cannot be adequately challenged. A more focused approach to understanding these ideological underpinnings can also help account for the uneven effects of the excessive demand regime by explaining why, for instance, some disabled migrants and among them, several participants interviewed for this study, were initially granted permanent status while others were not.

Such an analysis also shows that eugenics today is less about the straightforward exclusion of any one group than it is about managing "the quality of the population" (Rose,

2007, p3). As Rose explains, this means "growing capacities to control, manage, engineer, reshape, and modulate the very vital capacities of human beings" (p3). It is precisely this goal of intervening in order to 'grow capacities' that accounts for how services oriented towards people with ID retain a eugenic and discriminatory quality through their insistence that individuals orient themselves towards normative standards of independence and development. Indeed, such service systems often seek to act upon the "vital capacities" of people with ID. And while these intentions are not inherently oppressive, they mobilize dangerous hierarchies that can carry displacing effects, for instance, when there is a finding of incapacity. Under the IRCC, these medicalized findings of incapacity are presented as 'risks' to the Canadian public through a framework that is once again consistent with Rose's observation that medical authority today is more about "the assessment and government of risk" (p10). What Rose means by this statement is that "medical imperialism" (p10), and its related power to define and shape truth claims as well as individual subjectivities, relies on the categorization of "risky" subjects (p77) even while it seeks to act upon the "vital capacities" that are assessed through this risk-oriented lens.

Tracing (In)Capacity and Risk Assessment in Current Immigration Practices

In the absence of strong data on excessive demand – a gap made apparent in recent calls for the IRCC to improve data collection in this area (CIMM, 2017) – we can begin to grasp the connections between how people with ID and migrants with disabilities are assessed for eligibility and opportunities for belonging by applying a historical and theoretically informed perspective towards current legislation and administrative decision-making tools. Viewing the excessive demand provision through a broader conceptual context that centres an intersectional understanding of ID shows that immigration medical exam screening tools contribute to a multi-pronged risk assessment process conducted by visa and medical officers, the results of which can

easily override the often-discussed immigration 'points system'. Before we explore the intersectionality of ID in further detail, some discussion of the IRCC's risk-oriented framework, including points-based assessments, and the role of ID within this system is warranted.

The points-based assessment process, lauded by many as a neutral means of assessment that officially ended race-based exclusions, contains it owns shortcomings. We have already seen how this system has been challenged as carrying a racial and gender bias. Abu-Laben (1998) draws together much of this criticism in her research, explaining that under the points system, "so-called indicators of worth are socially constructed and reflect the prevailing Canadian political and economic power structure" (p76). Writing before the introduction of the IRPA, she points to preferences around age and language as two examples of these tendencies. But as flawed as it may be, the points process does not even apply to the many disabled applicants whose inadmissibility is determined through an excessive demand finding. As Hanes (2009) has observed, "the point system did not and does not apply to people with disabilities and, even if a disabled individual met all of the above criteria, the individual could be denied permission to immigrate to Canada". Similar to Hanes, Satzewich's (2015) recent study of visa officers suggests that findings of criminality or medical inadmissibility override a positive points outcome because these categories of risk are top considerations in any assessment process, to the extent that they affect decisions made about "an ostensibly qualified applicant" (p52).

In the context of excessive demand, risk assessments are directly informed by medical exams conducted by panel physicians with support from panel radiologists and other practitioners who perform specific tests. Results are then submitted to medical officers based in Canada. These officers are IRCC employees who work at one of four regional medical offices. Conversely, panel physicians and panel radiologists are not directly employed by the IRCC and

can be based anywhere in the world. They are however required to undergo IRCC training. The training begins with a reading of the IRCC handbook which, at the outset, draws attention to Section 38 1(a)(b) and (c) – medical inadmissibility related to risks to public health, safety, and excessive demand. The primary duties of panel physicians are described in Section 3.1 of the handbook (IRCC, 2013), which clearly states that they may not determine inadmissibility or communicate with applicants about these decisions. Instead, their job is to complete the tests outlined by the IRCC. The handbook explains this role in the following way:

> "Panel members, depending on their field of work, are authorized to perform IMEs, arrange for diagnostics and investigations, and complete immigration medical forms. They do not have the authority to assess or determine whether the medical conditions of clients are grounds for inadmissibility. More specifically, panel members do not have authority to give clients an opinion on their medical admissibility. That determination rests solely with Canadian immigration officers" (IRCC, 2013, Handbook, 3.1).

As this excerpt suggests, a determination of inadmissibility is completed by a medical officer employed by the IRCC but is nevertheless based on information collected during the immigration medical exam by a panel physician. This means that in performing immigration medical exams, panel physicians represent an important gatekeeping function.

The handbook goes on to describe some of the routine tests that applicants must undergo as part of the immigration medical exam:

> "For all clients, the Canadian Immigration Medical Exam will include an examination by a panel member and a medical assessment by a CIC medical officer. Where necessary to establish compliance with the IRPA and the Immigration and Refugee Protection Regulations, clients will be asked to undergo further medical examinations" (Handbook, 3.1).

The medical exam requires that panel physicians collect an applicant's medical history and perform a physical examination, in addition to an age-specific chest x-ray and laboratory tests (Handbook, 3.1.1). Throughout the exam, physicians are asked to pay special attention to "abnormality" (Handbook, 4.7). To facilitate the identification of any 'abnormalities', the

Handbook provides a table that indicates additional instructions for physicians to follow based on the results of the physical exam. Many of these additional tests relate to physical impairments or health issues and address different aspects of a person's physicality, such as their vision, weight, and muscular attributes. Four of the questions indicated in the table relate directly to cognitive capacity; these questions are strikingly repetitive and ask about "mental and cognitive state", "intellectual disability", and "developmental milestones"; one of the questions asks, "[a]re there any physical or mental conditions that may prevent this person from attending a mainstream school, obtaining full-time employment or living independently now or in the future?" (Handbook, 4.7). The IRCC's preoccupation with capacity, suggested by the overlap and repetition between questions focused on mental and cognitive functioning, constructs migrants with ID or ID-related attributes as a special category of threat requiring additional layers of screening.

Repeated references to perceived cognitive deficiencies within immigration medical exam screening tools suggest that special attention is indeed being given to intellectual capacity. As mentioned, these tools will be discussed in Chapter Six. For now, it is necessary to note that migrants with ID remain one of the groups most adversely impacted by the IRCC's screening process. Data shared for 2013-2016 reveals that the highest number of refusals on excessive demand grounds are for "renal failure" followed by ID, HIV positivity, and then "[d]evelopmental delay" (CIMM, p27). However, intellectual impairment moves from the second to the top-ranking category of refusal for medical inadmissibility when we combine the numbers provided for ID and "developmental delay" – often a euphemism for ID which, in the context of IRCC assessments, is a term applied to children that can include ID in addition to other disabilities that are framed through the concept of halted development (IRCC, 2013,

Developmental Delay in Children), as we will see in the next chapter. These figures provide further reason to focus on immigration medical exam guidelines for assessing intellectual incapacity.

Related to these statistics are the nature of the medical guidelines themselves. Out of the 24 guidelines associated with the list of "conditions of significance" provided to panel physicians (IRCC, Handbook, Appendix IV, List of IMEIs), six relate to ID. Legal research led by the Parkdale Legal Services Centre in Toronto, which shares a summary of immigration medical exam processes, has also noted that medical examiners are instructed to remain alert to the potential for ID among adults (Chang to Schweitzer, 22 June 2016 [cited with permission]). All of this suggests that the level of guidance provided for testing for ID is disproportionate to the reported percentage of people actually labelled as having an ID who are currently living in Canada (Statistics Canada, 2017). Additionally, the number of migrants with ID may be much lower than other disability communities when we consider that many members of this community can face profound barriers to migration given the potential denial of their legal capacity and the fact that many remain confined in institutions around the globe. The small size of this minority group and the barriers that many people with ID face to migration outside of the immigration system suggest that the importance placed on 'screening out' these potential migrants is likely motivated by much more than practical considerations of 'risk', and is instead connected to cultural and value-based fears.

Dichotomizing Development and Regulating Resource-Use: Intersectional Approaches to Intellectual Disability

The special focus on people with ID within immigration medicine both under the IRPA and in earlier legislation is bolstered by historical research related to deportations that I

conducted prior to the present study (Spagnuolo, 2016c). As described earlier, this research builds on studies in eugenics and migration suggesting intersectional links between disability and xenophobia in immigration policy. The results of this research show not only that deficiency-oriented views of disability structure Canadian immigration practices, but that these ideas are inherently bound up with thinking around intelligence and capacity that are also racialized (see for example, McLaren, 1990; Spagnuolo 2016b). The co-constitution of ID and racist ideologies is traceable to early public health measures and efforts to regulate transnational migration through the categories of moral and economic 'risk'. In Chapter Two, we saw how these efforts were premised on settler colonial goals of creating a 'healthy' white nation and how related ideas about intellectual deficiency and race surfaced in anti-immigrationist discourses. This means that while settler medical knowledge sought to shape the nature of the white population, it simultaneously presented Indigenous, racialized, and disabled populations as the antithesis to these colonial development goals – so much so that it supported views of these 'undesirable' groups as the embodiment of degeneracy and dependency.

Chen's (2016) study of "slow constitution" addresses such fears of degeneracy, employing the notion of incapacity to draw ID more closely into conversations about racism on global and local scales. To begin, Chen shifts the focus away from historical research that argues that associations between Asian people and the category of Down's syndrome – once known as "mongoloidism" – were ever entirely dropped (Kelves, 2004; Wright, 2011). Instead, they emphasize how these early connections reflect ideas that racialized people are intellectually inferior and specifically that "Asians [we]re understood as lacking capacity" (p240). This striking example of the co-constitution of racialized and disabled identities carries broader ramifications which, as this section argues, are also evident in immigration policy today.

Furthermore, the fact that "disability continues to lurk in the description of races" (p242), as Chen puts it, is further suggested by global colonial discourses that continue to characterize some nations as "developing countries" (p247). These development discourses imagine that certain nations have already attained a 'normal' level of development while others are lacking this capacity for (linear) progress. Of course, these designations of developed and underdeveloped societies are based on normative standards influenced by a host of subjective values, not least of which are racist and racialized perceptions of inferiority and the sub-human status historically accorded to people with ID and people of colour.

Scholarly criticism has drawn attention to the negative impacts of development agendas premised on such assumptions of inferiority. For example, anti-colonial critiques of development goals in the form of Northern interventions in Southern disability advocacy engage with the racist dimensions of this hierarchical form of thinking (Wehbi, 2011). Broader challenges to development agendas resist Hegelian notions of linear historical development (see Biccum, 2010), and help undermine the imperative to assess and rank a country's developmental 'progress'. Especially pertinent is Heron's (2007) point that the "development binary" (p56) upon which such linear measures are premised, are suggestive of "the North's putative superiority" (p8) and "positional superiority of whiteness" (p88). With this binary in mind, Heron challenges the desire to intervene to promote the 'development' of others as "unproblematically good" (p6). Her criticism recalls Chapter Three and Four's discussion of the faulty premise of many support services for people with ID, which can lead to displacing effects. From a critical disability perspective, the work of Nguyen (2015) presents a compelling critique of the way in which disability has been conceptualized and measured within development projects based in the Global South. Nguyen's findings resonate with many that are forwarded in

this dissertation, particularly her focus on the framing of "development as a historical structure that produces new expressions of inclusion and exclusion within its regimes of knowledge" (p82).

As valuable as they may be, these critiques of global development interventions do not generally address ID as an inter-related concept that shapes development practices. Yet the consequences of development-oriented interventions aimed at people of colour living in poor countries in the Global South and people with ID living in Canada can be conceptualized in similar ways. Existing lines of criticism have helpfully shown that nations that have not attained a normatively and racially-informed level of development can fall under the coercive paternalism of the Global North while simultaneously being positioned as 'dependent' on the charitable disposition of more 'advanced' nations. In development-aid contexts, for example, the emphasis may be on interventions aimed at encouraging the 'independence' of certain nations. As Eriksson Baaz (2005) puts it, there is "a perceived need to enhance *sustainability*" and remedy issues related to dependency that are specifically related the incapacity of Global South institutions and "aid-dependence" (p7). In much the same way, people with ID are often subjected to coercive paternalism as a result of their perceived 'underdevelopment' and 'dependencies' and the related imperative to remedy these supposed defects.

The assumption that people with ID pose a burden as a result of their support needs, sustains a charitable as opposed to entitlement-based approach to distributing resources. Under this model, disability resource-use more readily supports the old eugenic argument that disabled people are potentially exploiting or unfairly benefitting from the work of more 'developed' citizens. Simultaneously, these individuals can be viewed as delaying the progress of a normative and seemingly productive population. Baynton's (2016) history of disability and American

immigration practices shows that dominant fears of disabled migrants and the desire to screen out these arrivals was roused by the belief that they would delay the nation's progress (p78). These beliefs are also apparent in early calls to institutionalize people with ID who were thought to 'hold back' their family members. Addressing decisions among cold-war era families to institutionalize their relatives with ID, Burghardt (2014) explains that these actions were encouraged by government, "as the most responsible and civic-minded response to the 'tragedy' of a disabled child" (p136). Once again, we can see how translocal and transnational thinking around (in)capacity and (under)development overlap in meaningful ways to shape opportunities for belonging. To further appreciate how intersectional views of ID and related concepts regulate access to permanent status in Canada, we can return to colonial processes and contexts where notions of 'risks' are assessed.

Situating Racialized and Disabled Forms of 'Risk' in Colonial Context

The link between incapacity, dependency, and transnational and colonial views of development serve as a powerful means of framing economic risk through the idea of 'wasted' and 'exploited' resources. This is especially true in the case of people of colour residing in poor countries the Global South and people with ID who hold permanent status in Canada. To fully appreciate how a radical fear of incapacity and its intersectional possibilities has served to bolster excessive demand screening, we ought to explore these links in more detail. Ahuja's (2015) recent work on the treatment of colonized populations is instructive in this regard. Ahuja documents how a white colonial authority's assumption that colonized racialized populations were 'dependent' could fuel both resentment towards this community's use of resources and a sense of paternalistic responsibility towards their 'care; (p50). Specifically, Ahuja shows that the enforcement of western medical practices in colonial settings, which include practices such as

forcible medical confinement in quarantine zones, was linked to an imagined Christian duty to help colonized peoples. Simultaneously, this established a view of racialized 'others' as 'dependents' who were benefiting from white medical authority. These quarantine practices and related medical interventions provide an important example of how translocal displacement can be shaped by global colonial processes involving forced and coerced forms of medical confinement.

The effects of imagining such relationships as 'charitable' can be seen in Ahuja's description of the resentment that was fostered towards Hawaiian people on the part of the white colonizing population. In one example, colonizers accused Hawaiians of taking advantage of the "free food" provided at a leper settlement where many remained segregated (p51). The idea that racialized people are underserving and taking advantage of the resources offered by a supposedly more advanced colonial power is echoed today in xenophobic attitudes applied towards migrants with disabilities. These discourses mobilize linear views of development and capacity to support the idea that disabled migrants do not deserve access to Canadian health and social services. We can detect similar attitudes in the IRCC's stated mandate to protect publicly-funded health and social services (Government Response, 2018). Satzewich's study of Canadian immigration (2015) points towards such thinking by noting the distinctions between the majority of (non-disabled) applicants who are "physically fit and healthy", and those seeking to "take advantage" of Canadian health services (p7). In another recent study of Canadian immigration policy, Huot et al. (2015) show how the same rationale has been used to restructure Canada's policy on refugees, creating different designations of '"legitimate refugees"' and 'illegitimate' asylum seekers. These distinctions, according to the authors, are partly underpinned by the belief that so-

called illegitimate asylum seekers are abusing health and social services and gaining access when they are not entitled to do so (p5).

The imperative to guard public services from 'unfit' and 'undeserving' migrants who risk exploiting them is undermined by the actual motivations of many migrants. Evidence shows that migrants from countries in the Global South are not always interested in accessing health or social services in the Global North. Holmes (2013), for example, shows that many poor migrant farmworkers in the United States prefer to return to Mexico for health services due to "economic, cultural and linguistic reasons" (p103). Similarly, interviews conducted for this study with disabled migrants and their relatives (presented in Chapter Seven), reveal a reluctance and disinterest among some migrants with disabilities and their families towards using Canadian services; this was the case even after some individuals attained permanent status and were formally entitled to access services. Some of the reasons participants provided for not accessing services have to do with displacing effects that manifest through discourses of 'undeservedness' (Alia). Yet relationships to access and desire are complex and far from uniform. While some participants stated that their motivation for migrating to Canada was unrelated to these services (Al, for example) or that they did not plan on accessing them (Jack), others explained that they came to Canada partly for these very reasons (Shiva, for example). Overall, while access to health and social services may be an important draw for some migrants, this desire for access is not universal. Assumptions that migrants seek to use health and social services must also be read in light of research documenting the many barriers in obtaining culturally appropriate services in the Global North, especially among migrants with disabilities (see for example Groce, 2005; Khanlou et al., 2015). My chapter with El-Lahib (in press) draws on a related body of research to show how "service gaps", in addition to 'outsider' status, can shape experiences of translocal

displacement among migrants. In relation to services we argue that "disabled migrants who cross geographic borders to arrive in Canada can face new challenges and forms of displacement in the service sector when they encounter displacing processes" (n.p.).

Assumptions around access are a motivating force behind the excessive demand regime's concern with potential service-use. These assumptions also work to reinforce hierarchies of (in)capacity and (under)development by reading and ranking potential service-users as potential burdens. The importance of understanding these hierarchies relates to the fact that identities produced through medical assessment processes that ask about support needs can carry displacing effects. Indeed, these identity-shaping practices rely in large part on many similar predictive techniques and typological forms of thinking that Day (2014) has linked to effects that may be considered through the lens of subjective displacement. In the previous chapter, Day's insights allowed us to consider how the ways in which MCSS mobilizes the predictive potential of SIS-testing is implicated in the creation of false needs and fake opportunities that may clash with individual realities, forming "ideological constraints" (p131) that can carry displacing effects. While "the personal psychological self" is impacted by these processes, we saw how material realities are similarly shaped (p82). Likewise, these processes interact with immigration policy to effect spatial displacement. They do this by regulating the mobility of migrant applicants through inadmissibility findings which profoundly impact their relationship to access and their sense of entitlement even when admission to Canada is granted. Further discussion of these experiences will take place in Chapter Seven. For now, it is simply important to recognize that the effects of excessive demand testing can be situated among the many legacies of globalizing and colonial practices and related and ongoing processes. Recognizing these legacies

is part of the work involved in unpacking the influence of (in)capacity as a conceptual force behind excessive demand screening that justifies that view of disabled people as 'burdens'.

Unfounded anti-immigrationist claims that migrants are over-burdening the health system can be traced back to the early twentieth century and to fears around Canadian asylums becoming over-crowded with foreign-born inmates (Menzies, 2002, p386; Spagnuolo, 2016c, p132). This history of xenophobic scapegoating suggests the need for a more thoughtful study of actual access to services among migrants with disabilities. In a step towards addressing this gap, El-Lahib (2016b) demonstrates that the opportunities that Canada potentially shapes for migrants are not straightforward. According to his research, assuming that Canada is a '"land of opportunity"' without qualifying this claim by identifying the many barriers to access is troubling in that this assumption reinforces a colonialist ideology of "northern superiority" (p772). In El-Lahib's words, "the construction of immigration through opportunity discourses implies that immigrant-sending countries, especially those located in the Global South, lack such opportunities and build on neocolonial discourses that construct the Global North as a better place through a comparison between the North (here) and the South (there)" (p771). Once again, we can see how a hierarchical ordering of (under)development that draws upon notions of (in)capacity is articulated in immigration discourses. As the previous example suggests, these very same discourses are active in shaping (neo)colonial relationships.

(Neo)colonial processes and neoliberal forms of imperialism related to globalization have also been recognized as a source of displacement linked to war, poverty, and environmental degradation, along with other forms of injustice that compel so many migrants to relocate (see for example Holmes, 2013; Delgado Wise, 2009). Furthermore, the same conditions remain a major cause of disability-related impairments in the Global South (see Meekosha, 2011), where

disability rates are known to be the highest (WHO, 2011, World Report on Disability). These are important considerations, given that the majority of migrants to Canada come from countries located in this region (Statistics Canada, 2017, Key Results from the 2016 Census). Disabled people hoping to migrate to Canada from countries characterized as 'developing' are thus more likely to be poor as a result of such structural injustices and due to the deep associations between disability and poverty (WHO, 2011, World Report on Disability). This means that prospective applicants can easily be framed as economically 'risky' under the current assessment framework.

As we have seen throughout this chapter, the notion of risk is one of the many manifestations of entrenched – yet underexplored – understandings of (in)capacity and (under)development that facilitate discrimination again disabled migrants. As Chen (2016) has shown, these concepts are applied on various scales and not simply towards individuals. Turning to the national scale, Castles (2009) has argued that there is a general assumption that the rate of migration is linked to the development status of a country. This belief that underdevelopment fuels migration helps account for resistance among many countries in the Global North to accept migrants from certain African countries which, as Castles notes, rank among the lowest in the world in conventional assessments of development. Related to this, he observes that Northern countries often frame African migrants as a threat and "tend to define African migration as a problem" (p13). This remains the case even though the size of the "African Diaspora" in Europe, for example, remains relatively small (p12). In this context, the imposition of an inferior development status on migrants from certain African countries is directly connected to racialized anti-immigrationist discourses whose aims can be summarizes through Abu-Laben's (2009) phrase, "keeping 'em out". In the example provided by Castles, we can see how economic and race-based thinking draw upon the ID-related notion of underdevelopment and shape

immigration discourses in ways that do not accurately reflect the demographic realities associated with transnational migration.

Recalling Chapter Three and Four's discussion of Ferguson's notion of an "economics of uselessness" and its relationship to capacity and ID (Ferguson, 2004, p58), the IRCC's understanding of economic risk can be read through the capacity-oriented medicalized framework established within excessive demand testing, with its stated goal of saving health and social resources for ('deserving') Canadians. While economic and labour market needs have always been linked to migration, since the 1960s Canadian immigration policy has increasingly centred economic contributions in evaluations for membership, promoting "a human capital approach for immigrant selection" (Huot et al., 2015, p10, citing Akbari and MacDonald, 2014). This trend has been even more pronounced since the mid-1990s (Huot et al., 2015, p2, citing Akbari and MacDonald, 2014). However, challenges to the impartiality of the points-based system show that the focus on economic benefits undervalue forms of labour typically performed by women. This same system places women – especially those who are poor and thus likely racialized and based in the Global South – at a further disadvantage by defining and rewarding forms of skilled work that involve certain "educational opportunities" that are not often available to them (Abu-Laben, 1998, p77). Furthermore, immigration recruitment strategies continue to favour applicants based in Europe and the United States, creating more opportunities for migrants from these countries through the more numerous application centres that are located in these Northern regions (p77-78). Immigration screening has subsequently focused on perceived "threats to the economy" (Huot et al., p10), as is apparent in evaluations of asylum seekers. As we will soon see, the concept of incapacity and underdevelopment embedded within this screening system is strongly imbued with (neo)colonial and racialized conceptions of what

counts as ‘progress’ and who counts as a ‘burden’, and which are informed by views of people with ID as an identity group inherently marked by undesirable traits.

Returning to the IRPA’s general risk assessment framework, another study of excessive demand by El-Lahib (2015) concludes that risk-oriented discourses which present the need to “protect Canadians” (p220) and their interests from “potential threats” (p223) posed by migrants draw together racist, ableist, and neocolonial lines of thinking (p211). In his analysis, El-Lahib explores the concept or ‘risk’ through three documents used by immigration officials: Inadmissibility, Evaluating Inadmissibility, and Admissibility, Hearing and Detention Review Proceedings. In viewing the first two documents, which are of interest to this study because they comprise the broader background within which the immigration medical exam is situated, it may seem surprising that there are only a few references to excessive demand. However, this is likely due to the fact that excessive demand is discussed within these documents alongside security risks and broader considerations of medical inadmissibility that relay overt fears of contagious diseases. Nevertheless, it is by considering this broad framework for assessing risk that El-Lahib is able to highlight assumptions about who is “worthy of being protected” (p217) and enjoying human rights (p219).

El-Lahib’s findings suggest that immigration practices attempt to protect Canadians from the assumed threat posed by a racialized ‘other’ and in doing so, replicate colonial discourses aimed at controlling colonized peoples, all while reinforcing a North/South divide (pp222-223). This anti-colonial critique can be readily applied towards the sample of medical decision-making tools that make up the immigration medical exam and which will be explored over the course of the next chapter. Especially salient are El-Lahib’s conclusions that racist and colonial processes are at play in medical inadmissibility determinations. These insights help lay the groundwork for

an analysis that presents (under)development and (in)capacity as operating concepts that are key to the enactment of biopower through medicalized risk assessment processes. Without adequate recognition of these concepts, it will be hard to articulate a comprehensive challenge to the excessive demand regime and its risk-oriented framework.

Containing 'The Mobility of Race'

Risk assessment is undoubtedly central to the IRCC's screening mandate. Satzewich (2015) explains that from an immigration screening perspective, the highest risks relate to security and medical inadmissibility while the lowest are fraud and the lack of certain skills (pp52-53). When viewed through the lens of excessive demand and by following Rose (2007), it becomes apparent that the concept of risk is closely tied to medicalized efforts aimed at capacity-enhancement. These medicalized interventions in the name of enhancing capacity can include projects to promote individual capacity as well as the overall capacity of a nation. In the context of immigration screening, these goals unfold through assessment processes that seek to identify and rank (in)capacities – including 'excessive demands' posed on health and social services. As we saw in Chapters Three and Four, similar efforts can be traced within developmental services aimed at encouraging 'independence' among persons with ID. Through such initiatives, local disability support systems that focus on incapacity are complicit in ideological thinking that sustains ableist immigration screening. We can thus detect a broad failure across multiple jurisdictions to challenge normative standards of (in)capacity and independence and problematic citizenship cultures that valorize these constructs.

In transnational migration, enhancing capacity means selecting applicants who can contribute economically and without drawing on Canadian resources in non-normative ways. The emphasis on 'non-normative ways' is important here as it suggests that dependency is

indeed a socially informed category. This challenge to dependency recalls critiques forwarded by Bakerlaw (2009) and others that certain services are arbitrarily and unfairly targeted by excessive demand assessments which overlook other forms of resource-use. The result of course is that disabled migrants are framed as potential 'burdens'. With this understanding of dependency at its basis, we are better equipped to consider how the ranking of disabled migrants through excessive demand testing as 'more' or 'less' capable takes place through cost-benefit assessments that are informed by medicalized predictions. In this sense, the economic risk posed by potentially 'burdensome' migrants is linked to an assessment of that individual's "vital properties", to borrow once again from Rose (2007, p32). The next chapter takes a close look at these assessment tools. Equally important, however, are the intersectional underpinnings and historical legacies of related risk-oriented regimes and screening practices.

Risk and dependency are undoubtedly bound up with notions of (under)development and (in)capacity. A closer look at the intersectional nature of these related concepts and their various ideological manifestations in colonial practices helps sharpen our understanding of their role in Canadian immigration practices. Colonial legacies of racialized quarantine measures (see Ahuja, 2016) and their mobilization of the concept of vitality can help us understand disability exclusions that are justified through the language of 'risk' to the economy. As Ahuja has found, the desire to segregate and monitor people of colour in colonized countries was linked to the fear that these groups would 'infect' white populations; this fear is part and parcel of the trend of managing the imagined quality of a population based on biomedical constructions of risk that are informed by assumptions about race and disability. To carry out some of these regulatory goals, quarantine and medical testing methods "worked in tandem" with practices such as "sex education", according to Ahuja's account (p79). Sexuality was an important focus of these

campaigns, and the resulting spatial displacement of colonized people was part of a system of knowledge based on moral fears of miscegenation which, as Ahuja explains, were deeply medicalized. In one example, the threat of what was known as venereal disease (VD) as constructed by white colonizers was used to target women of colour as potential 'carriers' and support forms of "sexual and racial surveillance" (p79). These risk-management efforts recall early eugenic fears of atavism based on the belief that 'less developed' (i.e. racialized) human traits could emerge among white populations and slow down overall (white) social and civilizational development.

Chen's (2016) approach to ID as a racially-constituted category has shown that theories of atavism were also used to account for perceptions of the 'incapacity' of people with ID. This notion of incapacity is applicable at an individual and much broader socio-economic level. Related layers of application are evident in the use of (in)capacity as a measure to assess the economic development of nations through a linear model that draws upon the (often-imposed) development goals of a society. These development-oriented capacity assessments reinforce Chen's description of the perceived threat posed by the mobility of race and the fear that race was "moving from body to body" (p239). Just as fears of miscegenation and ID drew upon beliefs that white populations would become less capable if elements from 'other' races emerged within them, so do restrictionist immigration discourses aim to limit the mobility of certain populations. As a means of screening out potential 'burdens', excessive demand testing can be read through these broader trends which operationalize hierarchies of (in)capacity and (under)development.

Explicit examples of the displacing effect of these hierarchies can be seen in the forced confinement and quarantine measures that are intrinsic to histories of immigration policy. This

makes Ahuja's text a valuable one for furthering our understanding of the ideologies that shape displacing experiences according to dominant understandings of health. Similarly, and taking a more disability-oriented approach, Baynton's (2016) study of American immigration policy in the early 20th century shows indications that the "contagion of genes" or heredity threats linked to disabled people actually superseded the threat of contagious diseases and related quarantine measures (p73). Ensuing public health imperatives thus shaped immigration policy with the aim of screening for "defectives" who could 'infect' the nation. These 'defectives', Baynton explains, were thought to be "losers in the labor market" who would slow national progress and harm America's efforts for international "economic dominance" (p78). The idea of disabled migrants as "threats to progress" (p69) provides further impetus for applying a development-oriented framework centred on (in)capacity and ID to the study immigration policy, as well as to broader experiences of displacement. By grasping these connections, we are better positioned to assess recent challenges to excessive demand screening and build upon, while also moving beyond, critiques that centre an anti-discrimination approach.

As one key dimension of spatial displacement relates to forced movement, histories of mobility provide an important starting point for unpacking the relationship between development and capacity. In Coleborne's (2015) history of insanity and immigration in Australia, she addresses how imperial powers sought to regulate mobility with the goal of shaping specific white settler identities. Special attention was given to "inappropriate forms of mobility" (p29), with anxiety running high around the movement of Indigenous peoples as well as "certain forms of social fluidity" that included 'miscegenation' (pp29-30). The threat of spatially and socially mobile racialized bodies 'infecting' white bodies and colonial development goals through their supposedly impaired intellectual capacity was forwarded by eugenicists and white supremacists.

Coleborne's work helps account for ongoing practices of segregation and strategies to contain and restrict the mobility of people with ID and racialized people and along with them, fears of contagion and 'underdevelopment'. The threat posed by 'underdevelopment' is equally apparent today in immigration policy that seeks to control the mobility of communities marked as undesirable. Efforts to regulate mobility return us to dominant perceptions of underdevelopment and incapacity and to the racialized dimensions of these practices, which can be productively addressed through a colonial framework and governmentality of (in)capacity.

To understand how the mobility of race and disability continues to threaten Northern immigration regimes, we can consider how immigration screening frames the potential economic risks posed by migrants with disabilities applying to Canada from poor countries based in the Global South. The key consideration here is that efforts to act on disabled migrants' 'vital capacity' for economic development relate not only to their personal identity, but also to the perceived developmental status of their broader society. This is to say that fears related to 'underdeveloped' nations bringing 'incapable' individuals into the Global North shape risk assessment along several lines. Prior research has already shown that assessments informed by a points-based system centred on labour and investment discourage many applicants from the Global South (see for example, Abu-Laben, 1998). Less evident, however, are the ways in which hierarchies informed by (in)capacity and a medicalized political economy can also work to prevent these migrants from settling in Canada. Focusing on ID helps develop this second layer of analysis around specific understandings of development and economic risk. Finally, the effects of these inter-related concerns arout (under)development are evident in the ways in which the excessive demand provision unevenly impacts various groups of migrants. Digging deeper into the 'burden narrative' that surrounds disability shows that it is not simply the case that all

disabled migrants are equally affected and framed as risky subjects. Because the notion of economic risk that emerges through the IRPA's framing of disability is rooted in the inter-related connections between development as an individual condition associated with race and ID, and development as an economic measure of a nation's capacity, it should come as no surprise that poor and racialized migrants from the Global South and migrants with ID might be impacted by the excessive demand provision in unique ways.

The data discussed at the start of this chapter suggests that migrants with ID face high rates of inadmissibility. But equally relevant to understanding the disproportionate impact of excessive demand is the racialized nature of both ID and poverty as well as the close links between disability, poverty, and race. Demographic data shows that on a global scale, the vast majority of disabled people are racialized people who reside in poor countries the Global South (WHO, 2011, World Report on Disability). Additionally, we know this is largely due to structural and direct forms of violence generated by colonial processes (see for example Meekosha, 2011). Furthermore, given that disabled people are among the poorest people in any given society (WHO, 2011, Summary, p11), those residing in poor countries in the Global South likely experience intense forms of economic marginalization and related injustices. To provide a more concrete example of the uneven impact of the excessive demand regime on migrants from the Global South, we can turn to the opportunities available to mitigate inadmissibility findings. This example will not only show how the inter-related concepts of (in)capacity and (un)development are operationalized by the regime; it will help illuminate the intersectional possibilities of ID as a category that already reflects many of these understandings.

The Differential Impact of Excessive Demand and the Privilege of Protest

The ways in which excessive demand is mitigated and challenged also carry an uneven impact. Once an applicant receives notice that they pose an 'excessive demand', the only recourses available to them require influence and wealth. Tracing these options from start to finish helps reveal the differential impact of the provision on poor and racialized applicants. To begin, when an applicant first learns that they pose an excessive demand in IRCC terms, they receive a Fairness Letter explaining the finding. They can then respond to this determination by a specified deadline by writing what is known as a Fairness Response. At this stage, applicants can contest the claims made about their disability and if they wish, propose a 'mitigation plan' for offsetting the costs identified by the IRCC. These contestations around disability carry high stakes and applicants who fail to demonstrate that they are not an excessive demand by promoting a different understanding of their disability identity and associated resource-use are at risk of spatial displacement. This process, as we will see in Chapters Six and Seven, also involves issues of subjective displacement related to the struggle for self-representation and access to much-needed disability supports. A review of case law conducted prior to this study shows the importance of discretionary decision-making in cases where applicants challenged a visa and medical officer's understanding of their child's ID (Spagnuolo, 2016b). These findings recall earlier problems around testing for ID, raising questions about who exactly has the authority to make representational claims about an individual's capacity and their disability reality.

As I argue elsewhere (2016b), issues around discretionary decision-making and 'credibility' arise in struggles led by racialized mothers of children with ID to assert knowledge claims about their children's capacity. In these contexts, credibility has to do with the ability to

convince the IRCC of the truthfulness of claims about children's disabilities. As Satzewich (2015) explains, along with risk, credibility remains an important factor in a visa officer's assessment work (p50). Yet assessing the credibility or truthfulness of an applicant's statement allows the possibility for racial and other biases to arise. Satzewich's findings, derived from direct observation and interviews with immigration officers, show that visa officers who doubt an applicant's claims can indeed base their reasoning on perception. Satzewich explains that, "the use of various typifications of normality to assess applications as credible or non-credible" (p162) involves not only an individual officer's knowledge of normalcy, but also the knowledge shared within their workplace and "organizational culture" (p163). He quotes from interviews with immigration officers involved in screening for "genuine couples" (p161), who explain how they code their own perceptions in more professional language. And even while Satzewich does not discuss screening for medical inadmissibility, the ways in which IRCC officials assess the credibility of romantic relationships is worth illustrating as the discretionary nature of these forms of decision-making are situated in the same organizational culture involved in assessing excessive demand. One passage presented by Satzewich is particularly helpful in conveying the subjective nature of disqualifying decisions. Addressing how she assess a couple as 'genuine' or not, an officer reveals how her own idea of beauty is central to this evaluation: "I can't say she is ugly and he is too good looking for her. I will say something like they do not appear to be physically compatible" (p161). The officer's statement suggests that if she decides that one member of the couple is attractive and the other is not, she is less likely to believe in the truthfulness of their relationship claim.

Similar to my earlier findings around knowledge struggles related to (in)capacity (2016b), Bakerlaw's study (2009) notes cases of mitigation plans not being accepted. In some

cases, IRCC officials assumed applicants would "take advantage" of Canadian services even when they stated they would not use these programs (p15). Once again, similarities between local disability service systems which promote trust issues between clients and providers are apparent here. Particularly, the problems that immigration applicants face in establishing their own credibility are remarkably similar to the challenges around self-representation in developmental services assessments described in Chapter Four. Concerns with and perceptions of (un)truthfulness appear to be active in structuring uneven power dynamics in both translocal and transnational assessment practices related to disability, suggesting once again a set of broader cultural understandings that work against disabled people.

Despite the many problems with the IRCC's discretionary decision-making structures, not least of which include the struggle over knowledge claims and the displacing effects these generate (discussed again in Chapters and Six and Seven), the possibility of proposing a mitigation plan remains an important option for contesting an excessive demand finding. These plans are essentially statements where applicants agree to offset the 'excessive' cost of their identified needs by paying out of pocket and refraining from using publicly funded services. Refraining from using certain services can also include a promise by the applicant to provide unpaid care work in the home. The first approach requires the applicant to demonstrate that they posses the financial means of paying – which is simply not an option available to most racialized people from the Global South, as El-Lahib and Wehbi (2012) have argued. Similarly, the Migrant Workers Alliance for Change and the Caregiver Action Centre, two civil society groups active around migrant workers and caregivers' rights in Canada, have pointed out that due to the low wages they receive, migrant caregivers who arrive in Canada through federal work schemes are unlikely to have the wealth and legal support required to submit "an effective mitigation

plan" (MWAC and CAC, Submission to CIMM, 2017). Importantly, and once again revealing the adverse impact of current practices on particular communities, these caregivers are predominantly racialized women from the Global South.

Equally concerning from an equity perspective are issues around procedural fairness related to an applicant's right to appeal a visa officer's final decision in situations where a Fairness Response fails to convince the officer that the applicant does not pose an excessive demand. As Bakerlaw (2009) explains, applicants caught under the excessive demand provision cannot approach the Immigration Appeal Division unless they are family class applicants (p6). This means that the vast majority of applicants who are impacted and who fall under the economic class of migrants (CIMM, p27) do not have this appeal option, leaving only two options available to them, according to Bakerlaw. First, these applicants can appeal the decision on humanitarian and compassionate grounds, which allows for the Minister to intervene and override excessive demand considerations (see IRPA, Section 25(1))[12]. However, as Bakerlaw (2009) explains, if that attempt fails, they cannot appeal the decision to the Immigration Appeal Division (p6). Second, an applicant can request a judicial review through the Federal Court. These reviews often consider the validity of the excessive demand determination, asking whether the cost assessment was accurate and reflective of the disabled person's needs and the proposed mitigation plan, for example (see Spagnuolo, 2016b, for examples).

[12] 25 (1) Subject to subsection (1.2), the Minister must, on request of a foreign national in Canada who applies for permanent resident status and who is inadmissible — other than under section 34, 35 or 37 — or who does not meet the requirements of this Act, and may, on request of a foreign national outside Canada — other than a foreign national who is inadmissible under section 34, 35 or 37 — who applies for a permanent resident visa, examine the circumstances concerning the foreign national and may grant the foreign national permanent resident status or an exemption from any applicable criteria or obligations of this Act if the Minister is of the opinion that it is justified by humanitarian and compassionate considerations relating to the foreign national, taking into account the best interests of a child directly affected.

The trouble with the two avenues available to the majority of affected applicants for contesting an excessive demand determination is that the success of an application on humanitarian and compassionate grounds and the ability for an applicant to request a judicial review requires a degree of privilege and influence. Given the discretionary nature of a Ministerial Intervention, it is realistic to assume that both the role of public perception and the likelihood of an applicant having social, educational, financial and other forms of status and privilege can shape the success of such an application. And while having the financial resources to hire a lawyer is an important advantage during all stages of the application, including in crafting a Fairness Response and an application on humanitarian and compassionate grounds, appearing before the Federal Court without a lawyer is an unthinkable undertaking.

While legal aid clinics provide one means of accessing free legal support, these options are not readily available to the majority of applicants. For instance, those applying from outside of Canada are ineligible for legal aid (Bakerlaw, 2009, p20). Furthermore, Bakerlaw found that free legal support is often only provided for certain types of cases, including "refugee applications, sponsorship appeals, and deportation hearings" (p21). Nevertheless, challenges to the excessive demand regime that take place through the federal courts and the Supreme Court of Canada make up an important part of the history of policy reform in this area. Now that we have explored some of the key operating principles behind the excessive demand provision, including the fear of underdevelopment and incapacity, the linking of racialized people to these constructs, the implication of colonial processes, and the adverse impact on communities who are ascribed these identities, we can turn to recent histories of Canada's immigration legislation and to political advocacy efforts in this area. The next section of this chapter will focus on these reform efforts in order to help identify how and where some of these issues around (in)capacity and

(under)development have emerged, and to suggest the need for strategies that directly challenge these problematic constructs.

Assessing Reformist Approaches

The range and diversity of political actors involved throughout the history of law and policy reform around Canada's excessive demand regime suggests the intersectional nature of this system of exclusion. Taken together, the many organizations involved in this history represent racialized migrants, people with ID, disabled people, racialized people with disabilities, and migrant workers. Key organizations have included CCD, the Migrant Workers Alliance for Change, the Ethno-Racial Disability Coalition of Ontario, the Canadian Association for Community Living, and legal groups representing disabled people (ARCH Disability Law) and people living with HIV/AIDS (HIV and Aids Legal Clinic Ontario). A number of these organizations have collaborated throughout the campaigns described in this section, spearheading reform efforts that have resulted in changes to how excessive demand is assessed. As important as these efforts have been, to date none of the challenges to the regime have involved any overt reconceptualization of (in)capacity or explicit attention to the conceptual role played by people with ID in the IRCC's formulation of excessive demand. This section discusses how the potential for this reconceptualization of capacity, development, and ID is present within these struggles, while accounting for why it has not yet been clearly articulated and documenting some of the challenges in shifting towards such an approach.

As this discussion will demonstrate, the history of reform efforts around excessive demand reveals the many pressures that civil society groups face in formulating their demands in ways that enable dialogue within existing systems. To this point, Mitchell and Snyder (2015) note the unfortunate tendency among rights-based groups concerned with neoliberal processes to

adopt approaches that employ neoliberal discourses. We can see this tendency in the ways in which various critiques of excessive demand promote recognition of disabled people as productively 'contributing' to Canadian society. As mentioned at the outset, this strategic deployment of the notion of disability contributions is largely a result of the system in which these forms of advocacy and resistance occur and, as Mitchell and Snyder acknowledge, the many "political pressures" that disability organizations often face in their efforts to deliver results (p82).

Among the many challenges launched against the excessive demand regime, we can trace a discourse that insists that people with disabilities can and do productively contribute to Canadian society. But due to the fact that the notion of 'contributing' has not been explicitly reconceptualized within this discourse, it risks leaving in place what Mitchell and Snyder call "claims to successful normalization" (p80). While grounded in a desire to address discriminatory thinking, such claims can work to minimize or mask disability as a form of difference. Stiker (1999) makes a similar point in his critique of the rehabilitation industry, which outlines the "technocracy of absorption" (p164) that risks erasing the differences that disabled people represent. This absorption or "will toward integration" (p164) occurs when interventions aim to address and erase the "alterity" (p55), or "erase differences" (p129), that are represented by disabled people and by their "exceptionality" (p128). Like Mitchell and Snyder (2015), Stiker (1999) is drawing attention to how the failure to reconceptualize inclusion by critically accounting for disability alterity can result in assimilation. Later on, we will see how an assimilationist agenda surfaced in discussions around the productive contributions of disabled people that took place during the CIMM review. For now, the important point is that any possibility for changing the situation of disabled people can be limited by rights-based

approaches that are grounded in current citizenship cultures and that overlook the dominant values they enact.

While recognizing the many benefits of these rights-based strategies as well as the conditions that govern and restrict this form of political engagement, it is apparent that there is a tension between the means employed – particularly the insistence on disability 'contributions' – when compared to the overarching goal of abolishing the excessive demand provision. The history of Hilewitz and DeJong v. Canada (2005) illustrates this trend, which applies not only to immigration reform but to other disability policy reform efforts, including those concerned with developmental services in Ontario. The focus in this particular example, as in the rest of this dissertation, remains the political economy of medical decision-making that seeks to categorize and rank individual (in)capacities, predict potential needs, and measure these imagined outcomes against problematic and largely unchallenged normative standards centred on a general fear of incapacity and underdevelopment.

These considerations will be explored as this section develops and in Chapter Six, we will see how the failure to dislodge the excessive demand regime following the 2017 CIMM review is linked to the tendency to work towards improving, rather than removing, its assessment mechanisms. Indeed, calls for reform have expressed the need to correctly weigh not only the costs associated with disability supports, but also the benefits of including those assessed as having the potential to productively 'contribute' to Canadian society. As argued below, such strategies leave unchallenged hierarchical understandings of (in)capacity and (under)development and suggest the invisibility of the governmentality of (in)capacity. Inadvertently and likely intentionally, they also condone sorting and ranking individuals according to these concepts. The tension between ends and means is equally apparent in

strategies that promote more balanced cost-benefit analyses while simultaneously calling for the repeal of Section 38(1)(c). Such an approach leaves in place normative understandings of 'contributions' that continue to justify exclusion through findings of 'real' incapacities among supposedly non-contributing persons with disabilities. A closer consideration of the rationale that supports such evaluations and the hierarchies upon which they are premised is especially useful in accounting for the uneven and racialized impact of excessive demand, the differing impact across impairment categories, and the disproportionate impact on migrants with ID. Given these outcomes, it should come as no surprise that the history of legal engagement by disability organizations representing people of colour and people with ID shows close collaboration around excessive demand decisions. In the next section, we will briefly review some of this recent history before turning to a detailed discussion of the *Hilewitz* (2005) decision and its impact.

Hilewitz and Anti-Discrimination

Legal challenges launched by the Hilewitz and de Jong families against the government of Canada's determination that their children with ID posed an excessive demand are recognized for achieving a form of incremental progress in combating disability discrimination in immigration policy. This was primarily brought about by establishing the right to individualized assessments. Before turning our attention to this decision, it is worth pointing out some of the earlier forms of legal engagement around immigration decision-making on the part of disability organizations. CCD, a major national disability organization, was involved in a similar battle in 2001, when a migrant named Angela Chesters challenged an inadmissibility finding based on her disability through the Federal Court. During the Chesters case, which sought legal reform around the excessive demand provision, CCD served as an intervener. And while the case was unsuccessful, it is nevertheless memorable for challenging the application of the excessive

demand provision (CCD, Chesters Case). Furthermore, the intervention of disability organizations such as CCD in immigration court cases did not end in 2001. The following year, CCD sought intervener status once again in Deol v. Canada (D'Aubin, 2003) and not long afterwards, the Canadian Association for Community Living (CACL) and the Ethno-Racial Disability Coalition of Ontario (ERDCO) rallied around *Hilewitz*. The involvement of CACL and ERDCO in this 2005 Supreme Court case reflects not only the intersectional nature of the impacts of the excessive demand regime, but just as importantly, the particular relevancy of this struggle to people with ID and disabled people of colour.

The *Hilewitz* decision, a precedent-setting case which culminated in a 2005 Supreme Court decision, arose out of efforts to challenge discrimination against two children with ID, Gavin Hilewitz and Dirkje de Jong. For the purposes of this dissertation, the case provides a helpful point of departure for re-imagining the notion of capacity in immigration screening. Indeed, the initial decision to exclude Gavin and Dirkje was challenged on the basis that as a diagnostic and impairment category, ID should not lead to the automatic exclusion of any migrant. In 2005 the Supreme Court ruled that non-medical factors and namely the willingness expressed by these relatively wealthy families to pay for disability services out of pocket and thereby 'mitigate' the so-called excessive demand posed by their children, ought to have been considered by immigration officers. Notably, both cases involved special education and vocational training – two services that were recently removed from excessive demand criteria.

Vanhala (2011) documents how CACL and ERDCO mobilized around Hilewitz and de Jong with intervener status. The case thus involved collaboration between CACL, a national level group well-recognized for representing issues related to ID, and ERDCO, a Toronto-based group representing ethno-racial people with disabilities living in Ontario. As Ena Chadha, the

lawyer who represented ERDCO and CACL (and currently a Vice Chair of the Human Rights Tribunal of Ontario), recounts, the Supreme Court challenge arose when two lower court judges came to very different conclusions around Hilewitz and de Jong. One judge felt that one family's willingness to pay exempted them, while a different judge entirely ignored the other family's mitigation plan. The case then went to the Federal Court of Appeal where these families lost, and then onto the Supreme Court where they were successful (Chadha, 9 November 2005).

Their challenge to the excessive demand determination, according to Vanhala (2011), relied on a "social model analysis" of disability focused on the Canadian Charter rights of persons with disabilities. The case also took a broad view of immigration policy and argued that the excessive demand regime affected all Canadians with disabilities by framing them as 'burdens' (p137). Importantly, this challenge also took issue with medicalized forms of prediction around disability-related needs. An ARCH news release authored by Chadha (2005) reporting on the Supreme Court decision draws attention to a statement made by Justice Rosalie Abella that is worth quoting: "here the legislation is being interpreted in a way that impedes entry for *all* persons who are intellectually disabled, regardless of family support or assistance, and regardless of whether they pose any reasonable likelihood of excessively burdening Canada's social services" (p3). To summarize, Justice Abella's ruling took issue with the "categorical exclusions" impacting people with ID and promoted individualized assessments in their place. As Chadha explains, the initial problem with these inadmissibility decisions was that an individualized assessment had not taken place and instead the "medical officers ha[d] based their recommendations on a medical diagnosis, rather than considering the whole person" (p3). Chadha continues, "[t]hey did not think about what the cost of needed services would be, or what a "reasonable demand" might be" (p3). Chadha argues that the notion of reasonable demand is

relative and not fixed. She explains, "[a]s the population ages, the definition of "reasonable demand" may change substantially" (p3). Moreover, Canadian immigration policy does not exclude immigrants with high-risk behaviours, including "heavy smokers" or people who "participate in extreme sports" (p3). The struggle here is around defining excessive demand and economic risk in ways that realistically reflect actual costs and that do not target migrants with disabilities by only assessing applicants for disability-related needs.

The argument taken by Chadha and Justice Abella reflects an approach to anti-discrimination and disability rights which insists on moving beyond labels and assessing every individual in the socio-economic contexts that surround them. The legacy of *Hilewitz* is expressed in the Court's statement that, "rather than exclude persons on the basis of the condition alone, Parliament intended the medical officer to look at how the condition affects the individual" (*Hilewitz* v. *Canada*, 2005, SCJ 58 at para. 90). Similarly, the news release that followed the Hilewitz case applauded the Court's move away from categorical thinking and a "cookie-cutter methodology" (Chadha, 2005, p4). Under this framework, viewing how a condition impacts an individual would include considering the (unpaid) support role played by relatives and any financial commitment to mitigate associated costs. As previously suggested, nonmedical factors became legally relevant after *Hilewitz* even if they were not always considered in practice. Yet, where the *Hilewitz* decision falls short is in its overall strategy, which was simply to refine cost assessments and individualize them so as to avoid assumptions based on diagnostic labels. This is quite different from challenging the legitimacy of cost assessments.

The effective challenge made to "a cookie-cutter methodology" was certainly helpful in dampening the impact of the excessive demand regime in many cases and was beneficial to both

families at the time. However, anti-discrimination arguments are also known to carry certain shortcomings and the *Hilewitz* case must be assessed in light of this knowledge. Firstly, we should recall that anti-discrimination in disability terms can also include the insistence on the right to be accommodated by having access to disability services (Colker, 1998, p40); this is certainly suggested by Chadha's claim that excessive demand is unfairly targeting disability service-use and framing this as a risk while overlooking other 'risky' groups such as smokers and extreme sports athletes. The argument is more clearly reflected in the idea that migrants with disabilities deserve access to supports to enable their inclusion, as the following statement shows: "The CACL and ERDCO argued that it is not fair to treat immigrants with disabilities differently, and that immigrants with disabilities should be able to get similar supports and services that help their inclusion in society" (Chadha, 2005, p3). However, the right to access that is promoted in these arguments was not taken up by the Court. More to the point, even when the duty to accommodate is presented within an anti-discrimination strategy, it does not necessarily result in the underlying issues being addressed. Jones and Baser-Marks (1998) are clear about this problem and point out that, "anti-discrimination law is reactive and does little to address the underlying causes of the problem – the negative cultural response to disability generally and to people with disabilities in particular" (p78). The authors call instead for approaches that will tackle these underlying ideologies. In the interest of developing such an approach and without the intention of minimizing the benefits of *Hilewitz*, we can view the legacy of this decision through what it has failed to achieve and to explicitly address. Indeed, an important strategy that is present throughout *Hilewitz* and related cases and that needs to be addressed are reform efforts aimed at refining cost assessments.

Within CACL and ERDCO's struggle we can see a clear attempt to dislodge categorical thinking about disabled people and relatedly, the de facto linking of their impairment identity with a potentially detrimental economic impact or 'burden'. However, a closer look at the Supreme Court decision and the context surrounding *Hilewitz* suggests that the positive potential of ERDCO and CACL's message was not entirely grasped, while the anticipated impact of the ruling has disappointed many disability advocates. Arguably, the failure of what has become known as the *Hilewitz* decision to alter the excessive demand assessment process by mandating individualized assessments can be linked to the lack of engagement around the inter-related concepts of (in)capacity and (under)development. On paper, *Hilewitz* does require that immigration officers take an individualized approach, but the history of policy practice since this decision has shown otherwise. This section argues that a much more explicit challenge to the concepts underpinning the notion (in)capacity, forwarded from an ID perspective, is needed if we are to successfully discredit the excessive demand regime. Immigration discrimination based on race and disability would be positively affected by this approach, given that both identity markers are bound up with notions of (under)development that mutually reinforce understandings of (in)capacity.

Demands that immigration officials should adopt a more holistic view of migrants with disabilities and avoid a "cookie-cutter methodology" by considering the social and economic factors related to their supposed excessive demand still suggest the view that it is possible to assess for incapacity. In the case of the IRPA, incapacity is coded as an economic burden. Importantly, so-called 'holistic assessments' for incapacity-as-burden resemble the ways in which the Supports Intensity Scale claims to move away from categorical thinking around incapacity by assessing both the abilities and the needs of people with ID through thematically-

arranged categories that attempt to capture 'real life' conditions and even 'positive' attributes. Calls for the IRCC to focus on the positive contributions of persons with disabilities reflect similar discourses, while a closer look at the notion of disabled migrants' 'contributions' reveals deficit-oriented thinking about disability. Once again, reframing excessive demand assessments to focus on 'contributions' is grounded in the assumption that it is possible to both measure and predict an individual's capacity to contribute and to weigh this against their incapacity and the incapacity of other applicants. While this approach may help challenge negative perceptions of disabled people, for example, by tackling the issue highlighted by El-Lahib and Wehbi (2011), that "people with disabilities are not seen as potential contributors to the economic life of Canada" (p99), it also adds to a balance sheet approach that is structured by a system of thought based on both the possibility and the need to measure and rank (in)capacity.

After *Hilewitz*: Applying the Balance Sheet Approach

A critical re-thinking of *Hilewitz* and related reform efforts ought to focus on the potential limitations of these advocacy strategies as well as their contributions in creating helpful openings for discussions around capacity and development. By presenting such a critique, it is not my intention to dismiss these prior efforts as unhelpful. Rather, the point is to recognize that the excessive demand regime has successfully resisted calls for repeal and to help inform future advocacy by considering why this is the case. The immediate context surrounding *Hilewitz* shows that the strategy of positively adding to the balance sheet was employed alongside arguments for the right to accommodations. Claims made by CACL and ERDCO that "Canada Immigration fails to consider the positive contributions that persons with disabilities make to society" (p4), clearly relay this message. As I argue in a previously-cited study (2016b), legal struggles around excessive demand determinations following *Hilewitz* sought to show that

migrants are ‘less disabled’ (p1005). This focus on minimizing disability reinforces a hierarchy of impairment and capacity and it is derived from the balance sheet approach which was only refined after *Hilewitz*. The result is that rather than adequately combating disability discrimination, the court actually “perpetuated categorical ways of viewing disability by upholding the assumed link between disability services as a source of economic burden” (p1008). To break this cycle and move away from a cost assessment model that ranks (in)capacity and (under)development, we need to first understand how various medicalized modes of assessment are used to justify exclusion under the excessive demand regime, and then challenge the legitimacy of conducting these assessments.

The failure to achieve this broad reconceptualization of (in)capacity and address the underlying logic of the excessive demand regime can also explain an important gap after *Hilewitz* related to attempts to limit its application. In one instance, Vanhala (2011) notes an early, albeit unsuccessful effort by the federal government to limit this principle to business class applicants, as seen in *Colaco* et al. v *Canada* (p139). But even after *Hilewitz* was supposed to be applied broadly to all classes of applicants, there were still problems in realizing this new standard. Bakerlaw’s (2009) report suggests that *Hilewitz* led to improvements around migration and disability (p27), but they also note that an applicant’s “eligibility for a service” continues to play an important role in excessive demand decisions “if it can be established that an applicant is not eligible for the service” (p16); this was the case even with the official decision to move away from categorical assessments based on diagnostic labels. Further to this, my own previous study and Bakerlaw’s each found that claims made by applicants were not always believed because their credibility was being called into question when they presented non-medical factors related to their situation (Bakerlaw, 2009, p17; Spagnuolo, 2016b). The consideration of non-medical

factors is also an area where racialized and gendered forms of discrimination can easily come into play, given that it involves a discretionary form of assessment. Evidence pointing to women of colour not being believed by immigration officers recalls these dynamics (Spagnuolo, 2016b).

The CIMM review (2017) was also critical of how the *Hilewitz* decision has been applied and recommended improvements in this area (p2). While an analysis of the challenges in applying *Hilewetz* is beyond the scope of this study, these complementary observations from various sources indicate that categorical thinking could still play a role in excessive demand evaluations. Furthermore, it is suggestive of a much deeper tension between the means and the ends applied in reform strategies. Specifically at issue here are strategies concerned with refining assessment methods that forward an anti-discrimination approach while leaving in place the view that disability services can indeed be evaluated for their excessive cost and that disabled people can be arranged within a hierarchy of (in)capacity. Under the current model, disabled people continue to be associated with negative outcomes and any gains made tend to result from migrants distancing themselves from the lowest rung of the capacity ladder or, as we will soon see, by associating themselves with their supposedly more capable non-disabled relatives.

Bakerlaw's (2009) study points towards some of these negative associations, showing that eligibility for services continues to be an important determination. Their report forcefully demonstrates that excessive demand is about making value judgments around which costs are worth supporting (pp27-28), an idea that echoes anti-discrimination calls for the right to accommodations and to abolish the excessive demand provision on the grounds that it undermines this right. However, the persistence of the excessive demand regime suggests that these anti-discrimination arguments have not proven effective and that a more systematic investigation into the 'value judgments' that support such evaluations, their underlying

ideologies, and the assessment tools that embody them, is valuable at this point. Taking into account the need to push beyond current discourses invoking anti-discrimination, we may ask instead how existing critiques that challenge excessive demand through this lens could support a new way of conceptualizing disability that will better address underlying notions of (under)development and (in)capacity and inform future challenges to the excessive demand regime.

If we consider Satzewich's (2015) account of how actual decision-making by visa officers who carry "high case load[s]" (p57) and who rely on "views of normality… as filters" to speed up the assessment process (p55) occurs, then we can appreciate the consequences of leaving dominant conceptions of incapacity and underdevelopment in place. These considerations are especially important given that evaluative mechanisms shaped by excessive demand criteria are likely to perpetuate categorical-based thinking even when this approach is not officially recognized by the IRCC. In a recent handout to CCD for example, the IRCC claimed that "[n]o health condition automatically leads to inadmissibility" (IRCC, 24 March 2017). The IRCC's inability to recognize its own resistance in applying even the partial gains made through *Hilewitz* is further suggestive of the shortcomings of policy reform that overlooks underlying conceptual and moral issues. To challenge the excessive demand regime in a comprehensive way, can ought to direct our attention to the inter-related constructs of incapacity and underdevelopment with an appreciation of their intersectional nature and the (neo)colonial processes they support. Because *Hilewitz* emphasizes the need to consider impairment in a more individualized way, it does not challenge underlying assumptions that incapacity is in fact measurable. This is in keeping with policy reform around ID in Ontario which, as we have seen, has resulted in problematic responses to individual support needs.

Concluding Thoughts

This chapter has argued that ID and the inter-related notions of (in)capacity and (under)development are central to understanding the history of Canada's excessive demand regime and related reform efforts. Earlier sections of this chapter promoted an intersectional view of ID as an ordering device and useful framework for understanding colonial processes that shape mobility and displacement. Colonial projects, neocolonial development goals, and racist and xenophobic ideologies were discussed through to the co-constituted nature of ID and race and the various 'risks' articulated through these categories. These intersectional understanding of ID and ID-related concepts can better account for the persistence of exclusionary immigration laws. The review of reform efforts and recent challenges to excessive demand screening presented in this chapter has focused on areas where counter-discourses continue to reflect certain taken-for-granted assumptions around (in)capacity. Such a detailed examination has not only demonstrated that normative assumptions around (in)capacity continue to underpin the excessive demand regime, but that we must challenge these eugenic ideologies if we are to move beyond testing for excessive demand. An ID lens has been proposed as one way of critically engaging with a regime that is premised on these normative understandings of (in)capacity.

Building from this discussion, the next chapter is concerned with the specific challenges involved in reconceptualizing capacity and development under the IRPA. The focus of this chapter will be the 2017 CIMM review and the diversity of perspectives collected and curated by the Committee. This chapter includes a careful consideration of the limitations of certain discourses that invoke the possibility of disabled people making 'positive contributions' to Canada. It forwards the argument that while the potential for reconceptualizing disability is present in statements around 'disability contributions', in order to effectively challenge

hierarchies of (in)capacity and (under)development, we would need to go much further by making explicit the notion of incapacity and underdevelopment in relation to these imagined benefits. Otherwise, presenting 'contributions' as an unqualified term invokes normative measures that risk reinforcing capacity hierarchies and forms of "inclusionism" (Mitchell and Snyder, 2015, p80), leading to 'less disabled' individuals being deemed 'worthier' of inclusion.

Chapter Six: Logarithms of Development: A Critical Assessment of Immigration Medical Screening Tools

Introduction

Using the recent review conducted by Canada's Parliamentary Standing Committee on Citizenship and Immigration (CIMM) as a point of departure, this chapter considers why excessive demand assessments remain an appealing option to legislative authorities and why disabled migrants continue to be at risk of non-citizenship through this practice. Along with the policies and practices themselves, the discourses that emerge through policy struggles around excessive demand can aid us in understanding why Immigration, Refugees and Citizenship Canada (IRCC) chose not to repeal this provision when called on to do so. In this chapter, we will explore input compiled by CIMM and the subsequent report and recommendations issued by the Committee, placing these recent dialogues alongside the policy directives and medical assessment tools that shape the excessive demand process. First, we will consider why the CIMM report proposed interim measures that would improve the excessive demand regime even while it recommended a full repeal and acknowledged many inherent problems with the provision. This critical assessment of the CIMM recommendations pays attention to several discursive themes that surfaced during the Parliamentary review and that point towards a specific understanding of (in)capacity and (under)development. The limitations of conceptualizing (in)capacity in this way will be linked to the ultimate failure of the report to convince the IRCC to repeal Section 38(1)(c) of the IRPA.

Extending the previous chapter's discussion of underdevelopment and incapacity and establishing these as cornerstones of the evaluative methods enacted under the excessive demand regime, the second part of this chapter is dedicated to an in-depth look at specific policy

directives and medical assessment tools that are grouped under the immigration medical exam. This analysis suggests that in addition to directly targeting ID and incapacity, many of these screening instructions rely on the disaggregated characteristics that have stereotypically defined people with ID. Above all, this chapter seeks to demonstrate how the (presumed) experience of intellectual impairment and its association with dependency continues to shape biomedical definitions of ID and related perceptions of incapacity and underdevelopment – to the point where other disabled people are assessed through these measures. The ideological basis of dominant citizenship cultures can thus be read through the ways in which hierarchies of (in)capacity and (under)development are reflected in immigration screening tools. Before turning to contemporary debates and practices, the next few pages will explore ID as an ordering device within immigration medical screening and as a lens through which we may view the exclusion of other disabled people as non-citizens.

Intellectual Disability as an Ordering Device

In the previous chapter, we saw how an appreciation of the intersectional nature of ID and the neocolonial processes facilitated by this concept allow us to challenge the medical inadmissibility regime through a more comprehensive critique. Since this critique draws attention to the hierarchical ordering of (in)capacity and (under)development, it requires us to apply an ID lens and to consider some of the historical dimensions of this medical label. Recalling Goodey's (2016) observation, the idea of a "species-specific intellect" that emerged through the Enlightenment-era's valorization of 'reason' (p12) has underlined phobias of people with ID and framed them as representatives of its opposite (2011, p2). The emphasis on intellect as a defining characteristic of ID appears to persist regardless of the changing ways in which such vague qualities are defined (see for example Goodey, 2011). Carlson's (2010a) account also

speaks to the role of 'intellect' amidst these ambiguities. Remarking on the fluidity of two ID-related labels, she notes that "idiocy and feeblemindedness were interactive kinds in Hacking's sense of the term: they were classifications that were part of interesting looping effects, with permeable and amorphous boundaries that shifted with the professional, social and political tides of the day" (p106). Similarly, in her discussion of IQ testing, Carlson shows that the value of the test had much to do with its (perceived) ability to identify "the defective intellect" (p49). In her words, "the IQ test was able to definitively fix the level of this elusive, invisible, yet indispensable feature of humanness: intelligence" (p49). Turning to more contemporary examples, the role intellectual impairment in defining ID is further indicated in current definitions presented by the DSM-5 and the American Association on Intellectual and Developmental Disabilities (AAIDD). Each of these definitional models reference the intelligence quotient and then emphasize adaptative functioning as the ultimate indicator of this impairment (APA, 2013; APA, 2017; AAIDD, Definition).

Recognizing the close association between intellectual impairment and ID allows us to assess how immigration medical screening tools rely on this concept as an ordering device. Even when people with ID are not directly referenced, immigration medical exam guides invoke the concept of ID when they associate other disability and health-related experiences with the possibility of an impaired intellectual capacity. As we will see below, medical officers and panel physicians draw upon hierarchies of intelligence, rationalism, and development over the course of their assessment work. While remaining mindful of the broad-sweeping impact of the concept of ID throughout excessive demand evaluations, this chapter argues that even while the medical exam affects all migrants with disabilities by confronting them with the risk of spatial and

subjective displacement, it is the underlying fear of people with ID and the characteristics associated with this impairment category that shape medical screening for all applicants.

Importantly, the influence of measures that were initially aimed at people with ID and which can be traced in biomedical evaluations applied towards other disability communities is not unique to immigration medical screening practices. Local disability services are also subject to this form of conceptual influence. As an example, and as the introduction to this study notes, researchers have considered how the SIS – an evaluative tool specifically designed for people with ID – may carry potential 'validity' in measuring the support needs of people with psychiatric (Arnkelsson and Sigurdsoon, 2004) and physical disabilities (Smit, Sabie, and Prinzie, 2011). To provide the clearest example of how ID operates as an ordering device within immigration systems, we will consider IRCC screening tools aimed at detecting migrants with ID. However, and as we will soon see, these tools frame (under)development and (in)capacity as broad and inter-related concepts that allow them to impact all migrants with disabilities. Under the influence of these ID-related concepts, the medical exam constructs impairment hierarchies with differing relationships to dependency and related levels of underdevelopment and incapacity. In this way, ID operates as an ordering principle within the immigration medical screening process, so that even when migrants are not declared intellectually 'inferior' and 'incompetent', their experience remains affected by the broader concept of intellectual impairment. Such an argument adds further nuance to the critique that disabled people are positioned as 'burdens' within the excessive demand regime by exploring the conceptual, ideological, and practical workings of this assumption and by doing so in a way that challenges the degradation of dependency. Over the course of this analysis, we will encounter Goodey's (2016) suggestion that ID remains expansive and imprecise in biomedical terms, a veritable

"shape-shifter" and "category on the move" that is comprised of changing characteristics (p2). According to this account, the slippery nature of ID is the very same quality that lends this category its political importance.

Along with recognizing the conceptual and ideological position of ID in relation to dependency, we must recall that there is a significant degree of historical as well as contemporary overlap between dominant biomedical framings of psychiatric and intellectual disabilities. This is also true of disabilities which raise concerns around incapacity and intellectual reasoning, such as Alzheimer's disease and dementia. These connections should come as no surprise, as historical accounts of the forced confinement of psychiatrized people in Ontario reveal how the credibility and rationalism of inmates were regularly undermined by asylum authorities (see Reaume, 2009). Previous research has shown that up until the twentieth century, there were strong similarities in how Canadian health officials responded to madness and ID. Even after segregated institutions were built for people with ID, members of this community could still be found in what were known as asylums for the insane. Meanwhile, shared diagnostic labels and even a conflation of experiences associated with ID and those who were psychiatrized as mad people were not uncommon (Reaume, 2009; Spagnuolo, 2016c). The impact of ID, which holds the possibility (and probability) of incapacity as its central tenet, can indeed be read across various impairment categories, histories of disability confinement, and diverse social planning efforts. As explained in Chapter Four, Stephen (2007) argues that testing for intellectual capacity moved well beyond the intelligence quotient during the 1940s. During this period, the concept of capacity was broadened in such a way that employment-related policies informed by perceptions of 'aptitude' came to be applied against even 'average' women seeking to enter the paid workforce (see for example, p85).

While such broad connections remain relevant in the screening tools described in this chapter, the relationships between different impairment categories and inter-related notions of underdevelopment and incapacity vary widely. Arguably, ID remains the only impairment category which is defined by the permanent and even 'congenital' nature of symptoms associated with impaired intellect and a radical form of dependency. As Rapley (2004) suggests and as the analysis of developmental services presented in Chapters Three and Four demonstrate, prototypical ways of viewing people with ID have involved a discounting of their agency (p29), an overriding belief in their incompetency (p26), and related to all this, the tendency to assess them in terms of "whatever capacity" they are thought to hold (p16). In fact, even services geared towards supporting this population are oriented towards the "management of their (in)capacity and (in)capabilities" (p1). It is through their relationship to this pre-eminent symbol of ID – impaired capacity – that members of other impairment categories are likely to be deemed inadmissible. Along these lines, Goodey (2016) suggests that ID forms a master status of sorts, referring to it as "the vortex that sucks down those other groups with them" (p11). While the more intersectional reading of (in)capacity and (under)development outlined in the previous chapter, which centres the role of racism and colonialism, discourages such straightforward ascriptions, the relationship between ID as a sign of impaired intelligence and incapacity with other impairment categories remains an important one for the present analysis. With this context in mind, we can turn our focus to the normative measures that are used to identify people with ID. The remainder of this chapter introduces the underlying values and ideologies that inform these measures, showing how the inter-related notions of capacity and development manifest themselves in today's economically-oriented immigration selection process and within the political debates and reform efforts that culminated in the 2017 CIMM review.

A – 2017 Report of the Standing Committee on Citizenship and Immigration

Excessive Demand: What Has Changed and Why

The 2017 CIMM review could be remembered in a variety ways. The most obvious legacy of this process involved the gathering of evidence from various stakeholders outlining the problematic nature of the excessive demand provision and the subsequent creation of a report recommending a full repeal alongside many interim measures. Less positively, the Committee's work could also be remembered for its inability to convince the current government to act on its top recommendation and repeal Section 38(1)(c) of the IRPA, and the disappointment this generated among affected communities and their organizations. Perhaps less obviously, the report that resulted from the review and much of the evidence that contributed to its writing can be viewed as an extension of the many normative discourses around (under)development and (in)capacity that have been identified throughout this dissertation and that rely on the possibility of measuring, ordering (and, eventually, predicting) individual potential. Viewed through a critical disability lens that centres the ID-related concepts of (in)capacity and (under)development, the incremental gains reflected in the IRCC's announcement in 2018 that it would modify the excessive demand provision presents the possibility of drawing distinct divisions between migrants who are 'more' or 'less' disabled.

In his 2018 announcement, Minister Hussen estimated that the updated excessive demand regime would permit entry to roughly 75 per cent of the approximately 1,000 migrants previously rejected on medical grounds as an 'excessive demand'. As mentioned earlier, changes to the excessive demand regime involved removing special education, social and vocational services, and personal support services from the cost assessment, in addition to raising the cost threshold to $19,812, or nearly triple the previous amount (IRCC, 2018). And while the Minister

claims that his government is embarking on a research and consultation process and is interested in eventually eliminating the medical inadmissibility criteria altogether, this criteria still remains in place (CBC, 17 April 2018, 'It's good for Canada'). Once again, as Titchkosky would say, "planning for inclusion becomes the doing" (Titchkosky, 2011, p100). By emphasizing the preference for "planning" over "doing", Titchkosky is pointing out how the inclusion of *all* disabled people is often postponed until some indeterminate future time, while in the present, the reality of exclusion is excused through planning efforts that commit in some way to eventually addressing this problem. Along these lines, the IRCC continues to legitimize the exclusion of that 25 per cent of migrants, suggested in Minister Hussen's announcement, who will remain inadmissible. These individuals can be formally rendered non-citizens when their applications for permanent residency are denied under medical inadmissibility legislation. The imagined fairness of their exclusion is evident in statements that remind the public of the ongoing importance of screening for potential causes of excessive demand, to ensure "the protection of publicly-funded health and social services" (Government Response, 2018). Such thinking casts doubt on the willingness of this government to rethink the principles upon which the excessive demand provision has been established. It also confirms Titchkosky's (2011) point that "the normalcy of limited access" (p63), based on the view that "'[y]ou can't accommodate everybody'" (p35), depends upon the knowledge we produce about disability and the related divisions we create between social groups (p39).

By critically analyzing the CIMM review within the context of the IRCC's response and through an ID lens, we can begin to understand why a full repeal did not occur and how such delays – if we take the government's promise at face value – are even thinkable. As Titchkosky (2011) has observed, the inclusion of disabled people is too often placed in the future, making

their exclusion in the present seem as though it is a natural condition (pp100-101; p63). Pursuing the causes of this normalization of exclusion and modes of non-citizenship brings us into contact with the estimated 25 per cent of disabled migrants who might currently be characterized as 'excludable'. Not surprisingly, this bottom quarter includes those identified as having 'severe' disabilities or health-related needs. This category also indicates those individuals who fall at the bottom of the impairment hierarchy, which is too often viewed as the natural position of people with ID. Confusingly, and even while promoting changes to how special education needs are assessed and creating the impression that "[n]ew rules mean newcomers won't be denied permanent residency because of developmental delays" (CBC, 17 April 2018), the Minister failed to recognize that the modified criteria will continue to discriminate against many people with ID. Instead, the Minister's indirect promise to Canadians that the IRCC will continue to protect them from the 'most disabled' who require higher levels of support suggests that conceptions of ID will continue to shape the immigration screening process.

The contradictory claims about disability forwarded by the IRCC are not unique. Such contradictions even appear within policy discourses that promote that inclusion of people with disabilities on the basis of their (discounted) capacity. Often, these inclusion-oriented discourses understand capacity as the ability to attain some normative level of independence that allows for a predefined version of social contribution. These contributions might vary in nature and could include, for example, paid or volunteer work. The point is that these examples of the benefits of including disabled people, even when they carry the potential to reflect alternative values, do not explicitly acknowledge or challenge the paradigm of independence that allows for certain individuals to be labelled as 'non-contributing'. In their discussion of ablenationalism, Mitchell and Snyder (2015) identify such discourses as markers 'inclusionist' goals that adversely impact

disabled people who fail to approximate some norm, even while benefitting others. The authors demonstrate that inclusionism works by promoting "claims for successful normalization" (p80), thus acting upon preconceived hierarchies of disability and capacity. As we will see, these claims to disability success are taken up in many of the statements made throughout the CIMM review, with civil society groups strategically seeking to show that disabled people can indeed contribute to Canada in positive ways.

Making Disability Valuable: Productive Potential and Capacity in the Standing Committee's Report

Many of the witnesses who testified during the review called upon the IRCC to recognize disability contributions and to take a more holistic approach to assessing the positive potential presented by immigration applicants. The IRCC was encouraged to consider not only the costs of supporting disabled people, but the benefits of investing in their 'success'. Yet, this idea of benefits is not defined anywhere in the report and normative conceptions of 'contributions' leave open many possibilities, including the practice of screening out individuals who lack the potential to contribute in recognizable ways. The most threatening possibility, as mentioned earlier, is that undefined notions of 'contributions' reinforce the practice of assessing the capacities of individuals for their potential to reach certain normative goals, namely by contributing in normative ways. Given the strong historical linkages between a "lack of potential" and ID (Carlson, 2010a, p142), people with ID may be among those who are unlikely to be accepted as having a certain "contributory potential" (see Carey, 2009, p32), until dominant understandings of 'contributions' undergo a profound change. As it stands, the presence of this term in reform-oriented discourses and the role it has played in challenging the excessive demand regime invoke complex "policy assemblages" (Artiles, Dorn and Bal, 2016; Ureta,

2014) that contain a mixture of normative and damaging assumptions about (in)capacity, even while promoting positive views of some disabled people.

The idea that disabled people generate measurable contributions that can be factored into excessive demand assessments only promotes a positive view of some disabled people. This is because it does not challenge the consequences that result from a failure to contribute in ways that are normatively recognized. Mitchell and Snyder (2015) are once again instructive here, as their work shows that this form of "inclusionism" works through normalizing strategies centred on "downplaying rather than learning from people's differences" (p80). Downplaying disability differences in the context of the discourses reflected in the CIMM review is achieved by promoting the idea of 'contributing' without engaging with its normative basis. We will see specific examples of these discourses below. While reviewing the CIMM report, we can also consider how a much more critical view of the excessive demand regime would include redefining the very notion of 'contributions', or even arguing against the need to demonstrate these outcomes in order to disprove an individual's status as a 'burden'. Moving away from the onus to demonstrate contributions requires what Mitchell and Snyder refer to as "a greater respect for variation" (p177), and this helps forward the idea that difference is in itself productive. The idea of productive difference is, after all, very different from framing people with differences as being productive.

Before we proceed, it should be mentioned that the goal of presenting the many complexities and tensions inherent in the discourses enacted in the CIMM review is not to discount the positive work being carried out by the many civil society groups and advocates involved in this important effort. Instead, this analysis seeks to recognize the threat of assimilation (Stiker, 1999) as well as the fact that the tendency among disability rights advocates,

described by Mitchell and Snyder (2015), to adopt assimilationist claims is often due to the many "pressures" these individuals and organizations face (p82). Since these pressures can include a citizenship culture premised on values that support layers of established mechanisms for measuring incapacity, it is no wonder that political challenges to some of the broad-sweeping impacts of this culture become restricted to discussions about these specific mechanisms. Within this context, there can be few opportunities for conceptualizing the underlying principles of the systems that stakeholders are often required to operate within if they wish to be heard. The CIMM review centred specific mechanisms of exclusion by focusing on the excessive demand provision, but it do so without tackling the deep-seated values and hidden ideological assumptions that have sustained this regime.

Situating the 2017 CIMM Report

Before turning to the arguments presented in the CIMM review, we will need to situate this process in its immediate discursive context. In the IRCC handout to the Council of Canadians with Disabilities (CCD) dated March 24th 2017, the federal government explained that it had undertaken a study of the excessive demand provision, citing as motivating factors "negative media attention", "public calls for review and elimination of the provision", judicial reviews related to excessive demand, and the perception among some that excessive demand decisions are "discriminating against immigrants with disabilities" (IRCC to CCD, pp2-3). In the same handout, the IRCC also claimed that it turned its attention to the provision in October 2016 (CIMM, p15), several months before its meeting with CCD delegates (myself included). Interestingly, during the meeting in March 2017, the IRCC anticipated one the key changes that would be announced in April 2018, following the CIMM review. The IRCC handout acknowledged that excessive demand criteria applied to special education services were facing

particularly strong resistance by immigration applicants: "Continuing risk of negative outcomes when applicants seek judicial review, especially for special education cases" (IRCC to CCD, p2). The handout also explained that one of the reasons for the review related to the mainstreaming of special education, since "[m]any provinces and territories have integrated funding and delivery of special education into regular services" (p3). Changes to special education would become one of the most well-advertised revisions to the excessive demand definitions. What this suggests is that advocacy work predating the CIMM review influenced the eventual recognition that change was required to how excessive demand was being calculated.

In an atmosphere of broad public criticism of the excessive demand provision, the Parliamentary review was launched in October 2017. Over the course of its work, CIMM received witnesses and reports between October 24th and November 23rd, 2017, totalling 25 witnesses and 24 written submissions (CIMM, p7). The CIMM report compiles and interprets witness accounts and submissions and contains responses by IRCC officials to specific questions posed by Committee members. Written accounts shared by witnesses came from provincial and territorial governments, legal groups such as the Canadian Bar Association and HIV and Aids Legal Clinic Ontario, disability and immigration lawyers, and disability rights and migrant justice organizations such as the Council of Canadians with Disabilities, Migrants Workers Alliance for Change, and the Ontario Council of Agencies Serving Immigrants.[13] Many of the written submissions reflect similar strategies and while they do create the potential for changes in how disability and citizenship are defined, they tend to share in the limitations outlined above. This is particularly true in the sense that they do not challenge normative constructs around (in)capacity and the related notion of 'contributions' in any explicit way. However, since we can

[13] Also in the interest of transparency, I wish to share with readers that I was involved in this process in a volunteer-capacity and contributed to submissions shared by some disability organizations.

build upon these critiques, we should also consider how they present the possibility for more fundamental challenges to Canadian immigration practices.

It is equally important to appreciate how witness accounts were filtered and arranged in the final report. CIMM was obliged to compile and curate the feedback they received, selecting quotes and pieces of evidence shared by witnesses. The curation of evidence is another important element of the review process that must be kept in mind, as it necessitates the reinterpretation of witness accounts. A more detailed account of this filtering process requires a close reading of both the written and live testimonials – something that is well beyond the scope of this study, but that is nevertheless an important avenue to explore. Instead, this section will focus on the report itself, summaries of the written evidence provided by witnesses, and the interpretation of different aspects of that evidence. Related to this interpretative work are several problems in how the CIMM report frames witness evidence.

The report's framing of evidence is primarily achieved through a narrative that invokes the concept of 'health' and that conflates ill health with disability; the explanation of excessive demand, which refers to impairments as 'medical conditions' and states that it is "due to the *medical condition* of one of their family members" (p8) that leads to inadmissibility, is but one example of this confusion. While people with disabilities also include people with health-related issues such as chronic illness and chronic pain, this conflation creates confusion around how disability is being presented to the IRCC, particularly by generating tension around the social model framing of disability presented in many of the submissions which intentionally distance disability from health (CIMM, p28). These tensions go some way in accounting for the contradictory recommendations noted in separate dissenting reports by NDP and Conservative parties. As noted by these critics, the report's key recommendation for a full repeal is

simultaneously undermined by many sub-recommendations that focus on improving a system that is being recognized as unjust. In their report, the NDP called for an immediate repeal of the excessive demand provision and referred to "inconsistent half measures which allow for the continuation of this discrimination" (CIMM, p59). The Conservative Party, however, was reluctant to recommend a repeal until an assessment of the costs associated with this change could be completed, but nevertheless found that the report's recommendations "may be mutually exclusive" (p52).

Framing Disability Contributions

The CIMM report promotes a full repeal of the excessive demand provision as its top priority, but it also lists measures aimed at improving the regime. These measures include: enhancing monitoring of the impact of excessive demand; "continu[ing] to consult and negotiate with the provinces and territories on a repeal"; improving data collection around excessive demand; ensuring better training for IRCC officials and medical officers around excessive demand; reviewing the excessive demand cost threshold, how it is calculated, and "eliminating … those services that are not publicly funded" from the cost criteria; "expand the list of exempted persons" to the excessive demand measure; ensuring greater clarity in Fairness Letters advising applicants of an excessive demand finding; making the manuals and guidelines related to excessive demand publicly available; providing an assessment of the impact of a future repeal (CIMM, pp3-5). As the opposition parties noted, the inclusion of measures related to reforming the system contradicts the key recommendation to repeal the provision which, it should be noted, was supported by the majority of witness testimonies accepted by CIMM. In fact, the report describes near-unanimous agreement among those who participated in the review that the provision be repealed, citing all but two witnesses. Importantly, one of these witnesses included

the Province of Saskatchewan, whose reluctance to repeal was expressed as a positive desire to protect Canadians by ensuring their "timely and quality access to health, education and social services" (p16). Expressing similar concerns, the Conservative party's dissenting report points to the threat of costs being 'downloaded' onto the provinces (p52). Quite differently, the governments of Newfoundland and Labrador, the Yukon, and Nunavut spoke of the benefits of newcomers and were supportive of welcoming migrants with disabilities (p17). Conversations between the IRCC and the provinces and territories were described as "ongoing", but with all governments agreeing on the need for changes (p16).

Meanwhile, the Committee's report supports the emphatic calls for a full repeal of Section 38(1)(c) expressed by most other witnesses. However, the report's presentation of these arguments within a confusing framework that both conflates and then distances disability and health and contains contradictory measures as well as contradictory messages by witnesses, suggests that this broad desire to end discrimination may be hindered by current understandings of disability. As this dissertation has argued, these dominant understandings of disability relate to how (in)capacity is often conceptualized in biomedical as well as rights-based frameworks. Reconceptualizing capacity will help advance a clearer critique of the excessive demand regime, but this work can only take place once ID is centred as a category of analysis and once those who fall under this impairment label and who are often positioned at the bottom of the capacity hierarchy are deemed worthy of inclusion, regardless of their ability to demonstrate measurable contributions. While many witnesses argued for the importance of rethinking disability, describing the social model (p24), which separates impairment (natural) from disability (social), and presenting critiques of the medical model (p28), the final report does not reflect any explicit attempt to reconceptualize capacity in ways that challenge the values that underpin the 'burden

narrative' of disability that we encountered in the previous chapter. With such dominant conceptions in place, the final message of the CIMM report is not that difference is productive, as Mitchell and Snyder (2015) have shown, but rather that people with differences have the potential to be productive. According to this reasoning, certain individuals can be assimilated within current systems of valuation and the dominant citizenship cultures they reinforce. It bears repeating that this strategy of emphasizing disabled modes of productivity leaves open the possibility that some people with disabilities will be unable to meet current standards of inclusion.

Reviewing the CIMM report along with the written submissions that partly informed this work also reveals the co-existence of competing understandings of inclusion. Interestingly, some of these discourses promote anti-discrimination while reinforcing hierarchies based around established notions of (in)capacity. A more detailed study of the lengthy discussions that took place during the review could show further complexity, but the present analysis will focus instead on the final report as well as aspects of the written submissions referenced in that piece. This analysis must also acknowledge that the many voices and complex ideas included in these discussions and throughout the review cannot possibly be collapsed and simplified into a single report. Yet as the culmination of the CIMM investigation and the most accessible means of accessing the review process, the report plays a curatorial role in selecting which perspectives are given representational power. With these limitations in mind, we will see that there are noticeable themes that emerge in the report which reinforce the problematic tendency to view capacity in hierarchical terms. Once again, however, it must be emphasized that we must avoid viewing these results as reflecting the complete views of the witnesses who participated in the review.

Troubling 'Disability as Investment'

Within the CIMM report, the establishment of a hierarchy of (in)capacity can be linked to evidence presented from witness testimonies. The evidence that is cited in the report encourages the IRCC to focus on the contributions made by people with disabilities and the related need for an anti-discrimination approach that avoids equating disability with any perceived burden. Within the report, discrimination is linked to the targeting of disability services through the excessive demand regime's cost-benefit assessment and is understood as "impos[ing] obligations or disadvantages [on disabled migrants] that are not imposed on others" (CIMM, p23). Similar to the approach to anti-discrimination outlined above, witnesses argued that it is unfair for disabled migrants to have to agree to mitigate service costs or prove that they would not in fact use certain services (p34). Extrapolating from the summary presented in the report, to avoid such forms of discrimination and to arrive at a fairer understanding of the services potentially used by disabled migrants, the IRCC would have to view these as an investment rather than a potential burden. Calls for change that invoke this investment case thus directly address the 'burden narrative' that has long been at the centre of criticism in discussions of excessive demand policy, as explained in the previous chapter.

Along these lines, many witnesses urged the IRCC to focus on the potential contributions of disabled people (CIMM, p32), so that the provision of services can be reframed as an investment. It is worth observing that bringing about this change in perspective would require framing disability supports and accommodations not as 'excessive', but as part of the general publicly-funded system. While this strategy is a powerful one that could facilitate substantive citizenship and meaningful belonging, a problem arises when these efforts run up against dominant framings of (in)capacity as a measurable and demonstrable quality that can be viewed

along a linear scale. Even more problematic are the ways in which calls for inclusion that make an investment case for disability promise potential outcomes that reinforce the logic of development that has been used to exclude people deemed 'incapable' – as discussed in the previous chapter's analysis of (neo)colonial practices and legacies. A closer look at the investment strategy and the unqualified promise that disabled people do and will continue to 'contribute' to Canadian society will help illustrate these tensions.

Even while it suggests the potential for rethinking disability, the investment strategy presented in the CIMM report closely resembles the "assimilationist claims" described by Mitchell and Snyder (2015, p82) and critiqued by Stiker (1999). These similarities can be detected in the ways in which appeals to recognize disabled people's contributions reinforce neoliberal principles of capacity-enhancement premised on disability services-investment. The fact that capacity-enhancement is linked to investing in disability services is suggested by the argument that the 'right conditions' and supports enable 'contributions', as articulated in the following statement: "given the right set of circumstances they can bring positive change and impact to their communities and contribute" (CIMM, p36). Such reasoning places pressure on disabled people to contribute in ways that will meet the normative expectations of those around them, especially once they are granted the accommodations and supports they requested. Furthermore, the focus on capacity-enhancement, as the discussion of developmental services in Chapters Three and Four suggests, exposes disabled people to evaluative tools that encourage biopolitical interventions premised on the unchallenged paradigm of independence and related normative constructs. As Stiker (1999) has shown, this interventionist approach is at the heart of the rehabilitation industry, with its mandate to "retrain", "redeploy", and "reintegrate" (p128).

No discussion of rehabilitation would be complete without acknowledging the valorization of paid employment for disabled people. Indeed, Stiker (1999) draws attention to employment in his discussion of rehabilitation and integration (p164). Under a rehabilitative model, becoming 'ordinary', means "to be returned to ordinary life, to ordinary work" (p128). Supporting disabled people to 'achieve' paid work remains a common policy goal, especially in Ontario in recent years under the Accessibility for Ontarians with Disabilities Act (AODA), and securing meaningful work is indeed a goal to which many disabled people aspire. Systemic barriers to paid employment and along with these, economic marginalization, are undoubtedly real concerns that ought to be addressed. At the same time, a critical disability lens allows us to question this emphasis on work and normative measures of productivity, just as Sunny Taylor (2004) has done. Taylor, echoing many of Stiker's (1999) points and Mitchell and Snyder's (2015) critique of rights-based movements, is concerned with the emphasis on work, and how "[m]uch of the empowering rhetoric in disability movements is about becoming employed and about having equal access to mainstream society". Just as this chapter has argued for the exclusionary effects of current understandings of 'contributions', Taylor points out that not all disabled people will be able to work. She goes so far as to posit "a right not to work", which indicates "the right not to have your value determined by your productivity as a worker, by your employability or salary".

Expanding Taylor's critique, it seems that current approaches to disability inclusion that revolve around demonstrating 'contributions', either paid or unpaid, run the risk of reinforcing normative criteria that remain beyond the reach of many disabled people who simply cannot attain these standards. These ideas and practices stem from, interact with, and shape dominant measures of (in)capacity and (under)development. An ID lens, with its explicit centring of a

governmentality of (in)capacity, allows for critical engagement with such dominant notions of 'contributing'. Such level of engagement with questions of incapacity goes some way in attending to Russell's (1998) concern with current approaches to growth and development and her call for alternative economic arrangements and values "that might include all people as participants" (p143).

The aim of enhancing individual and societal capacities to support positive contributions relies on a view of progressive and measurable development that also suggests its inverse: developmental 'delay', 'deficiency', or ID. After all, the notion of contributing to society relates to an individual's imagined potential and it is precisely this "supposed lack of potential" that has defined people with ID (Carlson, 2010a, p142), and legitimized their ongoing exclusion. Carlson suggests that this "elusive notion of potential" (p141) forms a definitive link between ID and adverse development. She writes, "[by] virtue of his or her supposed lack of potential, the prototypical case of ID cannot be considered on the spectrum of human development" (p142). When we think of the related goals of progress and development and how they interact with biopolitical processes that act upon human potential, we can begin to see that many people with ID, who are often placed beyond the normative "spectrum of human development", to borrow Carey's phrase, are unlikely to be valued for their potential to contribute in socio-economic terms.

Even though CIMM witnesses helpfully problematized the link between disability and the idea of social burden (CIMM, p28), the report does not make space for a discussion of underlying values and related principles of capacity and dependency that continue to regulate access to formal citizenship. Instead, the report includes comparative discussions that invoke a hierarchy of needs and associated levels of risk to the economy. For instance, comparisons are

drawn between disabled people and "heavy smokers" (p34) and others who engage in behaviour perceived as risky or costly. While these comparisons are presented with the intention of dispelling disability stigma by relativizing notions of 'risk' and 'burden' by linking them to experiences not often associated with disability, the unintended consequence of naming other groups and behaviours is to reinforce the belief that 'risks' and 'burdens' can indeed be identified. Identification supports a form of knowledge-creation that enacts a tripartite model that includes measuring, ranking, and predicting an individual's potential. We often see the three prongs of this model at work in disability service provision, as the case of developmental services and the MCSS-run system has shown. Relatedly, such comparisons among categories of supposed risk support the logic that underlies a hierarchy a (in)capacity. Framed through this hierarchy, individuals whose needs are the 'highest' or who are considered to be 'risky' and 'unsupportable' can be identified, assessed, and treated according to the current exclusionary logic.

Narratives of 'Overcoming' and Disability Denigration

Alongside the idea that (in)capacity can be measured and ranked, the CIMM report presents the possibility that incapacity can be 'overcome' with the correct support systems. As Mitchell and Snyder (2015) warn, this would allow people with disabilities to participate in a society and culture that has not fundamentally altered its beliefs, including a marked fear of incapacity and ID. The authors explain that strategies for disability assimilation often involve tactics that include demonstrating how disabled people have already successfully been included within current systems (p80). Similar calls to recognize the success of disabled people's assimilation recur throughout the CIMM report and the written evidence upon which it is based, arising within discourses that recall the inter-related constructs of capacity and development. For

example, one written submission references the unrecognized contributions of disabled people, listing examples of well-known individuals, two of whom are Paralympic athletes and others who are elected or appointed political leaders (CCD to CIMM, p11). These normatively successful individuals fit the 'supercrip' model of 'exceptional' achievements. While there are many faces to the supercrip trope (Schalk, 2016), their successful 'assimilation' is often based on extraordinary feats characterized by their ability to not only 'overcome' their impairments, but to demonstrate their supposed success by inspiring and even out-performing non-disabled people (see Howe, 2011; Olsen, 2013). In other places, the notion of 'contributions' are referenced, but remain undefined and only loosely associated with the development of economic, social, and cultural aspects of Canadian society (Pooran and CLKL to CIMM, p2). Previously, we saw how such arguments, which leave unchallenged dominant conceptions of contributions, inadvertently reinforce discourses of progressive development and capacity enhancement. Thus, even while they suggest the possibility for alternative views of disabled people, the effects of such strategies carry the risk of privileging the 'least disabled' or the most 'assimilable' (see Mitchell and Snyder, 2015).

We saw in previous chapters how Ontario's support system for people with ID structures interventions with the goal of normalizing or assimilating service recipients according to dominant citizenship constructs. In these instances as well as in the context of immigration screening, it is helpful to view assimilation through the biopolitical lens of capacity-enhancement and a governmentality of (in)capacity. The extent of these efforts are far-reaching and opportunities for capacity-enhancement are not only placed on disabled migrants – entire families are drawn into these biopolitical evaluations. Accordingly, the CIMM report documents questions posed to IRCC officials about the economic benefits of "having the family in Canada"

(p14). This reference to the productive potential of (non-disabled) relatives of disabled migrants once again reinforces dominant conceptions of contributions. In this instance, it does so by employing a reform-oriented strategy that encourages the IRCC to focus on how the economic benefits of including presumably productive non-disabled migrants might outweigh the inherent costs associated with their disabled counterparts. Enacting this strategy, one witness, for example, appealed to Canada's need to attract "the best and brightest" and "most highly-skilled immigrants", arguing that excessive demand screening may foster family separation and deter these potentially productive individuals by threatening to separate them from their (disabled) children, parents, and grandparents (CIMM, p39).

Another inference drawn here is that disabled people occupy the status of elderly people or children – two groups who are not expected to contribute along normative and namely economic lines as a result of their very young or advanced age. The benefits of including the relatives of 'productive' non-disabled individuals is equally related to efforts to enhance the productive potential of those without disabilities. As the report explains, drawing on witness accounts, "it [their inclusion] increases support networks, promotes productivity, and reduces stress" (p39). There is an implied connection here between disability and stress that invokes the 'burden' of care work. So, even while the report reflects discussions of disabled people as potentially productive, it confuses these claims by reinforcing the perception that they also present a burden. In this instance, their productive potential is secondary and is instead linked to the greater potential associated with their non-disabled relatives. In many ways, and as has been suggested elsewhere (El-Lahib and Wehbi, 2012; Spagnuolo, 2016b), this move reflects one of the key shortcomings in *Hilewitz*, which enabled factors such as family income to be considered in excessive demand evaluations.

There are several other strategies reflected in the report that carry conflicting messages. In an effort to dislodge the excessive demand regime, for example, some witnesses draw attention to faulty assessment processes, looking at the mechanisms by which excessive demand is calculated and recommending improvements in this area. Examples of this approach include witness accounts that cite the IRCC's inability to accurately predict the cost of disability service-use (p35), and related to this, the inaccuracy of the excessive demand cost threshold in relation to current figures on health and social service usage among Canadians (p12). Some witnesses also called for a repeal of the excessive demand provision in addition to more up-to-date information on costing (p31), reflecting the report's overall failure to completely reject a policy that it characterizes as unjust. Recommendations to repeal the provision based on its illegitimacy are undermined by suggestions aimed at improving how this faulty system works. However, other witnesses (p32) do contest this focus on costing and efforts to improve such an approach to screening. Yet even within these critical accounts, the over-riding focus remains the positive contributions of people with disabilities – an unqualified belief that still leaves in place the possibility of a cost-benefit measure.

While many of the above arguments may be strategic in promoting incremental forms of change, they leave open the possibility that accurate predictions of migrants with 'high and costly' needs are permittable. From the perspective of the IRCC, it is this very possibility that continues to legitimize the exclusion of disabled migrants who are viewed as 'incapable' and as potentially failing to contribute to Canadian society along normative lines. One of the key problems suggested by the reformist discourses reflected in the CIMM report is that high costs are being wrongfully associated with productive and contributing persons with disabilities whose contributions – and whose relatives' contributions – far outweigh their support needs. For these

reasons, it is important for us to consider what might happen when disabled people cannot prove themselves as contributing members of society, or when their contributions do not reflect dominant understanding of this term and the ideologies up on which these valuations are based. While it is too early to assess the effects of the announced changes to the excessive demand regime, the likelihood of ongoing forms of disability exclusion through formal non-citizenship status are laid out in the IRCC's response to the CIMM recommendations. In short, the government's refusal to admit migrants with disabilities who pose a higher cost to society means excluding those individuals who are located at the bottom of the impairment hierarchy. These are individuals whose perceived incapacity and potential inability to contribute to Canada's development can be demonstrated through an excessive demand assessment.

Revisiting the IRCC's Response

The IRCC's framing of its own response to the Committee's recommendations which, as previously explained, involve the removal of special education, social and vocational, and personal supports from the definition of excessive demand, and the tripling of the cost threshold (IRCC, 2018), serves to amplify the problems contained in the report's impartial critiques of the excessive demand regime. Through various adjustments to its excessive demand policy, the IRCC only agreed to enhance opportunities for inclusion for the 'least disabled', thus "facilitating the arrival of families where a member has a health condition that may require less costly services, focusing the provision on those with conditions that require very costly treatment and care" (Government Response, 2018). The explicit nature of the decision to focus on screening out migrants with disabilities who require "very costly treatment and care" is a direct commitment to enacting a hierarchy of (in)capacity by encouraging Canada's growth and development through immigration policy. The IRCC's framing of this decision presents the

exclusion of those at the bottom of the impairment hierarchy as a legitimate practice, while recognizing the inclusion of those at the top as a desirable form of change.

Other parts of the government's response are worth quoting at length:

> As currently defined, [the excessive demand provision] policy includes the assessment of ***costs for services that are critical for promoting inclusion*** [emphasis added], most notably special education, social and vocational rehabilitation services, and personal support services. Instead of treating these as costs that must be borne by society, ***these should instead be seen as investments*** that enable participation and inclusion [emphasis added]. With this in mind, the Government will seek regulatory amendments to remove these services from consideration under the excessive demand policy in order ***to better balance the fair treatment of persons with disabilities and the protection of publicly-funded health and social services*** [emphasis added]. This will benefit applicants with children who have disabilities and others needing these services.

Noteworthy here is the statement that disability-related costs "should instead be seen as investments" – a view that suggests that some disabled people are indeed a worthwhile investment because these individuals will participate in society in normative ways that are oriented towards dominant measures of development. We have already seen how the CIMM report links the idea of investing in disability to the potential contributions these migrants could make, and how this development-oriented discourse reinforces a cost-benefit analysis by formulating disability through a hierarchy of capacity. In a parallel way, the IRCC justifies investing in the 'least disabled' with the belief that these individuals will participate in society and that their inclusion will be profitable according to certain measures. Within this discourse, the notion of 'participation' reflects normative ways of belonging and contributing to socio-economic growth and development. Thus the ablenationalist (Mitchell and Snyder, 2015) tendency to assimilate disabled people rather than modify social structures and values to accept the differences they present, is evident in the IRCC's desire to include certain disabled migrants under its own terms. Under the upgraded cost-benefit framework of the excessive demand provision, the imagined fairness of Canada's immigration system can be upheld by the existence

of a hierarchy of (in)capacity that is considered both natural and measurable. The threat posed by those migrants who can be located at the bottom of the hierarchy and characterized as incapable is reinforced by the IRCC's response and through its stated commitment to ensure "the protection of publicly-funded health and social services".

Similarly, the IRCC's commitment to policy changes that remove certain services from excessive demand assessments, its decision to raise the overall cost threshold, and the presentation of these changes as "increase[ing] fairness by facilitating immigration for applicants with health conditions that typically require a limited range of health and social services" (Government Response, 2018), suggest a portrait of the types of impairments that will be accepted in Canadian society. Again, the fact that certain services are worth investing in means that certain people are also worth investing in, while others are simply not. The changes made to the government's definition of excessive demand clearly delineate those disabled people who "require less costly services" as eligible for inclusion. For this reason, the cost threshold remains in place, albeit slightly raised in the interest of more accurately identifying 'worthwhile' migrants. Excessive demand evaluations based on mainstreamed services such as special education were not only difficult to accurately assess, but were hotly disputed leading up the 2017 review. The IRCC had acknowledged that it faced legal challenges around these services (IRCC to CDD, p2), and so it is no surprise that special education was removed from the scope of the provision. Thresholds attached to other services, such as social and vocational and personal supports, were also removed. Importantly, however, such services do not include the residential supports that disabled people with more 'intensive' needs – and namely people with ID – often require. Limiting the changes to social and vocational and personal supports will help

include more individuals identified as having a certain level of 'capacity', while contributing to their 'development' and to society's socio-economic growth, normatively defined.

Individuals who require residential services and who are not considered capable of living on their own, provide but one example of how the excessive demand provision will continue to target migrants who are thought to pose a risk to health and social services. The imagined legitimacy of their exclusion – a notable outcome of the policy reform efforts described throughout this chapter – requires us to consider the beliefs and practices that generate capacity hierarchies in the first place. Titchkosky (2011), referring to the conviction that "'[y]ou can't accommodate everybody'" (p35), describes the ongoing exclusion of many disabled people and the ways in which "some bodies are made and regarded as 'naturally' a problem for some spaces" (p35). Until we can begin to question this normalization of exclusion, it is likely that migrants who are assessed as being 'more disabled' will continue to be excluded from formal citizenship unless their relatives demonstrate a level of 'contribution' that might offset this supposed burden. This disability cohort, framed as "excludable" (p39), faces spatial displacement through the denial of permanent status as well as subjective forms of displacement that coincide with the experience of undergoing a capacity-related assessment under the excessive demand regime.

In the next part of this chapter, we will turn to the issue of capacity assessments and to the immigration medical exam, invoking lessons from developmental services (Chapters Three and Four) to consider how the imagined risks posed by 'more disabled' migrants are measured. To do this, we will consider the assessment forms and directives associated with testing for ID – the impairment category that is most directly associated with incapacity. This array of IRCC paperwork, all which can be grouped under the immigration medical exam, provides a striking

example of how immigration policy conceptualizes (in)capacity. A comparative reading of these tools once again points to the complicity of provincial disability systems and ID assessment regimes in shaping displacement and non-citizenship. Such an approach provides a closer look at the denigration of incapacity and underdevelopment and will eventually allow us to analyze experiences of displacement among broader groups of migrants with disabilities through the lens of ID.

B – Immigration Medical Exam Instructions and Assessment Practices

Categorizing 'Excessive Demands': 'Grade A' versus 'Grade B' migrants

So far, this chapter has forwarded the argument that the updated excessive demand regime stratifies disabled migrants according to a hierarchy of impairment related to their imagined (in)capacity. In this context, (in)capacity is a concept that invokes intelligence and that can be understood through the inter-related concept of (under)development and the normative notion of positive social and economic contributions. The limited nature of the changes made to the definitions guiding the excessive demand provision can be further contextualized by considering how the stratification of migrants through (in)capacity assessments is reflected in other areas of the IRPA and within the immigration medical exam itself. The 2002 Act, according to Huot et al. (2015), stratifies asylum and refugee claimants according to categories that come with "varying degrees of rights and privileges" (p10); this affects how they are treated by the IRCC in important ways by defining, for example, which applicants can file an appeal if their application is initially rejected (p8). The disaggregation of asylum and refugee claimants into distinct categories was aimed at making the immigration system more efficient. Such efficiency-oriented thinking was also behind the introduction of the SIS in Ontario's developmental services system and surfaced in the Ministry's prioritization of assessments over

actual service provision. Importantly, Huot et al. demonstrate that Canada's efficiency-oriented immigration system is far from neutral and that the changes instituted under the IRPA impact much more than processing times. Instead, the authors link the stratification of asylum and refugee claimants to "neoliberal governance strategies" (p10). These strategies, of course, play an ideological role and are oriented towards a specific understanding of citizenship and belonging and to the regulation of social relations according to these values.

We have already seen how developmental services support the differentiation of people with ID according to medicalized assessment results, affecting resource-allocation and access to substantive rights along these very same lines. Just as importantly, this differentiation process enables the identification of the 'most disabled' individuals within the ID community and permits their segregation in specialized service settings (see Chapter Four). Similar governance strategies which rely on medicalized assessments and specifically, the categorization and ranking of applicants according to a hierarchy of (in)capacity, are enacted through the immigration medical exam and the various categories of risk that it constructs. There are several layers to this assessment process and different tiers of testing that are triggered by the initial medical exam. Each of these stages contributes to the production of a medicalized and documentary identity that allows IRCC medical and visa officers to eventually determine which individuals pose an excessive demand.

The first distinction that is made by the IRCC, however, is through the creation of exemptions to the excessive demand provision. These 'exempt' applicants do not have to undergo excessive demand screening. The creation of this category aligns with the changes to the refugee system discussed by Huot et al. (2015), which permits stratification in order to maximize the productive value of IRCC processes by reducing the costs associated with false claims,

‘smuggling’, and other ‘risks’. The creation of new designations under the IRPA, according to the authors, emphasizes the difference between supposedly ‘“deserving’ refugees” and ‘“underserving’ asylum seekers” and legitimate and illegitimate refugees (p2). The ‘efficiencies’ of the new system are thus linked to the IRCC’s ability to better detect the “threat to the economy” posed by false claims, for example, which are thought to result in the abuse of publicly funded services (p10). Similarly, the imagined gains of sorting permanent residency applicants who might pose an excessive demand from other migrants relates to the goal of avoiding any ‘abuse’ of public services. To avoid abuse, the IRCC attempts to restrict access to public services to those migrants who are thought to be more desirable and deserving of entry. As we will see below, desirability and deservedness are closely related to perceptions of dependency, but they also go well beyond these by drawing upon hierarchies of (in)capacity to construct knowledge about a migrant’s (perceived) development status and their related ability to contribute to Canada’s development goals. At play in IRCC evaluations, as Huot et al. have explained, is a “neoliberal rationality” that individualizes social issues (p10), while relying upon the categorical ranking of desirable applicants; this is no less true in the case of medical screening.

Returning to the immigration medical exam, the first distinction drawn through this requirement relates to exemptions to excessive demand screening. And while almost all applicants must undergo a medical exam, Section 38(2) of IRPA specifically states that 38(1)(c), the excessive demand provision, does not apply to an applicant who

> a) has been determined to be a member of the family class and to be the spouse, common-law partner or child of a sponsor within the meaning of the regulations;
>
> (b) has applied for a permanent resident visa as a Convention refugee or a person in similar circumstances;
>
> (c) is a protected person; or

> (d) is, where prescribed by the regulations, the spouse, common-law partner, child or other family member of a foreign national referred to in any of paragraphs (a) to (c) (Immigration and Refugee Protection Act, SC 2001, C.27).

This means that medical screening for excessive demand applies to "economic applicants and their family members, including live-in caregivers, provincial nominees, parents and grandparents, students, foreign workers and temporary residents" (CIMM, p12). Applicants are therefore either EDE (excessive demand exempt) and not subject to excessive demand testing, "Non-EDE" and exempt from it, or "Refugee overseas" (IRCC, Handbook, 2013, 4.3). Migrants who are required to take a medical exam that is oriented towards excessive demand screening are classified under two general categories: grade A and grade B. According to the IRCC, "[g]rade A indicates that there are no significant abnormal findings present and/or an abnormal history", whereas "[g]rade B indicates that there are significant abnormal findings present and/or an abnormal history" (Handbook, 4.4). While Grade B does not necessarily translate into an excessive demand finding, it certainly raises "red flags" – a term Keung uses in his description of fraud detection – (Keung, 5 January 2017) for the IRCC medical officers who assess these applications based on information provided by panel physicians.

Drawing unfavourable attention to an application is never a good thing. As Satzewich (2015) explains, in a backlogged system the level of scrutiny applied to each application is always uneven with additional scrutiny occurring when the risk of inadmissibility seems high, or when some suspicion is aroused related to the credibility of an application (p29; p140). Concerns related to 'fraud' are linked to perceptions of some applicants as being "more desperate" to settle in Canada (p141). This thinking follows a pre-conceived ethno-racial hierarchy in the sense that visa officers can choose to take a closer look at applications depending on the nationality and region from which the applicant is applying. Along these lines, Satzewich explains that officers

"define individuals from some countries or regions as more likely to engage in fraud to secure permanent residence in Canada" (p141). 'Grade B' ratings thus present one among many formal and informal sets of "red flags", to use Keung's term (5 January 2017), that can inspire risk-aversive officers to peer deeper into a specific application.

Under the immigration medical exam, grade B could indicate that a panel physician considers the applicant to have one of many capacity-related impairments. These include a "debilitating condition" (Debilitating Conditions, 2013, p2); "abnormal cognitive functioning" (p2), or "developmental delay" or "abnormal developmental milestones", if they are a child (Developmental Delay in Children, 2013, p2; Developmental Milestones, 2013, p2); abnormal activities of daily living assessment (Activities of Daily Living Assessment, 2013, p1); "a cognitive functioning score of 25/30 or lower" (Assessment of Cognitive Functioning, 2014, p2); "abnormal GAF [global assessment of function]" (Global Assessment of Function, 2013, p1). These categories are drawn from seven specialized guidebooks created by the Health Branch of the IRCC between 2012 and 2013, with revisions to some guides occurring between 2013 and 2014. Each guidebook is part of a broader set of 24 which serve as directives advising panel physicians on how to identify and report 'abnormal' conditions. Below, we will see how the seven guidebooks related to ID rely upon the concept of capacity as an indication of an applicant's ability for independence. Overall, these guides constitute a system of medicalized risk assessments informed by the disaggregated characteristics of ID as presented through the inter-related concepts of (in)capacity and (under)development. Traces of these ID-related tests are evident at the very outset of the immigration medical exam and are also reflected in the general exam forms, as we will soon see.

Automation and Discretionary Judgment in Medical Decision-Making

Every immigration medical exam begins with an in-person meeting between the panel physician and the applicant. During this meeting, migrants undergo a physical examination and their medical history is taken; they also undergo "age-specific laboratory tests and age-specific chest x-ray", that include testing for HIV and syphilis (IRCC, Manual, 4.0). Among other information produced, including biodata, a photo of the applicant, and a consent declaration, the immigration medical exam leads to the completion of a form that is of close interest to the present study and which must be submitted to the IRCC. This form is the Medical Report (IMM 5419, 2013), and it will be explored in detail below. It is worth noting that encounters with panel physicians during the immigration medical exam are one of the few remaining areas where in-person contact is required as a standard part of the application process. Satzewich (2015) found that in-person contact has been reduced since the 2001 Act and that decisions are now mostly based on written documents. Similarly, interviews only occur in cases where some question or suspicion arises around the paper application (pp215-216; p220). Satzewich's findings do not, however, apply to the work of panel physicians who do require face-to-face contact as a part of the general immigration medical exam. All the same, evidence collected in his study that points to uneven power dynamics during the face-to-face interviews that do occur between visa officers and applicants must be kept in mind.

Satzewich's research suggests the bureaucratic and dehumanizing nature of encounters between applicants and officials, where migrants are often treated as "standardized units that can be processed" (p216). Given that they carry the same risk-oriented goals and are mandated by the same system that structures the meetings with visa officers described by Satzewich, it is reasonable to assume that immigration medical exams are likely to present similar problems.

Elaborating on these problems, Satzewich writes that, "interaction is generally routine to reinforce the client status and subordination of applicants" (p217). Additionally, a high degree of suspicion shapes these official encounters, which occur within an organizational culture that encourages the social separation of the client population from their assessors (p22). Rapley (2004) has shown that the ID label works in a similar way during artificial assessment scenarios, and in the previous chapter we encountered how some of these problematic power dynamics are at play in DSO client encounters. As Chapter Four explains, the displacing effects of these experiences are not limited to the risk of spatial segregation or separation, but encompass the subjective understanding of the individual, shaping their future experiences. When we discuss interview findings in Chapter Seven, we will return to some of these consequences. For now, we will consider how such relationships are structured through policy directives and practices under the IRPA.

The question of discretionary authority recurs throughout the CIMM report and in research by Satzewich (2015). For Satzewich, the new immigration system is marked by a loss of both in-person contact and discretionary decision-making power. He relates this loss to the need for organizational efficiencies, explaining the IRCC's hope that by reducing time spent with applicants, higher case volumes can be processed more quickly (p184). Within the immigration medical exam, the use of algorithms to structure a multi-layered testing system and indicate when additional medical testing may be needed reflects both a desire for objectivity and a general trend towards automation. A similar organizational culture was described in Chapters Three and Four, which documents the decision to implemented the SIS within Ontario developmental services. Both immigration and developmental services systems face time constraints, long wait lists, and the mandate to allocate resources in a fair and objective manner,

but according to highly subjective criteria. To respond to these pressures, these systems employ assessment processes that rely in part on the medicalization and disaggregation of an individual's "vital properties" or potential (Rose, 2007), with the imagined promise of objective and nearly automatic forms of decision-making.

The move towards automation in immigration medical exam testing is further signalled by the use of a new digital technology known as EMedical at certain clinics where panel physicians perform IMEs. More than a documentation method, EMedical enables panel physicians to input information into a system that will generate a binary result – either a grade A or grade B. The IRCC Handbook to panel physicians explains, "[a]n Immigration Medical Exam grade will be provided automatically by the system based on the reported findings" (Handbook, 4.4). The Handbook states that a B-grade cannot be manually changed to an A-grade whereas an A-grade *can* be changed to a B-grade upon the discretionary judgment of the panel physician when "the panel member believes that there are significant abnormal findings" (4.4). The processes that take part in this trend are organized through the algorithms presented in the specialized guidebooks discussed in the next section. These algorithms are hierarchies presented within a flowchart of potential risks that outline a path of mandatory and recommended assessments. Up until 2018, the results of IMEs were stratified as well, with the 'worst' or most complex cases going to a specialized centre. This practice was recently changed following the CIMM review, which promised a more centralized approach (IRCC, 2018b). Centralization, however, has not proven to be an adequate response to complaints about stratification, as automated and divisive practices can be mutually reinforcing methods (see for example Molnar and Gil, 2018). With these concerns in mind, the following sections trace the path to medical inadmissibility, showing along the way the many pitfalls inherent in these approaches.

Immigration Medical Exam Instructions: Raising 'Red Flags'

Working backwards from an excessive demand finding, we arrive at the first set of assessments and immigration medical exam forms. These are the physical exam and the medical history-taking forms. These exams can trigger additional tests if 'abnormalities' are suspected. Further testing, laid out in the seven specialized guidebooks provided by the IRCC, can be performed by the same the panel physician who conducted the physical and who recorded the applicant's medical history. In some cases, additional tests by specialists are recommended in the guides. Viewing the first stage of this encounter through the lens of ID, we can see how ID-related impairments are targeted during the physical. This initial exam is followed by more explicit recommendations to screen for ID-related characteristics among a vast cross-section of applicants who may be identified as having physical and other impairments. The prominence of ID within these screening tools suggests that the concept of impaired capacity plays a pivotal role in screening for excessive demand, shaping the experiences of disabled migrants who do not even bear the ID label.

To begin, panel physicians are given instructions to screen for certain conditions during the initial exam and to remain attentive for what the IRCC refers to as impaired intellect and issues related to cognitive development. The importance of pre-screening for these ID-related qualities requires physicians to apply a different degree of emphasis in their search for different 'conditions'. The differential emphasis placed on ID can be seen in the paperwork that needs to be completed for a Medical Report. Within the report, questions 28, 29 and 30 (IRCC, 2013, IMM 5419, p3), draw the panel physician's attention towards an applicant's "Mental and Cognitive State", "Intellectual Ability", and "Developmental Milestones ("for all clients less than 5 years of age"). Comments are allowed on the form, but physicians must select whether the

applicant is ‘normal’ or ‘abnormal’ according to each category. Each of these three questions is associated with at least one specialized guidebook that explicitly invokes ID. The number of guidebooks referencing ID appears to be disproportionate to the emphasis placed on other impairment categories. Furthermore, a close reading of these directives reveals significant overlap between various questions posed throughout the guides, suggesting not only redundancy, but a degree of cultural ‘phobia’ of people with ID that is in line with Goodey’s observations (2016).

Other screening questions on the Medical Report point towards directives that implicitly, though in many cases explicitly, test for ID. As mentioned, there are seven specialized guidebooks that are noteworthy for their clear use of ID-related concepts. This set of seven fits within a broader set of twenty-four specialized guidebooks, referred to as immigration medical exam instructions, that are used for varying categories. These categories are:

Activities of Daily Living Assessment
Assessment of Cognitive Functioning
Body Mass Index
Breast Examination
Developmental Milestones: Chart of Early Childhood Development
Global Assessment of Function
Height/Weight/Head Circumference Percentile for Children
Resettlement Needs Assessment
Serum Creatinine
Urinalysis
Cancer or Malignancy
Cardiac Disease
Cognitive Impairment in Adults
Debilitating Conditions
Developmental Delay in Children
Diabetes
Hearing Impairment or Deafness
Hepatitis/Liver Disease
HIV Screening
Hypertension
Psychiatric Conditions
Renal Disease

Syphilis Screening and Management
Tuberculosis[14]

The seven guidebooks that directly – although not exclusively – reference ID are:

Activities of Daily Living Assessment
Assessment of Cognitive Functioning
Developmental Milestones
Global Assessment of Function
Cognitive Impairment in Adults
Developmental Delay in Children
Debilitating conditions

Guidebooks and medical assessment tools within this collection either specifically focus on screening for ID or directly include ID within testing methods that also screen for other impairment categories. The guides, all written and implemented between 2012 and 2013 with revisions taking place up to 2014, can be situated in the same policy-era as MCSS' introduction of the SIS and launch of Developmental Services Ontario.

Amidst evidence that eligibility for services continues to shape admissibility findings (Bakerlaw, 2009), category-based assessments of migrants that are facilitated by guides and that aim to identify specific impairments are indeed worrisome. Huot et al.'s (2015) study, which found that reshaping assessments of refugees and asylum seekers through the creation of categories led to new designations that conferred the power to act upon subjects, is instructive here. The categorical separation of applicants was done, for example, by detaining certain individuals (p9), while allowing for their rights to be ignored and "justify[ing] surveillance" (p10). Similarly, immigration medical exam instructions enable IRCC officials to classify migrants in ways that can lead to a denial of the rights associated with permanent status. This occurs, for example, by promoting the use of mitigation plans in which migrants may agree to

[14] Appendix IV, List of Immigration Medical Examination Instructions (IMEIs), B – List of IMEIs related to conditions of significance.

abstain from using certain public services in reaction to excessive demand findings, all while triggering modes of surveillance based on their disability and health-related service use. Such categorical thinking in the case of not only asylum seekers and refugees, but also permanent residency applicants, upholds broader designations of legitimate and illegitimate, deserving and undeserving migrants, as suggested by Huot et al. (p2).

This dissertation has argued that an intersectional understanding of ID and the lived experiences of people with ID can further our understanding of how the divisions described above are conceptualized and enacted, as well as the displacing effects they shape. This is nowhere more evident than in the immigration medical exam instructions. It bears repeating that as a symbol of impaired capacity, reduced potential, and dependency, ID occupies the lowest rung on the impairment ladder. Not surprisingly then, under the immigration medical exam, it is a subject-position for which all migrants are tested. Not only do ID-related concepts filter into the guidebooks that inform the many screening tests considered in detail in the sections that follow, but testing for ID becomes a requirement when *any* 'debilitating condition' – whether health or disability-related – is detected (Debilitating Conditions, 2013). Similarly, the additional sets of guidebooks that support screening for ID and ID-related attributes can trigger further testing by specialists.

The seven guides addressed in the next section are also referential in the sense that they often refer to each other, using algorithms to instruct panel physicians to complete screening or assessment tests according to other immigration medical exam instructions. In the following section, we will carefully consider the relationships between these guidebooks and assessment tools. As we will see, the directives can be considered as both screening tools as well as

assessment tools that present a clear scale for organizing perceived medical pathologies through the inter-related concepts of (in)capacity and (under)development.

Overlap and Indeterminacy: Testing for 'Developmental Delay' in Children

As explained earlier, question 30 on the Medical History Form asks about developmental milestones and pertains only to children under five. This question requires panel physicians to consult a specialized guidebook that is coupled with a grading tool, the Chart of Early Childhood Development (Developmental Milestones, 2013). The grading tool refers to milestones up to five years and includes physical as well as cognitive functioning. From an ID perspective, the targeting of children under five presents an important form of screening given that people with ID are currently identified under dominant biomedical models through the chronic nature of their impairment, which must be present at a young age, during the "developmental period" (Tassé, 2013). The Developmental Milestones guide (2013) requires panel physicians to complete a form that includes a chart outlining normative developmental stages for young children and that refers to cognitive as well as physical experiences. The chart includes descriptions of "activities to be observed during the exam" and ones that are to be "related" to the panel physician by parents. These activities cover physical experiences, such as "sits with support" (p3), as well as intellectual experiences, such as "understands a two-step command" (p4), or "knows the days of the week" (p5).

The overall structure of the tool relies on a linear development model based on age and that upholds the possibility of underdevelopment. It is precisely this idea of 'lagging behind' one's chronological age that invokes the concept of ID in testing for *both* physical and cognitive activities. The idea of 'lagging behind' one's actual age is indeed a stereotype of persons with ID and it has been employed to infantilize adults with ID as 'perpetual children'. Within this

discourse, which contrasts chronological with developmental age, people with ID can be described as having a "mental age" that is distinct, and often behind, their actual or physical age (see for example Carlson, 2010a, p23). The application of this stereotype to people with physical impairments suggests that underdevelopment, as framed in the immigration medical exam, is a much broader concept that extends beyond ID and impacts other disabled migrants when they are viewed through this assessment regime. In the case of immigration medical exam screening through the Milestones guide, the stereotype is applied to people with potential cognitive and physical impairments through the notion of 'delayed development'.

The fact that this test for 'underdevelopment' is built into the initial immigration medical exam questionnaire – the Medical Form – is significant because it forefronts the notion of incapacity and underdevelopment in the first encounter between migrants and the physicians who are acting under the IRCC's mandate. Equally important, the Milestones test is closely related to questions 28 and 29 of the Medical Form (2013). Respectively, these questions refer to "Mental and Cognitive State" and "Intellectual Ability". As the similarities between the titles of these categories suggest, it is difficult to tease apart the separate screening tools available for ID and ID-related experiences that are shaped by concerns around incapacity. Questions 28 and 29 are indeed closely related, if not indistinguishable in the absence of clear definitions of the meaning of 'cognitive' and 'intellectual' state from the IRCC. The guidebooks associated with each of these questions also present strong thematic overlap with the Milestones guidebook. And while there are seven immigration medical exam guidebooks that refer to and are informed by notions of intellectual impairment and (in)capacity, including the Milestones guide, the Milestones guidebook, Activities of Daily Living Assessment, Developmental Delay in Children, and

Debilitating Conditions guidebooks are the only ones which address physical experiences. The other three guidebooks are exclusively concerned with cognitive experiences.

The thematic overlap between the many guidebooks that invoke ID-related attributes raises questions around the reasons for replicating these screening tests. There is no clear indication as to why the IRCC has separated these tests since the terminology used throughout the guides is both imprecise and inconsistent. For example, the term "developmental delay" is used in the guidebook for screening children and appears to refer to ID, but this term is not used within a parallel guidebook intended for adult applicants. Instead, this adult guidebook refers to "cognitive impairment in adults". A comparison between the two guides suggests that testing for "developmental delay" carries the same implications as testing for "cognitive impairment", yet the difference in terminology is not clearly accounted for. The overlap between these designations and the general inconsistency around this terminology is ironically consistent with broader definitional trends around ID and the slippery nature of these categories.

The history of ID reveals that this impairment category has always seemed imprecise and has been characterized by a myriad of flexible definitions, as Goodey (2016) has suggested. Just as Goodey promotes a view of disability as a historically contingent category (p2), Carlson (2010a) argues that ID has been "viewed differently in different contexts" (p113). Not surprisingly, as Carlson explains, the criteria for identifying people with ID "have been continually in flux" (p93). Honing in on the role that the concept of intelligence plays in determining this criteria, Goodey (2011) demonstrates that people with ID are always defined in relation to those who are considered to be "intelligent people", such that there is a continuous "social reciprocity" linking these opposing representations (p2).

Given these conceptual and historical relationships, it seems apparent that the differently-named adult-oriented and child-oriented guidebooks employed during the immigration medical screening process occupy a similar position in relation to efforts to identify ID. This is because each guidebook proposes an approach to pre-screening and assessing for ID that is relatively autonomous in the sense that they do not require the completion of an additional form, such as the Milestones chart, the Activities of Daily Living Assessment, or Global Assessment of Function. These two somewhat more autonomous guidebooks are likely intended to permit panel physicians to quickly respond to questions 28 and 29 of the Medical History Form, which then trigger further testing where results indicate an 'abnormality'.

The guidebook for Developmental Delay in Children (2013) is a screening tool that also overlaps with the Milestones guidebook and testing tool. The two guides are connected by the warning to panel physicians, articulated in the Developmental Delay guide, that a finding of 'developmental delay' could indicate a child's inability to reach "normal developmental milestones" (p1). The key difference is that the Developmental Delay guide does not address physical experiences and applies to a much broader age range; the guidebook instructs panel physicians on how to identify developmental delay in all children and not simply those under five. Within this guidebook, the IRCC defines developmental delay as "a significant delay in the process of development" and contrasts this with the possibility of a temporary delay (p1). Once again, the emphasis is placed on the relative permanency of the impairment.

In her study of the history of ID, Carlson (2010a) draws attention to this notion of permanency by outlining how "prototypes" of ID have framed the experience as one that is "static" and that "will never change" (pp141-142). She suggests that this idea of "a static condition" (see p38; p44) is further linked to the belief that people with ID lack potential (pp141-

142). By contrasting temporary developmental issues with the permanent nature of a 'developmental delay', the IRCC screening guide reinforces the belief that people with ID are unlikely to contribute to Canada's development on account of their lack of 'potential' and their own developmental 'challenges'. This negative suggestion speaks directly to the problematic nature of discourses employed in the CIMM report which base the importance of repealing the excessive demand provision on the potential contributions of migrants with disabilities. Examples of ID-related conditions provided in the IRCC guidebook include "cerebral palsy, autism, trisomy 21" (Developmental Delay in Children, 2013, p1). These are all diagnostic labels that either indicate, are conflated with, or are closely related to ID. For example, Trisomy 21 refers to Down's syndrome, which is considered to be an ID, while autism and certain experiences of cerebral palsy often co-exist with ID (APA, 2017).

Other indications that this guidebook is intended to screen for ID include the fact that physicians are instructed to focus on the same performance areas that are set out in the American Association on Intellectual and Developmental Disabilities (AAIDD) definition of ID and which shape SIS-testing. These areas include social, speech and language, behaviour, cognitive and neurological (Developmental Delay in Children, 2013, p1; AAIDD, Definition). There is of course strong overlap between each of these areas, and their disaggregation only reinforces the biopolitical aims of capacity-oriented assessments that employ linear ranking. It is less important to the present discussion that the aims of these tools may differ and may reflect a desire to intervene in order to improve the vital capacity of individuals, to borrow from Rose (2007), or to prevent their membership in the first place. More relevant to my analysis is the fact that in both cases, the overarching focus of the assessment process remains potential normative contributions to Canada's development. These concerns are enacted by measuring an individual's relationship

to certain capacity-related standards. Recalling the excessive demand criteria, the guide for Developmental Delay in Children is geared towards determining whether the individual's 'condition' might improve, whether the person might live 'independently' or require support, and whether special education and other services will be needed (p2). Once again, these characteristics rely on the idea of permanency and dependency, invoking stereotypical notions of ID. If a 'cognitive delay' is suspected, the guidebook explains that specialist testing is required.

Testing for 'Cognitive Impairments' in Adult Applicants

When it comes to screening adults with ID or ID-related conditions, the IRCC provides a separate guide, called the Cognitive Impairment in Adults guide (2014). This guide is intended as a screening tool and does not include its own assessment scale. However, an unfavourable result triggers the use of three additional guides which do facilitate these more formal assessments (p2). These scale-based guides are the Activities of Daily Living Assessment (2013), Global Assessment of Function (2013), and the Assessment of Cognitive Functioning (2014); their completion is mandatory if an applicant 'fails' the screening test for cognitive impairment. Out of the three tests that are triggered by the screening guide for Cognitive Impairment, the Global Assessment of Function and the Assessment of Cognitive Functioning deal exclusively with intellectual capacity, while the Activities of Daily Living Assessment – much like the Milestones tool – addresses physical experiences. The screening guide for Cognitive Impairment in Adults (2014) tests for "impaired cognitive functioning" (p1). This guidebook, however, bears a confusing title, as the terminology is inconsistent with the two previous guides that refer to incapacity, underdevelopment, and ID in children. Despite this confusion, the guide presents itself as an important stage in the overall immigration medical exam and carries the warning that the condition for which it screens is a high risk: "It is particularly important to screen and

identify clients with cognitive impairment …. "[s]uch conditions may have a significant impact on Canadian medical and social services" (p1).

Due to the perceived importance of screening for "impaired cognitive functioning", the assessment is mandatory for anyone who is aged 75 years and over. Dementia, a condition most often experienced during advanced age, is specifically named as a condition related to impaired cognitive functioning (p1). Here we can detect the influence of ID and the notion of incapacity on another distinct impairment category. But this influence should not be surprising since, in addition to identifying ID, Canadian capacity laws that establish the use of substitute decision-makers and powers of attorney are often applied to individuals with conditions such as dementia and which are generally associated with old age. But unlike ID, these conditions are not viewed as 'congenital' or 'chronic', in the sense that they are neither life-long nor present early on in life during the 'developmental' stage. The same capacity regimes also affect psychiatrized people and impairments that may not necessarily be viewed as 'permanent', untreatable, or related to intelligence and IQ results.

As suggested earlier, conditions often associated with aging and psychiatric experiences have been historically conflated with ID through catch-all terms such as 'feebleminded'. Distinctions between these impairment groups eventually led to segregated forms of confinement, for example, in specialized institutions for people with ID (see for example Brown and Radford, 2015), nursing homes for people with dementia, and psychiatric facilities for people with psychiatric disabilities. Even though the screening guide for cognitive impairment can certainly be applied to people who are not labelled with an ID, such as elderly people at risk of dementia or Alzheimer's and psychiatrized individuals, the centrality of ID as a concept shaping the way in which these different impairment experiences are problematized requires

close attention. Once again, the conceptual position of ID relates to the fact that impaired capacity is more closely associated with this category as a result of its framing as a permanent and profound condition often signified by the assignment of a low IQ rating.

As mentioned, the Cognitive Impairment in Adults screening guide triggers the use of three additional guides that are intended to structure a more formal assessment process informed by specific numerical scales. Under these directives, as with all the guidebooks reviewed so far, screening for the potential for ID-related conditions in the context of the immigration medical exam prohibits the use of an interpreter who is familiar with the applicant. The statement that the interpreter must be "unbiased and has no connection to the client", and the warning that relatives and friends cannot fill this role, is included in all the guidebooks (see, for example, Global Assessment of Function, 2013, p1). The adversarial nature of this statement stems from the risk-oriented mandate of the medical exam, which presumes a degree of fraud and misrepresentation. In practice, restricting an applicant's choice of interpreter means that applicants, including those with IDs, may face disability-related barriers to communication that could support the perception that they likely have a 'cognitive impairment'. This is especially problematic given that individuals with communication disabilities who use communication assistants in ways that might include interpretation may already have trusted individuals with whom they work. It can take time to develop effective communication supports and for disabled people to train assistants to effectively support them. According to Communication Access Canada, assistants who may support people who have "unclear speech, or communicate using a picture, symbol, letter board or a communication device" are "authorized and trusted by the person they assist" and are individuals who "know[] how the person wants them to assist with communication" (CAC). The requirement that an interpreter have "no connection" to the applicant undermines certain forms

of communicative support and is one of the many ways in which immigration medical testing upholds uneven power dynamics and ableist principles. This particular example also further suggests that accessibility and equitable grounds for communication are secondary to the potential threat of fraud. Nevertheless, applicants who fail the screening, regardless of whether this is the result of a communication barrier, will then face the many tests that are triggered by the supposition of a cognitive impairment.

The first of the required tests that we will consider is the Assessment of Cognitive Functioning (2014). This assessment is mandatory for people 75 years and older and anyone with an 'abnormal' finding related to their mental and cognitive state, nervous system, or intellectual ability. It is also recommended for anyone with an ID that affects "their current or future ability to function independently" (p1). The guidebook points out that there are many ways of testing for cognitive functioning and it does not provide its own ranking tool. Instead, the guidebook requests that panel physicians convert their scores "to a scale or 30" (p1). Since it is unclear what this scale of 30 refers to, it is difficult to compare the resulting score to those used by the AAIDD and American Psychological Association (APA) in defining ID, which reference a score of 70-75, or 20-25 per cent below the 100 mark that reflects the centre of the IQ bell curve (see APA, 2017). But even while the guide does not recommend any specific scoring tools, there are indications that the IRCC has in mind a standard IQ test. The fact that the guide includes the warning that physicians must consider contextual factors such as an applicant's educational and cultural background as well as their level of literacy (p1) – all of which are factors that are known to impact perceptions of intelligence – provides some indication that IQ is the assumed measure here. Furthermore, we have seen how there is strong continuity between IQ and newer

measures of ID, with IQ remaining a "dominant, if silent partner" in these assessments (Rapley, 2004, drawing on Greenspan, 1994, p48).

The problematic nature of IQ testing in the context of developmental services has been addressed at length in Chapters Three and Four of this dissertation. The use of the IQ scale during the immigration medical exam carries similar problems related to power dynamics and to subjective forms of displacement potentially resulting from pseudo-scientism. The IRCC's advice to panel physicians to take into consideration contextual factors is indeed a sign that some of these problems have already been recognized. Yet, in addition to this caveat, the guidebook suggests that panel physicians can use "anecdotal information from family members" in determining the raw score they will assign to an applicant. What this means in practice is that evidence directly or indirectly collected without the involvement of the individual whose IQ is being assessed can influence their final score. In this way, the monitoring of an applicant's IQ could potentially be constant throughout the encounters that they and any members of their family have with panel physicians, and even when an applicant is not aware they are being tested. The consequences of this testing are serious: if an applicant scores 25 or below, they (p2) are given a grade of 'B' on their medical exam (p2).

Excessive Knowledge and Additional Numeric Scales: Testing Global and Daily Functioning

In addition to assigning a grade out of 30, panel physicians test for cognitive impairment by employing of the Global Assessment of Function (2013). The Global Assessment of Function outlines how to assess functioning based on a numeric scale and it is a required test if any cognitive 'abnormality' is detected during the medical exam. As the guidebook explains, this assessment tool is strictly concerned with cognitive functioning and does not consider physical

impairments. The Global Assessment of Function may seem redundant given the tests reviewed above which assess for IQ and other ID-related concepts that inform perceptions of (in)capacity. Nevertheless, the Global Assessment of Function's specific purpose is described as supporting the "identification of clients with possible diminished capacity" (p1), relating this impairment to "how well or adaptively clients are meeting various problems-in-life". Given its focus on "problems-in-life", the Global Assessment of Function is more akin to the adaptive functioning tests applied by the AAIDD and APA, while the Assessment of Cognitive Functioning reviewed above provides a closer parallel to IQ testing. However, as my reading of Rapley (2004) suggests, adaptative functioning and IQ testing may not really be all that different and it is possible that IQ has maintained its role in diagnosing ID *despite* the official shift towards adaptive functioning tests. The "silent partner[ship]" (p48) involved in these diagnostic exercises can be seen in the AAIDD and APA's decision to employ both tests when diagnosing ID (APA, 2017; AAIDD, Definition). In the context of the documentary identities created by the IRCC, applying the Global Assessment of Function after an applicant is assigned an 'abnormal' score (i.e. 25 or below) during their cognitive assessment allows for the creation of additional – and potentially excessive – knowledge about their presumed (in)capacity. This enables IRCC officials to more firmly document the potential excessive demand posed by these 'incapable' individuals and ultimately, to justify their exclusion.

Perhaps even more surprising than the additional layers of testing for ID and ID-related characteristics is the mandatory requirement that a Global Assessment of Function must be applied if *any* "debilitating condition" is detected during the medical exam (p2; see Debilitating Conditions). These 'red flag' conditions may include such physical impairments as "multiple sclerosis", "pulmonary diseases", "musculoskeletal disease", and cancer, to name but a few

examples (Debilitating Conditions, 2013, p1). The requirement to screen for these "debilitating conditions" is set out in a separate guidebook (Debilitating Conditions, 2013). Anyone identified in this way is then subject to a capacity test. Through this screening requirement, a much broader category of migrants with disabilities and with health-related conditions can be assessed for ID-related characteristics. Once again, the centrality of ID as a concept that is active in shaping Canada's excessive demand regime is explicit in the way that it serves as a subject-position for which a much larger cohort of applicants can be assessed. The result of such testing is evident in the summative evidence presented through the Global Assessment of Function, which enforces a binary view of an applicant's "functional status". Notably, after completing their examination, physicians are required to fill in the blank in the following sentence: "I have assessed the client's functional status as ___" (p3). In the space provided on the form, a panel physician can enter the numeric grade that results from the Global Assessment of Function test. Anyone familiar with adaptative function testing in Canadian jurisdictions may find this simplified statement, which uses a single numeric value to suggest (in)capacity, to be severely reductionist in nature.

Taking a closer look at the IRCC's assessment tool shows that the Global Assessment of Function (2013) applies a numeric scale that ranges from 0 to 100. A rating of 0 indicates that the panel physician did not have sufficient information to perform the assessment. The rest of the scale is divided by degrees of 10, with 90 indicating "absent of minimal symptoms" (p3). Throughout the guidebook, there are recurring 'problem characteristics' that are described in varying degrees within each category. Taken together, the central themes of these characteristics relate to inter-personal conflict, risks to safety, a lack of independence, an inability to work or to have friends, an inability to care for oneself, and impaired reasoning. For example, the 10 to 20 range suggests different degrees to which an applicant may pose a danger and physical risk to

themselves and to others, and the degree to which they may require support for self-care and communication. This section uses disparaging phrases such as "persistent inability to maintain personal hygiene" and "gross impairment in communication". The 30 to 50 range references employment issues, ("no job, "unable to work" and "unable to keep job"), as well as inter-personal issues ("no friends"), and different degrees of interpersonal conflict ("is defiant at home"); the same range also outlines different relationships to 'reason', with descriptions such as "influenced by delusions OR serious impairment in communication or judgment" and "severe obsessional rituals"; the next grouping continues the theme of interpersonal and work-related concerns, indicating "flat affect" and "conflicts with co-workers" (p3). To obtain a mark of 60, an applicant would present with "moderate" symptoms, and would thus be expected to have a job and to socialize. The 70 to 90 range appears even more normative, with 70 indicating "meaningful interpersonal relations", 80 indicating symptoms as "transient", and even 'normal' reactions to certain life events; 90 is described as "generally satisfied with life" among other indicators of 'well-adjustment' that the authors of the guidebook draw upon (p3).

All of these disaggregated characteristics or 'symptoms', to use the language of the tool, are intended to assist panel physicians in filing a report that would inform a medical officer's assessment of a potential excessive demand. Since excessive demand is based on the use of health and social services, the assessment results that influence this determination involve a needs-based view of migrants with disabilities that aims to document their potential service-use. In light of this aim, we can question whether IRCC assessment guides that resemble adaptive functioning tests, such as the Activities of Daily Living Assessment (2013), are really all that different from the SIS, with its stated aim to support people with ID in accessing resources. The purpose of IRCC assessment tools are of course dramatically different from the SIS, given their

explicit mandate to identify and rank potential 'burdens' to public services and to spare Canadians the associated costs. Furthermore, while the SIS and the many IRCC tools reviewed above all tend to assign a numeric score, the SIS is much more comprehensive than the single-paged Global Assessment of Function and similarly condensed assessment guides. There is nevertheless strong overlap between some of the methods employed as well as the categories for which individuals are being assessed.

In the case of the SIS and many of the immigration medical exam instructions discussed so far, assessments are oriented towards a numeric scoring system based on capacity-related categories that are considered important to daily living and to normative assimilationist expectations. Score results help position an individual's potential needs on a linear scale, inadvertently supporting a hierarchy of impairment by facilitating the perception that they have 'high or low needs' or present 'excessive or minimal needs'. In the case of both the Global Assessment of Function and the SIS, the possibility of representing a holistic view of an individual's identity may be limited by the pre-defined categories outlined on the assessment forms and related challenges involved in bringing these categories into dialogue, treating them as interactional, and with the degree of contextual nuance suggested in comments by Bill (see Chapter Four). These potential shortcomings remain in place regardless of the complexity of the assessment form and regardless of whether the tool presents the assessor with ten or a thousand different options.

Interestingly, and recalling Artiles, Dorn and Bal's (2016) interpretation of the concept of "policy assemblages", which draws on Ureta (2014), the Global Assessment of Function reflects a linear assessment model even while it suggests a degree of recognition of the social model of disability with its emphasis on disabling environments. The Global Assessment of Function

(2013) includes the disclaimer that the tools is "not used to assess impairment in functioning due to physical (or environmental) limitations" (p1). Yet the IRCC's statement about physical impairments could generate significant confusion, because it remains unclear why the many indicators of 'abnormality' outlined on the form are also not viewed in relation to environmental factors. One possible explanation for this contradiction is that a relational or environmental view of ID and related impairment experiences would undermine the legitimacy of the assessment, challenging the deterministic view that necessitates such screening in the first place. The co-existence of an environmental and relational view of disability influenced by the social model alongside the biomedical screening mandate and methods that shape these assessment tools generates significant tension within IRCC materials.

The nod towards the notion of disabling environments is even more confusing when we consider the Activities of Daily Living Assessment tool (2013), which invites panel physicians to rank the functioning of applicants with a range of impairments and health-related conditions, including cognitive and physical, across "daily living areas" (p1). However, there is no mention in this assessment guide of social interactions that might produce barriers or impact 'performance'. In the Activities of Daily Living Assessment, ID-related characteristics such as "comprehension" are assessed alongside physical experiences such as "mobility". Possible outcomes for each category differ, but they all refer to four possible levels that an individual can attain. These levels range from "Full" to "Null" and "Yes, with ease" to "No, totally dependent". The options available to panel physicians within this guide are consistent with the logic that shapes the screening tools considered earlier on in this section. The guiding logic is one which reveals how biopower is mobilized through its ability to categorize and differentiate individuals based on the perceived severity of their dependency and their related (in)capacity.

Assessing individuals based on such performance indicators is also consistent with the taxonomic history of ID. Carlson (2010a), for example, has identified how people with ID have been distinguished from the rest of the population as well from each other through "subdivisions" within the general category of 'deficiency'. These "subdivisions" are structured by hierarchies that rank and order individuals according to a criteria often "divided by severity" (p113). In much the same way, the guidebooks created by the IRCC enable panel physicians and IRCC medical officers to assess the imagined level of risk posed by an applicant from a development perspective that relates to normative social and economic goals. This is done by viewing applicants through disaggregated categories that are reflective of various hierarchies of incapacity and dependency, supporting the creation of medicalized documentary identities that are ordered around these ID-related concepts. Importantly, these identities suggest the 'development potential' of an individual in relation to the dominant needs, desires, and values of Canadian society and its related development goals. And while many groups of disabled migrants and migrants with health-related conditions are exposed to these testing methods, it also appears that the guides and assessment tools draw upon prototypical views of people with ID. In direct and indirect ways, then, IRCC directives enable panel physicians to screen for ID and ID-related attributes.

Documentary Identities and Conflicting Disability Realities

The medical assessment tools and screening guides related to the immigration medical exam suggest that people with ID remain one of the least desired classes of migrants. IRCC policy directives position these applicants as being less capable and more disabled, presenting 'less potential' in relation to Canada's socio-economic development. The practice of ranking applicants according to the perceived severity of their incapacity and underdevelopment is

however a natural outcome of a system that has absorbed a widespread cultural phobia of ID (Goodey, 2016) and of more 'severely disabled' individuals. In fact, during the CIMM review (2017), IRCC officials testified that assessments by medical officers consider "the severity of the illness and the degree of service that would be required to treat it" (p13). For this reason, during the immigration medical exam, additional tests are ordered depending on the perceived severity or complexity of an applicant's 'condition'. As mentioned, the decision to order further testing can be based on algorithms provided in the guidebooks.

Additional testing in cases where 'severe' disability is suspected creates many hardships for applicants, partly because of the time and energy this requires. Evidence shared in the CIMM report by two witnesses, both of whom are applicants for permanent residency and one of whom is a migrant worker, describe how the IRCC required their disabled relatives to undergo "numerous medical evaluations" (p37) and "years of repeated medical testing" (p38). The report's conclusion that, "medical assessment impose hardships on applicants because they can often take too long" (CIMM, p38), also echoes the stories that many participants in this study have shared. These participants detail some of the effects of exhaustive medical tests being requested. As Chapter Seven will discuss, their experiences can also be viewed through the lens of subjective displacement as well as through related forms of spatial displacement that result from (the possibility of) an excessive demand finding.

Much like the SIS and other assessment tools, the many guidebooks and forms that are structured through the immigration medical exam rely on the division of disability realities into discrete and measurable entities. The IRR organizes these disaggregated qualities into separate guidebooks so that they may be interpreted, ranked, and linked to differing tiers of risk. The disconnected nature of this assessment process makes it difficult to accept that a complete view

is being taken of an applicant who undergoes the immigration medical exam. Experiences of subjective displacement are an important consequence of the incongruencies that can result from the generation of false or disputed knowledge through this identity-forming process. The conflicts that arise between medical exam findings and the lived experiences of migrants with disabilities will be addressed in the next chapter, where an analysis of interview results will touch upon the suggestion, derived from evidence provided by Bakerlaw (2009, p17), that an applicant's view of their or their relative's disability does not necessarily match those produced through IRCC assessments. The theme of overlooking and misrepresenting the disability reality of an applicant is also presented in the CIMM report (CIMM, p32), and a closer look at this systematized practice is certainly overdue. Before turning to these lived experiences, a clearer description of excessive demand decision-making is required.

As suggested earlier, panel physicians share findings from medical exams with medical officers and eventually, with visa officers. In this way, information generated through exams directly inform assessments of the costs that are imagined to be associated with an individual's documented disability identity. From start to finish, as this chapter has shown, the assessment process involves layers of decision-making that include discretionary authority as well as the automatic and algorithmic channelling of applicants through various forms of scrutiny and associated assessment guides. Within this system, medicalized knowledge organizes the ways in which disability identities are presented in IRCC reporting, ultimately shaping whether applications will be accepted or denied on excessive demand grounds. The higher the imagined risk associated with an applicant's medicalized identity, the heavier the testing and the level of scrutiny applied. The final excessive demand assessment further stratifies migrants not only through the granting or denial of entry, but through the conditions imposed, both formally and

informally, which allow differing forms of access to rights and opportunities to be present within Canada.

The CIMM report also points out that excessive demand creates "two classes of permanent residents" within Canada: newcomers who can access public services and those who must agree (via mitigation plans) that they will not access certain services (p34). Up until 2018, the process for interpreting immigration medical exam results upheld a similar ordering system based on the logic of risk measured through what this dissertation has described as a capacity and development framework. Under this logic, a single medical office in Canada was dedicated to the assessment of medical exam results related to "complicated cases" (pp9-10). However, the IRCC recently announced that it would move towards a centralized approach to assessing excessive demand cases to improve "consistency" (Government Response, 2018). Indeed, challenges to the excessive demand regime articulated in the CIMM report (2017) point to both the inconsistent and unfair nature of decision-making in this area. This relates not only to faulty views of disability, but also to faulty evaluative processes. Witnesses pointed out that the comparisons being drawn around average and excessive service use are not in fact valid, given that the average costs identified did not even account for factors such as age (p32). Put another way, the current evaluative process is neither scientific nor objective. Additionally, the Canadian Bar Association suggested that "guidance" currently provided to medical and visa officers was insufficient, pointing out that assessments were too often missing information around "financial information" (p30).

The IRCC's response to such critiques has been to promise improvements through a refinement of its classificatory systems and assessment processes which, to date, have coupled automation and algorithms with discretionary authority. We have seen how a standardized

methodology paired with an interest in fairness and consistency, has justified the introduction of the SIS in Ontario (see Chapter Four). At the federal level, immigration medical testing already participates in this trend towards standardization in many ways, not least of which includes the multi-layered and category-based immigration medical exam. Research suggests that Canadian immigration practice is in fact becoming increasingly oriented towards the supposedly objective goals that result from such scientific methods. While objectivity is assumed to be linked to more 'scientific' (as opposed to discretionary) forms of decision-making, such pretenses can simply mask discretionary power, as a recent report by Molnar and Gil (2018) suggests (p10). The position of ID within this system is fundamental to understanding how many forms of discrimination operate and how they organize value judgments by invoking hierarchies of (in)capacity.

The characteristics targeted through the testing methods reviewed in this chapter are numerous and yet they are linked through their relationship to (under)development and a governmentality of (in)capacity. Indeed, the goal of the many labels, categories, and tests created through IRCC operating tools and directives can be viewed through the concept of "biovalue", which draws upon the notion of vital capacity – invoking, once again, Rose's (2007) terminology. As my previous analysis of Rose (2007) suggests, modern medicine is development-oriented and aims to act upon and ultimately enhance capacity. In immigration policy, there is a marked interested in evaluating applicants with the goal of extracting this form of biovalue. This is done through linear assessments and points-based systems that in a very general way, aim to predict whether an individual might pose an excessive demand on public resources as a result of their medical or disability-related needs – read as their lack of biovalue. In practice, such assessments are made through the use of biopolitical tools that rely on

categories of questions and forms which disaggregate, identify, and rate biovalue by deciphering the "vitality" of an applicant through various contexts and stages of their life. As Rose (2007) explains, "vitality is decomposed into a series of distinct and discrete objects – that can be isolated, delimited, stores, accumulated, mobilized, and exchanged, accorded a discrete value, traded across time, space, species, contexts, enterprises – in the service of many distinct objectives" (p7). A close corollary to vitality, biovalue must be disaggregated ("decomposed") in order to be assessed and processed for potential use. In the context of immigration, medical exam instructions facilitate this process.

Concluding Thoughts

If prediction is about assessing risk, which as Satzewich (2015) has argued, "is also linked to the predicting of behaviour and future actions" (p52), it is equally about predicting an applicant's potential to contribute to Canada's development through an assessment of their individual capacity and related personal development. The fact that predictive thinking provides an important way of interpreting biovalue can be seen in the role played by the future-oriented concept of 'potential' in medical assessments that centre capacity and development. Just as the use of biopolitical technologies such as the SIS can potentially shape subjective experiences of displacement and opportunities for belonging when they are used to predict and restrict possible fields of action through decision-making around resource allocation, immigration medical exams can displace an applicant's understanding of their own potential capacity and development. Even when applicants are excluded through excessive demand findings based on the representation of impairments that are not ID, the concept ID remains influential in structuring the very hierarchies of (in)capacity and (under)development that permit their exclusion. In this way, ID has the potential to influence how a broad range of migrants with disabilities are documented and related

experiences of displacement that are shaped by this assessment process. These conceptual connections place migrants with ID at an even higher risk of exclusion.

In fact, witness accounts shared during the CIMM review (2017) suggest that within the current assessment regime, prediction based on medicalized labels is 'ableist' in the sense that it leads to automatic exclusion for certain disabled people. This is a contested practice and it remains one which the IRCC denies (IRCC to CCD, p1; CIMM, p36). Nevertheless, the inclusion of certain impairment labels in immigration medical exam guides as 'red flags' for panel physicians to observe ought to be contrasted with the IRCC's claim that "no health condition automatically leads to inadmissibility" (IRCC to CCD, p1). As we have seen, the diagnostic labels named in the guides relate to a broad range of impairments and health-related conditions, including autism, Trisomy 21 (Down syndrome), ID, pulmonary conditions, multiple sclerosis, and dementia, to name but a few. The guides also mandate additional testing for ID-related characteristics (such as "abnormal cognitive functioning") in certain contexts, including the very broad context wherein an applicant presents with a condition that is considered "debilitating". Once identified as having a capacity-related impairment, an applicant receives a 'grade B'. Additionally, the qualities outlined in many of the guides explored above stem from ID-related characteristics that draw upon notions of incapacity and underdevelopment. This means that in addition to explicitly screening for intellectual impairment, ID maintains an influence on other forms of assessment that can lead to a 'grade B' finding, raising a 'red flag' that can ultimately lead to closer scrutiny and support an excessive demand determination.

The analysis presented in this chapter has only begun to address the problematic theoretical area of medical screening, which carries practical manifestations in IRCC directives and policy guidelines. The entrenchment of scientific methods, predictive techniques, and

positivist claims to objectivity, harbour many more problems than can be addressed here. The point that bears repeating is that ID serves as an important ordering device in immigration screening, and migrants undergoing the immigration medical exam are frequently tested in relation to this subject-position. The experiences of non-citizenship and displacement shaped by this ID-influenced system of knowledge also relay a profound struggle over the representation of disability identities. The next chapter considers the many forms of displacement related to struggles around some of the key processes and ideologies described throughout this study by turning to the lived experiences described through first-person interviews held with people with ID and migrants with disabilities, as well their families and those who work with them. Over the course of this discussion, it will become clear that the individuals who participated in this study encountered a system of knowledge that is built around a specific vision of the 'other' as incapable and underdeveloped: as 'foreign alien', 'underserving', and even 'sub-human'.

Part IV – Analysis of Participant Narratives and Concluding Discussion

Chapter Seven: Reading Disability Displacement Through Lived Experiences

Introduction

Up until now, this study has largely relied upon a critical analysis of official documents, legislation, and case law to forward a framework for analysing disability displacement in translocal and transnational contexts. Such a framework has helped make sense of the assessment processes that shape non-citizenship for people with ID and disabled migrants, fostering a deeper understanding of how displacement can be experienced within these marginalized communities. Earlier chapters showed that by centring ID as a lens of analysis, we can help account for medicalized assessment processes that draw upon the inter-related concepts of (in)capacity and (under)development. My argument has been that the IRCC and MCSS mobilize similar methods and ideologies in testing for (in)capacity. These similarities help relate the experiences of persons with ID who already hold formal permanent status to those of migrants with disabilities who must apply for this status. While participant narratives have also informed this analysis, they have yet to be fully centred in our discussion of displacement. However, a close analysis of lived experiences is required to truly grasp the interconnections between ID, (in)capacity, (under)development, non-citizenship, and displacement. The goal of this chapter, therefore, is to draw upon experiential knowledge relayed through the interview portion of this study, in order to further the development an analytical lens for studying disability displacement. This lens will help make sense of individual encounters with assessment regimes that shape non-citizenship and displacement.

A Constructivist Grounded Theory Approach to Interviewing

As mentioned in the introduction to this dissertation, the approach taken during the data collection, interview, and analysis stages of the project has been closely informed by Charmaz's (2014) discussion of constructivist grounded theory. This means that rather than postponing the analysis phase until data collection was completed, I conducted these simultaneously and with the goal of developing a fresh analytical framework. As Charmaz explains, constructivist grounded theory is an "iterative, comparative method" that is also "interactive" (p115). The central aim of such an approach is to devise theories that are useable and which will help "make analytic sense of their [participant] meanings and actions" (p132). This goal can be distinguished from research that is more strongly oriented towards causation (p229). So instead of searching for causes, the method I apply emphasizes "action and processes" (p113) and aims to articulate the "tacit meanings" shared by participants (p115). To support the development of a disability displacement framework, this chapter relies on quotations from participants, which are organized and analyzed through processes that have been identified as playing a central role in shaping the inter-related experiences of spatial and subjective displacement. As will be argued below, participant narratives around the Supports Intensity Scale (SIS)™ and immigration medical exam (IME) reinforce the overarching analytical thread of this study by showing how these medicalized assessment processes can support knowledge claims about individual (in)capacity by drawing upon the inter-related concept of (under)development.

Participant Recruitment, Characteristics, and Anonymity

Ethics approval for this research was granted by my governing agency. During the research phase of this project, 18 semi-structured interviews were conducted with 22 adult participants based in rural and urban areas across Ontario. These discussions took place over the

phone or in person in a location that was convenient to participants and that ensured privacy and comfort throughout our discussion. Most discussions lasted approximately one to two hours and all discussions were recorded with the consent of participants. In some cases, individuals chose to be interviewed together in order to support each other and the recruitment process made this option open to all participants. Following each interview, I transcribed the recording, removed identifying information such as names of people and places, and applied the pseudonyms that participants had chosen for themselves.

During the recruitment phase, I circulated posters and made direct calls or sent emails to key organizations and individuals, and benefited from snowball sampling and word of mouth. My involvement with disability communities and organizations also facilitated the recruitment process. Here it should be noted that communities of people with ID and migrants with disabilities are relatively small and that prior connections thus exist between myself and some participants. As mentioned in the introductory chapter to this study, I have an active connection with five of the 22 participants; these connections include one friendship and four active collegial connections; with the remaining 17 participants, I have had either no to minimal prior contact (14 participants), or a prior collegial relationship that has since ended (three participants).

My approach to requesting informed consent from participants was guided by my recognition of different communication methods and preferences so that in addition to the original consent form, alternative approaches were used with the goal of responding to a variety of communication needs. These included the use verbal scripts and clear language and easy-read methods to enhance understanding (see Appendix B for a sample consent form). Easy-read communication is a method that incorporates clear language (also known as plain language) and that uses images to support text and reading comprehension. This method represents an

accommodation that is often geared towards people with ID, although individuals with other communication needs, including differing levels of language fluency, may also benefit from easy-read documents. Recent research shows that this method is indeed popular among ID communities (Buell et al., 2016), with perhaps one of the strongest testaments to this preference being that People First New Zealand, a national organization led by people with ID, continues to promote easy-read communication and provide guidelines and directions related to its development (Office for Disability Issues, 2017).

Throughout the interview process, I also sought to facilitate a more conversational method derived from constructivist grounded theory. This meant that the initial guides I constructed were not strictly followed. Due to the fluid nature of these conversations, not all questions in the guides were asked and many new questions emerged, while the phrasing and style of these questions were often adapted to suit the nature of the conversation as well as an individual's communication needs and their relationship to the issues at hand. Additionally, since data collection and analysis took place simultaneously, interviews were constantly impacted by new insights and research directions. During the interview, participants were reminded that they were in no way obligated to answer questions, that we could stop the interview at any time as well as stop the recording at any time, and take breaks whenever desired. Participants were always asked for permission to start recording and following the interview, they were invited to contact me with any concerns. They were also advised of the possibility of a follow-up interview while being reminded that they could decline this follow-up request.

Care was taken to respect confidentiality and privacy and opportunities were created to discuss any concerns related to potential identification with participants. The deeply marginalized and relatively small size of the communities involved in this study makes the risk

of identification strong. Adding to this concern are the nature of the risks themselves: identification by government agencies, service providers, and service systems that regulate the all-important passports to belonging could impact the ways in which individuals experience these forms of access. Given these risks and the small nature of the sample size derived from the interview process, and in some cases participants' expressed concerns, careful measures were taken to minimize the risk of identification. These include but are not limited to, using general categories such as intellectual or physical disability and refraining from referencing more specific impairment categories or diagnostic labels; not referencing the specific names of people, countries, or the names of cities, towns, and regions within Ontario; not referencing the specific age of participants or those whose stories are discussed; omitting specific dates. While such details are certainly relevant factors, in the interest of preserving anonymity such specific information – including demographic information – is not discussed. A much larger data set would be required to facilitate an analysis of these details without creating the risk of identification.[15]

Additionally, there are other aspects of participants' identities that are not discussed to help preserve their anonymity. Participants identified in a range of ways that are not always acknowledged in this study, including as LGBTQ+2S, as racialized, as women, as members of certain religious and linguistic groups, and through their occupations. An analysis of how these aspects of identity interact with the processes described below is certainly important, but is once again limited by the size of the data set. However, issues of racism in immigration have been an

[15] Demographic data was not systematically or comprehensively collected. This decision was made as part of an effort to facilitate a more comfortable interview experience and was motivated by the belief that avoiding the collection of demographic data might reassure participants that care was being taken to preserve their identities; it was also hoped that avoiding these questions would help minimize the uneven power dynamics that are inherent to the research process by avoiding what might be experienced as closed-ended and direct questions. While certain demographic details could be observed and while some did indeed emerge through other interview questions and discussions, the decision to not present these in a table is primarily driven by a concern for participant anonymity.

explicit focal point throughout this dissertation, and many of these issues were emphasized by different participants. Some participants identified along ethno-racial lines and, in many cases, closer attention was paid to racism in the context of these interviews. While other participants did not discuss race or racism, an analysis that centres views of (in)capacity and (under)development, especially in relation to racialized countries in the Global South, does make reference to these aspects of their identities.

Participant Characteristics

Participants were recruited through two streams of the project, with separate criteria that included lived or professional experiences around ID and around migration and disability. As previously mentioned, interviews followed a semi-structured, constructivist grounded theory method and, rather than applying fixed guides and questions, I aimed to facilitate a more open discussion of participant experiences with developmental services and excessive demand testing. Four participants – Rocky, Bella, Brown, and Eileen – are people labelled with an ID who have experienced SIS assessments; five participants – Green, Elizabeth, Kathleen, Doreen, Sam, and Nielsen – are relatives of people with ID involved in a direct support role. With the exception of Nielsen, all of these participants have experienced a SIS assessment in Ontario. Out of this group, five participants are related and chose to be interviewed together. These include Brown and Green, and Eileen, Kathleen**,** and Elizabeth. Kathleen played a supportive role to Eileen during the interview and she is not quoted directly in the analysis of Eileen's narrative. Most participants who discussed the SIS assessment are white-identified, except for Brown and Green. Brown and Green are women of colour and relatives who moved to Canada from a country based in the Global South; in our conversation, we discussed developmental services as well as the excessive demand provision.

Participants with lived experience around migration and disability include Shiva, Anna, Al, Chester, Rose, Jack, and Alia, as well as Brown and Green. In addition to Brown, who has an ID, Shiva and Alia also identified as persons with disabilities who moved to Canada. Shiva and Alia are not however persons with ID. Shiva is a person of colour from the Global South and Alia, a white woman from the Global North. Among the nine participants with direct experience with excessive demand testing and IMEs, and in addition to Brown and Green, two participants are close relatives who chose to be interviewed together; these are Chester and Rose, who are both white and from the Global North. Chester, Rose, Anna, Al, and Jack each related to the excessive demand regime through the experiences of disabled relatives. In all cases except for Chester and Rose, the immediate relatives of these participants are persons who can be described through the ID label, including through diagnostic labels that are characterized by ID. Among these family applicants, Anna is a white women and relative to a person with an ID who was preparing an application for permanent residency; Al, a relative of a person with ID who belongs to a racialized ethnic group, had received an excessive demand finding; Jack, a person of colour from the Global South, received an excessive demand finding related to a sponsorship application; Alia, a woman with a disability, had also received an excessive demand finding. Shiva had not and neither had Brown. It is also important to qualify this summary by explaining that in most cases, the complete results and trajectories of individual applications for permanent residency are not discussed in any detail in this study. Rather it is the experience of being medically assessed and receiving an excessive demand finding – and not whether this was eventually or even successfully contested – that shapes our focus.

The last participant group includes individuals who work with directly affected people. This group includes Fred, Carebear, Frank, Sean and Anita, who drew upon on their knowledge

of professional and/or community experience with migrants or people with ID. Fred, Carebear and Frank, whose perspectives on the SIS we encountered throughout Chapters Three and Four, will not be considered in this chapter. However, Sean and Anita's insights into excessive demand testing are analyzed below. In addition to working with affected individuals, Sean is a person of colour who came to Canada from a country in the Global South and thus has direct experience with migration. Anita also has lived experience that is relevant to this study.

Analysis of Participant Narratives

The following analysis of participant narratives is organized thematically through a focus on key processes that displace and dehumanize people with ID and migrants with disabilities. This approach is in keeping with the grounded theory methodology described by Charmaz (2014), which highlights processes and actions. Medicalized assessments structured by developmental services and excessive demand screening are addressed in each section of this analysis, as are the inseparable subjective and spatial dimensions of displacement that are suggested by participant narratives. For example, personal narratives suggest how misrepresenting disability realities and individual support needs can result in a denial of opportunities to be 'present' in the community and lead to spatial displacement; these misrepresentations work through objectifying and dehumanizing claims about individual capacity which are subjectively displacing in the sense that they position people with ID and migrants as extreme 'outsiders'.

Despite the deep interrelations between these concepts and processes, to facilitate discussion of specific details and variations across individual experiences, key findings are loosely organized under a series of self-descriptive sub-headings. These headings include, Mobilizing the concept of ID during medicalized assessments; 'Being put away' and leaving

them behind: Relocation, (trans)institutionalization, and family separation; Struggling for access: Mis-representations, precarious presences and conspicuous absences; 'A torturous journey': Dehumanizing processes and the administration of the SIS and IME; and 'Not a worthy Canadian': Resisting current approaches to measuring human value and proposing alternatives. As the titles suggest, each of these sections contributes to a much broader understanding of the ways in which the concept of ID is mobilized throughout assessment processes. Importantly, these are medicalized processes that shape disabled people's realities by forwarding claims about support needs that are assessed through the concept of (in)capacity and in relation to normative understanding of linear development. As has been argued throughout this dissertation, medicalized assessment processes generate representational claims that can clash with disabled people's realities, their self-understanding, and their lived experiences. In turn, medicalized claims risk not only misrepresenting individuals, but can participate in processes that organize their present and future possibilities. For example, assessments that are experienced as dehumanizing and painful can result in forced isolation, segregation, and family separation. Such risks emerge through an analysis of the lived realities of spatial and subjective forms of displacement among migrants with disabilities and people with ID. The layered nature of these individual experiences gives rise to noticeable overlap between the thematic sub-sections that comprise this analysis as well as the translocal and transnational processes they invoke. The common threads articulated through the sub-themes closely revolve around the concept of (in)capacity, ID, and sub-human status, which we will now consider.

Mobilizing the concept of ID during medicalized assessments

Participant narratives related to disability and migration and experiences with developmental services in Ontario revolve around an intimate understanding of the role that

perceptions of (in)capacity play in shaping decision-making, non-citizenship, and displacement. This shared understanding of the role of (in)capacity was often expressed in relation to hierarchical assessment results, with many participants drawing direct connections between (in)capacity and notions of (under)development. It is worth noting that not all participants in this study have lived experience with ID, since recruitment criteria included migrants with a range of impairment categories, their relatives, and others who work with migrants with disabilities. Yet everyone who discussed the excessive demand provision invoked the concept of ID in their description of displacing processes and experiences. This strengthens the argument, forwarded in earlier chapters, that excessive demand testing revolves around assumptions of (in)capacity that are closely connected to the idea of intellectual impairment in addition to the inter-related concept of (under)development. Also in keeping with previous chapters, several participants framed these connections through an intersectional lens that draws upon the co-constituted nature of race and ID. This section addresses the intersectional framing of ID while highlighting the many other ways in which participants foregrounded ID in narratives of displacement and non-citizenship, setting the stage for a more focused look at these experiences. Throughout this discussion, we will also encounter complex relationships to capacity hierarchies that include resistance as well as acceptance, and in some cases, both.

Anita, a woman who has worked with migrants and who was asked about migrants with disabilities in general explained that many of the women she meets who face the threat of excessive demand have children with "developmental delays". This was also true for Sean's experience working with migrants. Sean was not specifically asked about ID during our discussion, but his comments centred this impairment category. As a racialized man who came to Canada from a country based in the Global South, Sean drew upon his knowledge of racial

profiling to critique how the IME visually identifies people with ID. He explained, “It’s discrimination that starts at the level of identifying with visible signs. You look at a person and say, ‘Oh I think they have an ID’. It’s just like targeting, like racial profiling, but this is medical profiling or disability profiling”. He continued, “they ask families to explain what your child is”. Shiva, a disabled person of colour who came to Canada from the Global South, centred the concept of ID while explaining his own ability to gain citizenship, stating that he has “a pretty good brain”. When providing more detail around the role that excessive demand screening plays in measuring contributions, Shiva invoked the idea of intelligence once again. He explained, “what I really think it [excessive demand screening] comes down to some of those value judgments around ability to contribute and participation”. Shiva provided the example of someone he knows who seems likely to get accepted because “she’s smart, she’s talented, and she’s got great academic scores”.

As previously mentioned, many of the migrants interviewed, such as Al, Anna, Green, and Jack, have some connection to ID through a relative. Chester and Rose, however, described their relative as a person with a physical disability. In all cases, however, relatives described their encounters with the IME through a direct connection between medicalized notions of (in)capacity and what this means in terms of possibilities for (non)citizenship and (non)presence in Canada. Importantly, the risk of spatial displacement and family separation is centred in most of these narratives. For example, Rose, whose relative has physical impairments, addressed particular forms of medical testing directed at her relative. Even though her relative does not have an ID, she described the imposed obligation to ‘prove’ that individual’s intelligence and the implications this carried in terms of where they would be allowed to live: “it’s like constant, trying to prove what [relative] knows. And then you know it’s bigger, because how it’s deciding

where you're going to live and whether you're accepted here". For Al, who identified as a member of an ethnic group that is often racialized, it was the psychiatric test that provided the determining evidence in an excessive demand finding against his relative. Al explained that while his relative with an ID passed initial medical tests, the panel physician searched until they found evidence of an excessive demand. Firmly placing psychometric testing at the forefront of excessive demand decision-making, Al stated that this was "the only exam that had an impact on the final decision". Recalling the algorithmic guidebooks described in Chapter Six, he explained that during the tests his relative was subjected to, "they [panel physicians] used different numbers from 1-10, can [relative] talk, 1-10, can [relative] understand these sentences, from 1-10, it was a long list of questions, from 1-10, can [relative] walk up the stairs, whatever".

Jack, who moved from the Global South and whose relative with an ID received an excessive demand finding, went so far as to claim that capacity is more important than any specific impairment identity or experience. His comments suggest that it is an individual's placement along a spectrum of (in)capacity, rather than the nature of their disability, that matters most during the IME. As Jack explained, "Immigration Canada is actually not interested in knowing about the kind of disability of [relative]"; instead the IRCC looks at "a list of 10 points" and issues tests that determine "if a person is mentally sane or not". This insight reinforces the claim that it is the hierarchical ordering of capacity and development that shapes decision-making through the IME. As Chapters Five and Six argue, this hierarchical ordering draws closely upon the concept of ID for its justification. As Shiva aptly stated, "the question [of acceptance] becomes where on the spectrum of severity of disability".

Both Al and Shiva drew links between ID, capacity, race, and ethnicity, applying a more intersectional framing of these connections than Sean. Importantly, Al added that his relative's

capacity was being assessed under circumstances that were unfair due to ethno-cultural, linguistic, and disability-related differences. He stated that as "an immigrant", his relative was "shy and not answering". This means, "it's very difficult to assess in a few hours or days what [relative's] capacities are, or what [relative's] deficiencies are". In addition to these barriers, Al explained that his relative "was alone with an unknown stranger". In describing the placement process, Al shared a detailed image of uneven testing scenarios that recall the many problems with IQ and adaptive function testing discussed in detail in Chapters Three and Four, along with troubled dynamics previously noted by Rapley (2004). Al also pointed to the importance of cultural and ethno-racial differences in the power dynamics shaping assessments for ID, reinforcing Chen's (2016) account of the co-constituted nature of race and ID.

Shiva drew my attention to similar problems, observing differences between how disability is experienced in the Global South and the Global North. He explained, "If you come from a part of the world that's not North America, then your lived experience with disability is going to be more significant than it is here. So for most disabilities here that would be considered moderate or mild or severe, but where you come from those disabilities could well be significantly impactful". In this quote, Shiva is suggesting that an individual's placement on an impairment hierarchy is impacted by racialized forms of privilege and forms of access to supports and services that are affected by their location in either the Global North or Global South. We will return to these issues of cultural representations of disability and specifically, to the contested representations of ID and incapacity and related experiences of subjective displacement later on.

The important role that capacity hierarchies play in structuring access to developmental services in Ontario may seem more obvious than in the context of migration. However,

participants' relationships to these capacity hierarchies are complex regardless of whether they are seeking services as citizens or applying for permanent status as migrants. While nearly all participants were critical of the rating scales they encountered during the IME and SIS, some invoked these scales to advocate for their own inclusion. In the case of Brown, a racialized woman with an ID who migrated from a country in the Global South, narratives shared by her and her relative Green emphasized that Brown's 'borderline' ID status and ability to work is what allowed her to obtain Canadian citizenship. In Brown's case, medicalized perceptions of her 'borderline' ID status and recognition of her ability to work were key to her ability to move to Canada. Green credited the support of a physician, who supported Brown's identity as a working person during the application process: "he said, I know, Brown will do it in Canada […] I know she will do well... I know what I have to do." Conversely Anna, a migrant woman seeking permanent residency with a relative with an ID, is critical of the hierarchical ordering of applicants. She complained that "clearly there's a perception that people with disabilities are worse". Yet at the same time, and similar to Green, Brown, and several other participants, Anna positioned her relative along a linear scale by expressing a desire for local disability services that can help enhance their capacity. Anna explained that "I want my [relative] to have a job and be as independent as possible. That's why we're working hard on [relative's skills] and other things".

As this dissertation has argued, (in)capacity hierarchies are also active in shaping translocal realities through Ontario's developmental services systems. Elizabeth, who was interviewed along with her relative Eileen, a woman who is labelled with an ID, explicitly characterized the SIS as a form of capacity testing. She suggested that the tool presents a limited portrait of people with ID and pointed to significant oversights in terms of its ability to reflect all

aspects of a person. She stated, “I have a feeling this measures how high functioning you are and what you’re capable of doing, but there’s a whole other perspective on your capacity, your psychological state, how you feel about yourself”. Throughout our discussion, Elizabeth promoted an alternative understanding of capacity, arguing that the SIS does not fully reflect an individual’s needs. Her critique recalls Al’s discussion of psychometric testing within immigration medical screening as inaccurate due to ethno-cultural, linguistic, disability, and other aspects of identity that are not accounted for by the test. As we will see in the next section, most participants relayed a similar view of the SIS and IME and felt that these represented problematic approaches to assessment. For some participants with ID and their relatives, personal narratives also revolved around how SIS results incorrectly framed their (in)capacity. For these participants as well as for those with lived experience with disability and migration, inaccuracies resulting from capacity-related assessments directly influenced decisions that shaped forms of spatial displacement and non-citizenship, including institutionalization, family separation, and segregation. At the same time, participants regularly contested and negotiated SIS and IME assessment claims and the related process of identity construction.

‘Being put away’ and leaving them behind: Relocation, institutionalization, and family separation

The narratives reviewed so far suggest that participants are aware of medicalized assessment processes that revolve around (in)capacity and the position of people with disabilities within these hierarchies, even while some may employ these hierarchies to their own benefit. In this section, we consider in more detail how IRCC and MCSS decision-making practices draw upon the representational power of the SIS and the IME through a shared reliance on linear scales of (in)capacity. We will see that they do so in ways that not only parallel, but that can

shape spatial displacement and non-citizenship through mutually reinforcing relationships to subjective displacement. As this dissertation has argued, spatial forms of displacement, which are translocal and transnational in nature and can include deportation and institutionalization, are often coerced and inseparable from subjective displacement. Drawing on Bakewell's (2011) displacement framework and my previous work with El-Lahib (in press), these chapters have argued that subjective displacement involves institutionally structured modes that support a sense of "being out of place" (Bakewell, 2011, p23), and threats to individual agency. This model allows us to consider translocal forms of displacement experienced by people with ID and which are based on their precarious position and perception as 'species outsiders' who lack decision-making power. These inter-related modes of spatial and subjective displacement encompass concerns shared by nearly all participants with ID and their relatives. Notably, they also touch upon forced confinement, segregation, forced isolation in one's home, and the threat of 'removal' from one's home. While the first section of this analysis is concerned with narratives of spatial displacement and relationships to home and belonging among people with ID – much in keeping with my earlier work with El-Lahib (in press) – subjective dimensions of displacement are nevertheless present. In fact, participants draw our attention to these subjective dimensions by directly invoking assessment processes that misrepresent their own or their relative's disability reality – particularly their (in)capacity – and by explaining how these misrepresentations shape their present and future possibilities and actions.

Participants who are relatives of people with ID discussed the DSO evaluative process through a hierarchy of (in)capacity. All participants, including Sam, Elizabeth, Doreen, Nielsen, Bella and Rocky, linked the threat or experience of spatial displacement to some perception of (in)capacity. Several participants faulted SIS results for mis-representing their reality or the

reality of their relative, and the system for failing to respond to their urgent needs. These participants linked these representational failures to forced dislocation, as Eileen's story helps demonstrate. Eileen, a white woman with an ID whose relative Elizabeth described her as having 'high needs', expressed a desire to stay in her own home. She stated this as her top priority. During the same interview, Elizabeth added that Eileen's ability to remain in her home and avoid institutionalization is a challenge due to the lack of funding available to provide for Eileen's 'high needs'. Elizabeth related this lack of funding to both the developmental services system's inability to recognize Eileen's needs through the SIS assessment as well as to the limits imposed on Passport funding levels. In Elizabeth's words, "the DSO evaluates her needs and then the SIS says, these are her needs. But the programs themselves are maxed out at $30, 000." She explained, "it's [amount] for her to be independent." Discussing a SIS assessment, Elizabeth explained that the results showed that Eileen "was getting all the support she needed". She then contrasted the inadequacy of MCSS funding for people labelled with ID with funding for people with physical impairments and/or disabilities, suggesting how a hierarchy of capacity as well as a hierarchy of impairment shapes access to supports: "they were shocked when I told them someone in Independent Living gets $60000 a year. $60000." People with ID "Half that. $350000. Most people get ten."

Elizabeth's critique reveals how the threat of spatial displacement relates to the position of people with ID within an impairment hierarchy. This positioning can leave individuals with fewer supports for non-institutional forms of living. In Eileen's case, SIS results apparently failed to reflect her support needs and provide evidence to help her obtain much-needed funding. Further discussion with Elizabeth centred the importance of the MCSS system in structuring the

constant threat of displacement. She pointed out SIPDDA's failure to provide alternatives to group homes and home shares.

Other participants, such as Doreen, described the threat of institutionalization for people with ID and the harm this can generate. Doreen explained that "lumping them together in group homes" limits the ability of people with ID to live and to learn. A participant named Sam was equally critical of group homes and home shares as dominant housing options. The experience of Sam and his relative Robin, a white woman with an ID, links the threat of spatial displacement more directly to a view of the SIS as a form of capacity assessment, the results of which have the potential to inform decisions that could displace individuals into institutional settings. Sam explained that Robin was at risk of homelessness and was awaiting a SIS assessment and funding for supported living. According to Sam, the SIS results created a barrier to this goal because they reflected a lower view of Robin's capacity. While Robin was not previously considered by the family to have 'high needs', the SIS results presented this claim. According to Sam, the most troubling effect of the assessment was a statement in the DSO assessor's report that Robin wanted a placement in a group home. However, Sam stated they had had "never requested those things" and as a result, had to fight the assessment results. He linked this false assumption on the part of the assessor to the perception of Robin's incapacity, suggesting that the assessor had overlooked Robin's preference for other housing options: "they had not imagined that someone her level of need [sic] of support would even consider moving out".

As several participants explained, MCSS provides few housing options for people with ID aside from institutionalized living in group homes or home shares. In practice, this means that the very process of being labelled with an ID carries a risk of spatial displacement. Rocky, a white man labelled with an ID, linked this impairment category with the perception of being

"stupid". His narrative is critical of the role of labelling within the MCSS-managed system. He stated that people with ID are "automatically labelled when they go through an agency". Rocky was equally critical of the SIS and explained that the assessment is simply a process that labels you: "so again they're labelling you. Whether you're a "four" of whatever." Rocky further connected the experience of being labelled to being 'put away', describing individuals with ID who had been spatially displaced and who "haven't even met their families in years, because they were put in group homes or institutions". Family separation and families who "have just given up" were an important part of Rocky's narrative, suggesting how the ID label and a lower placement on a hierarchy of capacity can lead to family separation and institutionalization.

Similarly, Elizabeth talked about people leaving their relatives "on the doorstep" and linked this to systemic problems within the MCSS system. In response to Eileen's support needs, the DSO had recommended that Eileen be placed elsewhere. Elizabeth resisted this solution, framing it as a form of family separation, stating "I'm not giving her over to someone else". In this example, the threat of Eileen losing her home and family and becoming institutionalized was linked to the system's inability to recognize and respond to her needs. In another example of family separation, Neilson described how her relative Allan, a white man with an ID, has 'high needs' which meant that he 'couldn't stay at home'. There were only a few places where Allan could live and Neilson wished he was closer so she could see him more often. In this example, forced spatial separation is directly related to an interpretation and rating of Allan's disability supports needs as 'high'. Equally important are perceptions about his ability to 'fit' within a limited number of existing housing options that correspond to this interpretation of his needs.

The impact of medicalized assessments is also conveyed by Brown and Green's fear that Brown's high capacity rating could result in her losing support once Green is unable to continue

in her unpaid support role. These concerns suggest that Brown's DSO assessment reflected a level of capacity that did not match her actual needs; it further suggests that capacity ratings – even when they are favourable – can carry displacing effects by putting individuals at risk of losing certain supports. Green explained that Brown is "at the bottom of the list" for housing supports, yet according to her own description, Brown does require some form of support. In this case, Brown's assessment results and high ranking work against her, once again suggesting a potentially inaccurate or incomplete reflection of individual needs. For example, while Brown is officially considered to have minimal needs, Green also described performing unpaid support work on her behalf. Green explained, "She is very independent, but she still needs some support. I am like the home support, doing all the stuff for her". Brown and Green's narratives further suggest that Green's decision to live with her relative is tied to the reality of poverty among people with ID and a desire to avoid an institutionalized setting; this was suggested by Green's fear that many people with ID are forced into poverty unless they have family support. She explained that "as the person lives in the house, that will be okay". She also mentioned the work she had done to ensure Brown could remain in her own apartment after she passes away, since "I know she will never be eligible for housing on her own". Green explained, "she's always lived like this, so she can't live in some – just any place." These statements suggest that Green is likely aware that there are few options for direct funding for "housing on her own", and that she feels that dominant models of supported housing are simply not suitable for her relative Brown.

As Brown and Eileen's experiences suggest, narratives shared by people with ID and their relatives include forms of family separation and spatial displacement related to capacity assessments. A comparison of these narratives with those shared by migrants show that the IME can shape similar risks. Migrant participants specifically linked efforts to regulate their mobility

to IME capacity assessments and to IRCC claims about excessive demand. Al explained that after his relative's psychometric test, security and stability were a pressing concern that related to their uncertainty about remaining in Canada. He attributed these effects to capacity testing, which "had a tremendous impact". Unlike Brown, the belief that Al's relative could 'contribute' to Canadian society were not endorsed by any panel physicians who could attest to an ability to work. Instead, Al's relative was labeled as an excessive demand. The excessive demand provision also posed a barrier to Jack when attempting to reunite with his relative who has an ID and is from the Global South. The following statements by Jack suggest how disruptive this spatial separation has been to his family and to their value system: "I have never left [relative] behind" and "our whole purpose to apply for immigration is so that we can live as a united family". According to Jack, the excessive demand provision severely undermines the importance of family reunification. Later on, we will see how his relative's low capacity rating, which resulted from an IME and incorrect assumptions about his support needs, led to an excessive demand finding.

Importantly, the threat of an unfavourable IME result can shape family separation even before an assessment takes place. Anita, for example, discussed how knowledge of the excessive demand provision inspired some settlement workers to advise mothers of children with ID "to exclude that child from their permanent residency application, before they even go through the process to apply for PR [permanent residency]". These children then remain in the Global South while their mothers work in the Global North, sending home remittances. Anita explained that there is a further risk that these women will have to "adopt [their] child out". The threat of adoption and its link to structural perceptions of, and responses to, (in)capacity recalls Elizabeth's reaction when a DSO advised her to place her relative Eileen elsewhere. Anita went

on to state that the separation of mothers and children (of colour) is becoming a reality for many migrant workers: "I have to be honest with you that some people are doing that because they are desperate to be able to provide for their families, to be able to provide for that child". For these women of colour, their migration to Canada and their decision to leave home is part of a broader form of spatial displacement that is tied to colonial processes and that must be kept in mind. As Anita explained, "there is war at home, there is poverty at home, homelands that are being colonized by Western powers and then left deeply impoverished and dependent on remittance economy".

Anita's knowledge of the colonial processes that structure the displaced realities of many migrants is deeply intersectional, once again recalling the co-constitution of race and disability through the concepts of (in)capacity and (under)development. Anita explained that the rejection of disabled migrants through the excessive demand provision stems from the same ideological framing of the notion of 'contributions' that degrades migrant workers. She stated, "if a person is not seeing as contributing to a capitalist economy in a particular way, they are seeing as non-desirable, so I would say that it is in keeping with the way migrant workers are treated in general". In Anita's view, these migrant labour programs are extensions of settler colonial racism and the privileged position of white migrants. In contrast, migrant labour serves as "an extension of slavery", as Anita explains. According to her, "those Black and Brown women … were seen as a resource". In previous chapters, we saw how the dehumanization of migrant people of colour relates to racist perceptions of (under)development and Canada's economic development goals. The experiences of migrants with disabilities and people with ID with medicalized assessment regimes can include subjective forms of displacement that also draw upon dehumanizing development discourses; examples of these processes will be discussed in the final

section of this chapter. First, we will consider how closely-related forms of spatial and embodied manifestations of subjective displacement impact people with ID and migrants with disabilities.

Struggling for access: Mis-representations, precarious presences, and conspicuous absences

The transnational processes that shape spatial displacement for many migrant workers resemble translocal forms of displacement insofar as they present a shared understanding of (in)capacity and (under)development that draws its legitimacy from dehumanizing discourses and ideologies. In the narratives explored below, capacity-related assessments conducted by the DSO, the IRCC, and public sector organizations, suggest how a profound devaluation of people with ID can structure their non-presence. This non-presence includes direct threats to individual lives, being removed from community spaces, and having one's right to be present in the community undermined. At times the devaluation of disabled lives is explicitly discussed by participants through an ID lens, while at other times it is simply in the background. All the examples provided, however, draw upon a recognition of the importance of (in)capacity assessments.

As previously explained, precarious presence and barriers to enacting substantive citizenship are closely connected to disability supports and to assessments related to these supports. In a very material way, inadequate supports carry the risk of death and profound forms of absence. Elizabeth, for example, explained that her relative Eileen needs certain supports to live and that despite their importance, she has had to constantly fight for them. Elizabeth stated, "she's alive because of all this advocacy". Eileen's embodied presence is thus profoundly threatened by the failure to fully recognize and adequately respond to her individualized needs. Similarly, and raising the risk of forced isolation, the lack of adequate disability supports meant that Eileen "was kicked out of" a community-based service. Eileen's precarious position in the

community recalls Anna's narrative about her relative with an ID. Anna suggested that being perceived as having a more profound ID resulted in her relative being denied services that would have allowed them to be present in the community. She described how her relative was denied publicly funded services because they were perceived as having no chance of making progress. This assumption that providing services to her relative was pointless draws upon the idea of 'incurability' and the economy of uselessness (Ferguson, 2004) introduced in previous chapters, which links medicalized capacity assessments to decisions around service provision. Extrapolating from Anna's story, we can see how a service provider had informally assigned her relative the static label of 'incurable' to justify denying them a service.

Reflecting on this experience of service denial and perceived 'incurability', Anna observed close parallels between excessive demand testing and local disability service systems. She explicitly linked the thinking behind the IME to the treatment that her relative experienced as a migrant with an ID living in Ontario. Anna argued that "[t]his law [excessive demand] implies that people don't want to see [relative] as a valuable person just because [relative] has a disability". Expanding on this she explained that she noticed, "the same kind of thinking" in attempting to access community-based and publicly funded services. In some situations, Anna realized that her relative was not welcome due to their support needs – "they told us that we don't want [a person] that needs supports". These structured forms of non-presence are directly linked to perceptions that Anna's relative is not valuable. She shared that their experiences with immigration and publicly funded services "turned into this one big frustration of trying to prove to people that [relative] is valuable and would actually be a great addition to any community […] any group. If people just want to see [relative] for who [they are] and not a label."

Chester and Rose's relative, who has a physical disability, experienced similar challenges when the IRCC sought information about their use of a public service, asking "whether [relative] was taking a space from somebody else. Like whether [relative's] spot […] could be offered to somebody else." The service provider responded and said, "[relative] was not taking up a spot, that there were plenty of spots". Given that this question would not likely have been asked about a migrant without a disability, it relays the struggle around perceptions of people with disabilities and migrants as undeserving of public resources. The answer, "that there were plenty of spots", reveals a different reality than the one imagined by the IRCC, in which the presence of disabled people creates a burden. The response further suggests a view of inclusion in which people with disabilities are not framed as a 'problem'.

The above examples suggest that Anna, Chester, and Rose's relatives, all white migrants with disabilities from the Global North, encountered translocal modes of exclusion based on their perceived incapacity. Further, these preconceived ideas about (in)capacity risked rendering these individuals 'non-present' in ways that closely relate to the excessive demand provision. Indeed, perceptions of people with ID and migrants as devalued outsiders are active in each of these narratives and are based on hierarchical understandings of (in)capacity. Rather than framing these migrants as a "great addition to any community," as Rose characterized her relative, their contribution to the community was at risk of being negated through dominant understandings of the term. These examples further reveal how the construction of the outsider status of these individuals and the associated threat of spatial displacement draw upon subjective forms of displacement that have to do with the devalued identities of migrants with disabilities.

Subjective modes of displacement are inseparable from spatial displacement because they shape the conduct of individuals and their ability to enact citizenship by limiting their future

possibilities to be present. The experience of Alia, a white woman who moved to Canada from the Global North, is instructive here. Alia initially received an excessive demand finding but later obtained status. However, due to her previous experience with excessive demand screening and being labelled 'a burden', she shared that she remains reluctant to access resources related to her disability. She explained, "I would never to say to anyone, oh you're a burden for using these services. But when I have to use it myself, I do, I think that". Alia suggested that she would feel subjectively threatened if she were to access the resources that she knows she is now formally entitled to: "I'm offering them the opportunity to say, yeah we were right, you are a burden." Alia's experience reveals that the impact of excessive demand screening is profound, regardless of whether one holds permanent status or has agreed to a mitigation plan. The threat of Alia being subjectivity reduced to the status of a 'burden' actively limits the actions that she feels are open to her, and this impacts her ability to enact substantive citizenship. Her insights reveal that excessive demand can actively shape non-citizenship in overt ways and regardless of whether spatial displacement occurs.

Similarly, participant narratives demonstrate how the existence of excessive demand screening and the IME structures transnational immobility and shape these forms of non-presence and non-citizenship. These dynamics were relayed by Sean, who is concerned with migrants with disabilities who never apply to migrate to Canada out of fear of the IME. Sean's experience working with migrants led him to argue that due to the excessive demand provision, adults with disabilities may choose not to apply to Canada because "they don't want to be found out and ridiculed by Immigration". Specifically referring to the IME he claimed, "they are terrified" and as a result, "the person then makes the decision whether or not to go through the medial exam and most of them don't. They just abandon the whole process". Sean's explanation

draws together the threat of dehumanization, "being ridiculed", and the stress and fear that excessive demand screening generates.

Discussing the MCSS system and his experience with the DSO, Sam's comments show that structured forms of immobility that enforce 'non-presence' are also active translocally and work through the ID label and developmental services system. The example he provided involves his relative Robin losing certain services when she moved. Participants suggest that access to the supports regulated by MCSS and administered through DSO testing are of paramount importance to avoiding forced immobility and isolation. However, Robin's experience, as relayed by Sam, suggests that immobility is shaped by the loss of access to services and forms of service ineligibility that can result when an individual changes homes. This threat of service loss could in practice discourage people with ID from leaving abusive or unfavourable situations, and it can certainly limit their choices and options for being present.

For Bella, a white woman labeled with an ID who lives on her own, having the right supports in place is directly linked to her ability to be present in the community. Bella shared that once she accessed services, she was able to get "back into the community". Without this support, Bella said, "I was a girl in a room with the lights off, depressed, no friends, nothing." She contrasted being isolated and quite literally left in the dark, with her recent ability to be present in the community and to be mobile, reflecting that "[a]ll the traveling I've done, all that good stuff. It makes me feel good". However, the Passport program also imposes limitations that can prevent individuals from being present. Bella, for example, explained that she was prevented from using this funding in ways that would have allowed her to get out and participate in community life according to her own values. She was critical of these restrictions and stated, "with the Passport I just find that the reasons, that you're not allowed to use the Passport funding

for, I just find that ridiculous. And that things that you really want to use it for, you have to fight for". Bella described, "[l]ots of rules", but focuses on one example where she was prevented from spending Passport dollars the way she preferred and which left her feeling offended and upset. "I found that insulting. And it's just – why do people have Passport funding if they can't use the way they want to use it?"; "I felt really upset and I was really upset." She further suggested that Passport decision-making is arbitrary, providing examples of what it can and cannot be used for. Situated within a narrative that emphasizes struggles over control and recognition of her decision-making ability, Bella's description of Passport funding rules conveys systemic problems within the MCSS-funded system. These include the many barriers that people with ID face in their attempts to enact substantive citizenship and exercise agency.

For Bella, struggles around finding a home and related experiences of spatial displacement were directly related to her disability status and struggle with poverty. Having previously experienced homelessness, she explained that more recently she had been denied housing due to her disability identity. She had also experienced harassment in previous communities. Bella stated that she has "moved around a lot ... And now I'm here. So I've been everywhere". These experiences of displacement can be connected to other parts of Bella's narrative that describe the devalued status of people with ID, including being harassed by people who "make fun of them or pokes at them or stares at them." Bella contrasts this with being seen as "a regular person". She suggested that people with ID are frequently 'being judged' by others. Even though she now has a home, Bella still faces challenges in belonging that relate to obtaining certain supports to participate in the community, as she is often told by support staff that she does not need them.

Throughout our discussion, Bella repeatedly explained that workers in developmental services do not listen to her. Even while these tensions are not directly related to the SIS assessment, Bella's account of the overall refusal of actors within the developmental services system to listen to and respect people with ID parallels her critique of the SIS. We will turn to this critique in the next section, and see how it relates to the risk of mis-recognition and to the struggle over representational control described by Bella. This lack of recognition is closely related to the association between ID and incapacity. The ways in which this connection has shaped Bella's ability to be present in the community indicates recurring power struggles around the representation of disability-related needs. These same representational struggles surface during SIS and IME assessments described by some participants. We will now take a closer look at how these processes are experienced and the contentious practices that are involved in shaping claims about an individual's (in)capacity and (under)development.

'A torturous journey': Dehumanizing processes and the administration of the SIS and IME

Chester's reflections on IME testing bring the connections between capacity assessments and subjective displacement into sharp relief. His framing of the permanent residency application process as a "torturous journey" reveals how the seemingly mundane nature of the medical assessment process masks a much deeper impact. The following quote by Chester shows that it is the very premise upon which the IME is based, "the whole idea of what the medical exam meant", that is so unsettling. He explained, "it's just part of the process, and yet it's what made this such a tortuous journey for us. I mean, not the medical exam we had to do, but what the whole idea of what the medical exam meant for [relative]". In this section, we will consider how the very need for the assessment and the ideological implications this carries are linked to the "torturous journey" that Chester recounted. This analysis builds upon the connections Anna drew

between the IME and the treatment her relative experienced as a migrant with an ID living in Ontario. This kind of thinking, she suggested, has to do with her relative being viewed as "not a valuable member". Her narrative shows that her relative's devaluation is due to a diagnostic process and that their social status would improve "if people just want to see [relative] for who [they are] and not a label".

Comparisons with other participant narratives suggest that the "torturous journey" shaped by the IME resembles the 'horrifying' experience of undergoing a DSO assessment. In the case of the IME and the SIS, the stakes are high. The end goals are access to formal status in one case, and in the other, to the services that enable individuals to enact substantive citizenship. Doreen, for example, described a profound disconnect between her relative's needs and formal recognition of these needs. She explained that the very process of advocating for services for her relative with an ID and explaining these needs was "demeaning". For Doreen, "[i]t was like they were coming from a different world". For this reason, "the whole idea of what the medical exam meant" must be considered through a discussion of non-citizenship and displacement that centres these radical disconnects and experiences of dehumanization. The final section of this chapter focuses on these experiences, taking an in-depth look at the impact of medicalized decision-making on broader conceptions of who counts as human. This section also points to how participants challenged and resisted current approaches to measuring human value and, in many cases, proposed alternatives to the arduous testing scenarios they described.

Interviews suggest that the immediate assessment experience was devastating for most participants and is deserving of much closer attention. This section therefore draws together experiences of dehumanization and subjective displacement, focusing on the painful assessment experiences relayed by participants and the mandatory nature of these tests. In many cases, these

experiences included assessment outcomes that resulted in spatial displacement and non-presence through excessive demand determinations or a lack of provincially-funded developmental services. For most participants, the SIS and the IME involved a significant time commitment and often included several rounds of assessment, coupled with long periods during which they waited for a response from the DSO or IRCC. In the case of the IME, assessments could be carried out over the course of many months while with the SIS, the gaps appeared much shorter and spread over several days. In both cases, however, the results were described as being long in coming. Furthermore, most of the participants who underwent a SIS had not seen any change or impact in terms of their access to supports as a result of having participated in an assessment, and some had not heard back from the DSO at the time of our interview. We will consider these experiential aspects of Ontario's developmental services system and the IME in separate sections.

i) 'It's not any of their business': Experiencing the Supports Intensity Scale

Most participants who took part in developmental services assessments described the SIS as an invasive and lengthy assessment conducted by the DSO. Some explained that while there were few noticeable changes in their access to developmental services following the assessment, the process itself was mandatory. Furthermore, and as discussed above, some participants felt the results of their assessment was inaccurate. We will consider each of these dimensions of the assessment process throughout this section. Above all, it should be noted that the majority of participants felt that the SIS was an uncomfortable and even upsetting experience and shared that the actual testing process was long and arduous. This was especially true for two participants labelled with an ID – Rocky and Bella. Along with other participant narratives, Rocky and Bella's comments demonstrate how people with ID and their families negotiate and often

struggle against the disability identities that are constructed through the SIS. An analysis of these narratives points to power imbalances that are present throughout assessment processes and within the broader service sector. This analysis is equally attentive to the ways in which the SIS potentially positions participants within a hierarchy of (in)capacity and (under)development. In some cases, as we will see below, participants experience this positioning as dehumanizing and their narratives suggest that simply being labelled as having an ID carries this risk. These experiences can be related to the argument that capacity assessments and labels built around the presumed incapacity of an individual support a view of people with ID as species-outsiders who are incapable of exercising agency and self-direction. As previous chapters have explained, drawing on Goodey (2011), the ability to rationally direct one's own life has come to serve as the ultimate characteristic of the human species while an inability to do so has been used to define ID. It is no wonder then that the ID label itself can give rise to experiences of dehumanization.

Rocky explained that being labelled with an ID feels "degrading" and that it's similar to being viewed as "stupid". In his words, "it's degrading because people look at you wrong. So there are really implications to that. And it certainly has really affected my life. To the point where it's like, I'm 'stupid', you know." He suggests that experiencing the SIS is similar to the stigma associated with being labelled with an ID: "And [with the SIS] you're also scaled, so again they're labelling you. Whether you're a "4" of whatever. But how do you define that in how you get support?". Rocky's question around how support is defined and whether the SIS reflects an individual's actual needs recurs throughout his narrative as well as in comments shared by other participants. In fact, part of the problem with the SIS for Rocky relates to the claim that the results represent the needs of people with ID. To this point he stated, "devalued, right. It made me feel like wow, so that part of control of my life is taken away from me."

According to participant insights, the SIS is not only be an uncomfortable and tiring process, it can remove representational power. For this reason, Rocky found it "degrading" and "horrifying". He explained, "their point is so that they have an idea of what supports you need. But you can't define that by the supports. […] It degrades people. You know, I spent [number of] hours and had to take a break, I was exhausted. I came home and I was just like dying. It was horrifying. Horrifying experience and I was exhausted. I had to come home […] because I couldn't function anymore. I mean for me to have to do that, it says a whole lot". In our discussion, Rocky expressed the sense of dread that can result from seeing the SIS as mandatory. He shared his concern for those who must undergo this assessment, explaining "I knew it was eventually going to come to me." He explained, "I just dread people going through it. And I want to turn around and say we'll get through it. But no, no. As someone who has gone through it, not again."

One of the main problems Rocky has with the SIS is that it is invasive: "it invades people's privacy. You're asked about your sexual." The example provided by Rocky refers to assessment questions that are concerned with the sexuality of people with ID. There are several opportunities for such questions to arise during an assessment. For example, according to the SIS-A manual (2015), "safe sex practices" may fall under questions around "learning health and physical education skills" (p41). There are also direct categories related to "inappropriate sexual behavior" listed in the SIS-A form (2015, p3). Such questions would likely fall under what Carebear, a DSO assessor, described as being the "most embarrassing to ask". Expanding on his earlier point about the invasive nature of such questions, Rocky said, "[n]ot only are you having a SIS done, you are telling strangers all about your life and if you don't do it, you don't get the supports. So it's beyond crazy that we even have that". Rocky also addressed how other

individuals who participated in his assessment struggled against him for representational power: "And then [another individual] was answering questions." During the assessment, Rocky shared how this bothered him and stated, "Don't like it; don't like how other people are answering questions". In this instance, Rocky resisted and worked to regain representational control.

Elizabeth addressed similar issues with the representational authority of the tool, pointing to its power to influence decision-making in the developmental services sector. She claimed, "They [DSO staff] don't go out, they use the SIS almost exclusively in terms of decision-making." Much like Rocky, Elizabeth rejected the idea that the DSO assessment actually captures an individual's needs: "They ask the person to profile themselves – what is important to them – so they're very broad, but I don't see anything in here that looks at what happens if those things that are important to her are not there, what is the impact on the person." This comment, which may refer to the SIS and ADSS, reinforces the critique presented in Chapter Four by Fred, a former DSO worker, which claimed that the 'about me' portion of the assessment is superficial.

Elizabeth observed that the SIS simply assesses people for suitability for existing supports, describing an assessment process that revolves around service provider needs rather than the needs of people with ID: "All it did was develop a profile of where existing system and supports could plug in and support her. What's missing is what she needs of the system and supports." Earlier we saw how one of the consequences of misrepresenting an individual's support needs includes spatial displacement, such as institutionalization or forced isolation due to a lack of supports. According to Sam, his relative Robin was misrepresented by an assessment that stated that she was requesting a placement in a group home. Sam found the SIS results to be entirely divorced from his relative's identity, stating, "it was pure fiction. Nothing – who was this person listening to? How do you think they arrived at these results?" The above narrative

also suggests that some advocacy work has taken place in order to obtain a reassessment, and that representational struggles such as these ought to be considered in future research around how the SIS is implemented.

The time required to undergo a developmental services assessment and the nature of the process were troubling for Rocky, who felt "exhausted" by his SIS experience. Sam and Robin also found the SIS tiring and Robin "started getting really bored and tired really quickly". Elizabeth shared a similar reaction on the part of her relative Eileen, adding that the questions seemed inappropriate, and detailing how the assessor 'quibbled' over every answer: "For her, it was tiring. [Number] hours sitting and talking to somebody in [location] and quibbling over every single question. 'What do you mean by that?'. I mean, just – every question – if you ever read it, they're trying to get at things that don't relate to her life at all. But for her, it was just tiring. We did it in [number] chunks. The other people just couldn't believe the questions given the person sitting in front of the assessor. Yeah, oh my god." Brown, a person with an ID who underwent a SIS assessment along with her relative Green, explained that she was careful about how she answered questions and even refused to answer some. Brown's comment suggests the need to remain vigilant during the assessment process. Similar to this, Rocky pointed to issues of trust between those who control developmental services and people with ID. For his part, Sam indicated that service administrators don't trust families: "There's no trust because us, the families, and the system. If there was trust we wouldn't be second guessing". These issues of trust and struggles for self-representation, as reflected in practices of "second guessing" during SIS assessments, are also relayed in Elizabeth and Eileen's experience of "quibbling" over answers to interview questions. Such issues recall the AAIDD instructions to assessors,

discussed in Chapter Four, to distinguish between what clients think they need, and what is actually needed (SIS User's Manual, 2015, p73).

Sam's framing of the SIS assessment through the language of dehumanization helps account for some of the power imbalances and representational struggles that can occur between assessors, service providers, and individuals with ID and their families. He suggested that the SIS assessment is an objectifying process that transforms intimate details into scores. In his words, "you spend hours talking about all this really personal stuff and then they crunch it down into numbers". Sharing "all this really personal stuff" was a recurring issue for participants who questioned why the SIS was so invasive. Bella and Rocky, for example, each expressed discomfort with the nature of the questions and the level of detail requested by the assessor. Rocky provided the example of questions related to sexuality, while Bella explained that certain details are simply too personal to share: "I find that it's really uncomfortable for people, and for me it's really overwhelming. I don't like them, I hate them. It's not any of their business, really. I just find that a lot of the questions they ask people, it's not any of your beeswax, really". Bella linked the request for these details to feeling 'degraded', invoking language of dehumanization to account for her SIS experience, stating, "I just find that it's degrading to people… why do you have to go so deep?"

Bella described the consequences of not participating in a SIS, confirming other participant accounts which suggest that the decision to participate can be somewhat coerced: "it makes the person feel uncomfortable. Then the person doesn't want to talk… if you don't want to talk, then the assessment doesn't happen. Then you probably won't get the support you want." She claimed that the SIS is mandatory in order to access supports which, as we saw earlier, are needed in order for Bella to be present in the community: "people don't have a choice to talk to

people, to get assessed, to get the support they want… No, you just do it". Similarly, Green and Elizabeth discussed the importance of 'being on the list' by undergoing a SIS. Even while the assessment did not register any direct benefits, they viewed it as a required step in order to be recognized by the DSO and to eventually obtain supports. In Green's words, "She [Brown] does not get any benefits, but she is on the list. You have to get on the list." Green further described how odd it may seem to "get on the list" even though this does not lead to any resources: "she's on the list. It sounds so strange that she has to be on the list yet she's not going to get help".

The desire to be documented by undergoing an assessment appears to be coerced in the sense that it is a condition required to access supports that are essential to enacting citizenship and even avoiding death, as Eileen's experience shows. Yet at the same time, participants suggest that the DSO assessment can be experienced as a pointless process that fails to fully capture and/or deliver on their needs. The futility of the assessment process was suggested earlier by Bella's insight as well as by Elizabeth, who did not get the evidence that her relative Eileen needed to obtain certain supports. Sam shared a similar perspective when he described that his relative Robin was referred to a group home they did not request. Relatedly, Bella articulates a sense of frustration and futility in the following statement, explaining that she never heard back from the DSO after her SIS: "I have been assessed before, a bunch of times"; "[I] just think that it's pointless sometimes. Because you do through an assessment, and you never hear from them again. It's like, you go through this entire emotional thing and you hear absolutely nothing back from the person. Nothing. Nothing. And you're just like, what was the whole point of that?" Like Bella, Rocky explained, "it certainly didn't change a whole lot… No, just spent [number] hours in talking about all those – basically an invasion of privacy." Tackling the question of purpose, Rocky shared his view on why the SIS remains in place in Ontario, describing the jobs it

generates: “I get it, it creates jobs. It certainly creates the wrong jobs.” He is critical of how MCSS is spending its budget on assessments rather than on supports, arguing that “[t]he money they spent on that could have been invested on people. Invested in giving people choice and more opportunity.” Rocky’s critique recalls comments shared by Bill, the manager of a program for people with ID, about resources that are being wasted on assessment processes (see Chapters Three and Four).

Sam was equally critical of assessments for developmental services, stating that the process is “not transparent” and explaining that they were not given a sense of how the data would be used. Similar issues around power also surfaced in narratives explored at the start of this section. These power struggles, however, must be further contextualized through the threat of dehumanization that is connected to the concept of ID. As previous chapters have shown, experiences of dehumanization also relate to attempts to position people with ID as ‘species outsiders’ who cannot enact agency. Rocky, discussing the results of his DSO assessment, spoke directly to this point. He explained that there is no room for choice, as the result of the assessment process leads to “an agency that could potentially pick you up – you don’t necessarily have the choice”. The idea of being ‘picked up’ by an agency is profoundly objectifying, reinforcing the direct connections Sam drew between the SIS assessment and the objectification of his relative Robin through the conversion of her personal details into numbers.

Adding to this objectifying dimension of dehumanization, Eileen experienced developmental services through an intervention that attempted to alter her behaviour as the result of a SIS assessment that claimed that she needed this form of support. In Elizabeth’s words, they were “trying to modify her behaviour”. Elizabeth discussed this memory with Eileen during our conversation, and Eileen confirmed the she did in fact remember. This intervention and the

desire to transform Eileen's behaviour, which was resisted, is further evidence of how people with ID can be positioned as abnormal. It also suggests how service systems, guided by assessment results, can intervene to subjectively shape individual realities. Related to this point, Elizabeth directly addressed the way in which normalcy is constructed through the SIS. She focused on assessment questions aimed at "defining 'normal' functioning", asking, "how often to do you get on the bus and go somewhere? I don't go somewhere ever. Does that make me abnormal?" In her narrative, the problematic construction of normalcy was just as important as the formal removal of legal rights. Elizabeth pointed to issues of legal capacity, describing how relatives of people with ID are being encouraged to become substitute decision-makers. Disagreeing with this approach, she described how her own relationship with Eileen and their use of supported decision-making is based on her recognition of Eileen's capacity: "She can't always manage to implement her preferences, but it doesn't mean I take away her decision-making. She can make choices. She has that capacity."

Failure to recognize people with ID as complete human agents who can shape their own lives is central to their dehumanization; it is also deeply embedded within hierarchies of (in)capacity and certain approaches to service design and regulation. Particularly relevant here are the ways in which Rocky's SIS experience and struggles for representational control relayed by other participants suggest that the very process of being assessed can undermine self-representation. Elizabeth, for example, commented on the impossibility of many people with ID to participate in a SIS assessment on their own. She explained that based on what other relatives had told her, Eileen and many other individuals with ID, 'wouldn't get anything' if their relatives did not represent them during the process: "I've heard families say, '[i]f I hadn't been in the room he wouldn't have gotten anything'. I wonder what would have happened if I had left Eileen

alone with the assessor in the room." Elizabeth's observations, which draw on collective experiences, suggest that individuals with ID may be at risk of having their support needs – and thus their ability to exercise substantive citizenship – overlooked unless they are paired with a representative who does not have an ID. This speculative comment reinforces Rocky's experience of feeling undermined during his SIS assessment, as well as Fred's suggestion (discussed in Chapter Four) that the SIS fails to recognize people with ID as self-representatives. These insights support an interpretation of the SIS as a biopolitical tool that participates in a governmentality of (in)capacity. In this way, the assessment process may contribute to the subjective displacement of people with ID according to normative standards and problematic perceptions of (in)capacity.

The subjective displacement of people with ID and the failure to recognize them as complete individuals capable of exercising agency is not unique to assessment processes. Referencing the MCSS-run system as a whole and provincial capacity laws, Doreen drew explicit connections between perceptions of incapacity the struggle among people with ID to be recognized as fully human. She discussed how people labelled with a profound ID, such as her relative Allan, whom she characterized as someone with a "significant intellectual disability" who needs "24-7" care, are not always viewed as individuals. Doreen shared her observation that within developmental services, "I don't think you have any sense of them [people with profound ID] as having a personality, as having a personal identity". Linking human status to access to citizenship, she explained that Allan is a not full citizen even while he holds formal status, because his capacity has been formally removed: "I don't think he is recognized as a full citizen… and even in law, until we get the *Substitute Decisions Act* fixed, he has no status". The concept of profound ID invokes capacity hierarchies, yet it is important to Doreen as this allows

her to draw attention the injustices facing her relative and others who share a similar status. She is equally critical of the implications of this ranking system and links Allan's position within a hierarchy of (in)capacity to his dehumanization: "at the bottom of the heap here, there's this group of people who aren't anybody. They're really seen as nobodies. Because they have to be cared for".

Doreen is very clear about the need to rethink the concept of 'human' to include individuals considered to have more profound ID. During our conversation she argued for "a much deeper concept of humanity, of human dignity and respect" and concluded that "I don't think the system had fully adopted that". According to Doreen, a broader conception of what it means to be human would translate into more individualized supports, including funding. Doreen explained, "life is personalized and funding isn't. And that's what's missing". The problems she identified also appear to be present in the ways in which MCSS structures assessments through the DSO and SIS. Commenting on the results of her relative Allan's assessment, Doreen stated, "I'm not quite sure that the result of that assessment told the Ministry what the need actually was. And certainly I feel [Allan] would have been fully funded if it had told them". For Doreen, "ignorance" of people with profound ID is the biggest problem at MCSS and is suggested by "a complete ignorance of life for people who are dependent on support in order to live". Suggesting the need to change how people with ID are assessed for services, she explained that the method of identifying needs is "impersonal" and fails to capture important forms of differences between individuals. The consequence of this failure is an inability to understand individual needs, which Doreen suggested can result in forms of isolation and non-presence, such as being left in bed all day. Doreen noted that MCSS gains knowledge about individuals through "a standard approach". Instead, however, she feels that Ontario needs "a less impersonal system to identify needs for

disability. It's a very impersonal thing that this standard – there are standard assumptions and they don't cover the subtleties and the enormous differences, particularly with respect to people with severe intellectual disabilities. I just find the lack of understanding, the depth of the need, it's – people can't imagine just lying in bed if no one says it's time to get up."

Doreen's comments on citizenship, the lack of individualized supports, and an impersonal approach to assessing individual needs draw together many of the experiences of subjective and spatial displacement discussed so far in relation to service assessments. Above all, her comments suggest that standardized needs assessments can be based on assumptions that overlook individual realities and that can give rise to profound challenges around the basic ability to live and be present in the community. We have already seen how the subjective shaping of individual identities and opportunities to be present occurs when disability-related needs are mis-represented and inaccurately "scaled", to use Rocky's term, as well as when people with ID are overlooked as complete humans capable of self-direction. We have also seen how spatial displacement can be present as an inter-related dimension of these experiences and encompass forms of forced isolation, immobility, and the threat of forced relocation, especially to institutional settings. A related analysis of Bella's narrative suggests that struggles around representing support needs and struggles for control over one's life can impact a person's sense of self-worth. Bella described feeling "more confident" after obtaining supports, finding a home, and getting back into the community: "I'm more independent, I do things, I'm just more confident in myself than I was – more than I was than where I was living before". It is equally important to her to have control over her life, to "not to have people tell me what to do. I don't like when people tell me what to do". Bella expressed the hope that other people with ID will

gain more confidence through support, rather than facing judgment. She explained, "They don't need to be judged. They get it all the time."

The idea of self-worth and the need to advocate for the worth of people with ID is a recurring theme in participant narratives. For example, Elizabeth explained that the "value proposition", or the idea that her relative Eileen is a person who has value, needed to be constantly pushed in order for Eileen to gain access to the supports and opportunities she needs to survive. Providing another example of the physical violence that results from being perceived as 'valueless', Doreen discussed social responses to Allan's disability through the threat of sexual and physical abuse and related forms of spatial displacement. She explained that Allan had been "[s]exually assaulted and physically assaulted" and that this impacts his ability to remain in the community in certain ways. One example involving "total negligence" removed a valuable opportunity for Allan. Violence, in these instances, is inseparable from the embodied and symbolic realities of ID. On a socio-cultural level, the failure to accept people with ID as human agents and complete individuals structures their precarious presence.

ii) 'Not a worthy Canadian': Experiencing the Immigration Medical Exam

Addressing the notion of human value through the excessive demand provision and the ongoing denigration of certain migrants, Anita explained, "[t]t's something that has been in place for a long long time, and it very much relies on this idea that certain people are useful, and other kinds are not". Her insights into the nature of these value judgments help relate the sub-human status linked to ID with the objectification and exploitation of migrant workers who are, most often, people of colour: "it's a struggle to say that these are whole people and we should be valuing them as whole people." For Anita, as with nearly all other participants who addressed the question of migration and disability, excessive demand testing is also about deciding what kind

of people can contribute to Canada in normatively defined ways. Several participant narratives are especially useful in unpacking the problematic nature of normative constructs of 'contributions', especially as they relate to perceptions of (in)capacity. This analysis recalls the critique presented in Chapter Six, which points to discourses around 'contributions' within the CIMM report. Previous parts of this analysis have shown the effects of normative judgments through the lens of spatial displacement by addressing the importance of (in)capacity in IME assessments. The present section will, however, consider more direct experiences with excessive demand screening.

Much like developmental services assessments, participants described the IME and excessive demand screening as invasive, lengthy, and ridden with uneven power dynamics related to struggles for control over knowledge production and capacity-related claims. While the IME is a requirement for most migrants, the experiences of migrants with disabilities can be distinguished by a deeper level of invasion. For example, Rose explained that her relative was subjected to a closer form scrutiny and a more invasive experience: "[t]here's no privacy, they had to get access to all of [relative's] medical records, that was different for [relative]". Much like the SIS and the wait for developmental services and Passport funding, the IME could be dragged out over a long period of time. Al's explanation that his relative had to undergo several forms of testing until 'something' was found resembles Bella's description of being subjected to multiple rounds of scrutiny. In her words, "If one assessment isn't enough, then you gotta do another one." The searching nature of the IME and developmental services assessments, which participants noted carry issues around transparency, speak to the possibility that these processes are shaped by preconceived rather than neutral objectives. Not unlike the issues around trust and transparency that can be experienced under the MCSS-managed system, Chester explained that

"they [the IRCC] don't tell you anything, it [excessive demand screening] was very dragged out". Additionally, Chester's experience demonstrates that there is an additional financial burden associated with the experience of waiting for decisions, since migrant applicants must pay out of pocket for most exams: "We had to get another physical because the other one expired, because it took them so long to get back to us". Chester, Rose, and Al's recollections suggest that the assumptions guiding IMEs directed at migrants with disabilities are markedly different from those shaping medical testing for non-disabled migrants.

Participants reflecting on the length of the excessive demand assessment process also related the physical and psychological harm this can generate. The following examples show how prolonged assessment and decision-making processes can adversely shape individual subjectivity and embodied realities. Sean described the harm that migrants experience while they await the results of the excessive demand screening process, stating, "to be frank, the experience is perpetual and long so they go through an emotional rollercoaster". He added that, "often you see all kinds of situations where people are breaking down, often the psychological stress is absolutely visible and its perpetual. So how that affects their health in the long term". Anita spoke to the physical and psychological harm associated with waiting and the duration of spatial displacement that includes family separation. She described migrants who had become "sick" through stress, waiting, and being separated from their children: "it has a devastating emotional impact, psychologically, just in terms of like fear and stress, the amount of stress over that many years. I've seen a lot of women get sick, physically sick, from that kind of separation from their children. I've definitely seen a lot of depression, I would call it PTSD, it's very very serious". She also emphasized the delayed nature of excessive demand decision-making: "they waited and waited and heard nothing from immigration, whether they are facing medical

inadmissibility or not". Alia recalled her own application experience, explaining how the threat of displacement and the impact this can have on your life can "destroy you". In her words, "the anguish of having every time to wait for them to make a long decision. It was exhausting. I mean people may say it's obvious you have to wait but when your life is like hanging in the balance it's like waiting like, can destroy you". Alia centred the IME and the need for multiple rounds of testing, explaining that the experience of anguish was associated with "waiting for all these tests to take place". Additionally, she linked the close scrutiny she received to the financial burden imposed on her by the IRCC, along with a "bad feeling" that an excessive demand finding was very likely to occur: "I had a bad feeling about it because they kept delaying, they asked for more tests and more tests and everything was more money and more money".

The requirement to wait for months and even years for a decision is one that is shared by migrants with disabilities and people with ID who are awaiting Passport funding. Participants suggest that during this waiting period, individuals are aware of, and can even rendered ill by the threat of spatial displacement. They can also become involved in struggles around disability identities, often resisting the threat of subjective displacement represented by claims made about their own or their relative's (in)capacity and potential relationship to Canada's development goals. This is especially true when IMEs were thought to misrepresent an individual's need for services and supports, since these claims can result in an excessive demand finding and spatial displacement. Participant narratives also show how assessments related to ID lead to contested claims about an individual's (in)capacity that are deeply intersectional in nature. Along these lines, Anita described migrant applicants being "surprised by the diagnosis given to their children back home because that wasn't what they had previously been told by other doctors". She shared an example where a woman complained that her daughter's assessment resulted in a

lower rating because the assessor did not factor in her embodied reality: "[her] daughter was diagnosed with 'mental retardation' – like, that was the terminology used. This woman said, I know my daughter has mental delays but the problem is that they aren't also taking into account her vision problem. And so, when they don't take into account her vision problems and how they can respond to things, then she is being diagnosed with a much more severe mental delay that what she actually has".

At the start of this chapter, we learned that Al had noticed ethno-cultural, linguistic and disability related biases during his relative's IME that resulted in that individual's capacity and ID being misrepresented. Al directly challenged how the limited view promoted through IME assessments can exclude other values, particularly ones related to ethno-cultural and disability differences. He linked these exclusions to a normative and very limited understanding of what it means to be human, stating "different capacities and talent that [his relative] might have, and different cultural capacities… so all of these qualities that are for a human, valuable qualities, are not at all measured". Al added that the IME, "surely does not express who [relative] is in any way". Shiva shared many of Al's concerns and explained that with excessive demand screening, there are aspects of an individual that simply cannot be captured: "There are so many things that don't really translate. It's really comparing apples to oranges". He pointed to the importance of cultural differences in reading disability. At one point. and referring to the comparative nature of excessive demand evaluations, he asked, "How can you back those value judgments. You just don't have information about the lived experience or condition that the child found himself in before coming to this country to say whether they are going to be a burden or not".

The above analysis reinforces the intersectional and social nature of ID and (in)capacity, recalling Chen's (2016) point that capacity and development are intersectional concepts.

Interviews suggest that the IME frames ID and (in)capacity as a linear and quantifiable quality, much like the SIS, drawing conclusions around appropriate service-use on this basis. Clinical conclusions based on these assessment processes are especially problematic for migrants with disabilities who may be assumed to require access to services they do not in fact need. For Al and Jack, the IRCC incorrectly predicted that their disabled relatives need for certain publicly-funded services and labelled them as an excessive demand. Both participants disputed this prediction and Al explained that, "They were zero part of the equation in moving to Canada because the country I come from has those services". Jack rejected the assumption that his relative required access to the supports predicted by the IRCC, invoking some of the colonial dynamics discussed in previous chapters that support perceptions among those in the Global North that the Global South is underdeveloped and in need of charitable support. Jack pointed out "the mindset that people who come from less wealthy countries or less capable countries in terms of social services, come to Canada only to suck up all the resources in Canada." Explaining that even though his relative "does live in a country where there are not a lot of social services", they do not intend to access supports in Canada due to their values and desire to maintain a family-based support system: "we have taken very good care of [relative] and we would raise [relative] the same way when we immigrate to Canada".

According to participant narratives, the results of IMEs and the predictions they inform can be inaccurate by many accounts. Just as Sam and Robin experienced SIS results as "pure fiction", Sean referred to excessive demand claims as having "[n]o resemblance to reality". He concluded that this representational failure is due to the IRCC's inability to correctly predict the costs of services tied to IME assessments. He explained, "In every case that it's [excessive demand finding] happened they're wrong and they do not represent what the general cost is for a

raising a child with that kind of disability. So it's a very arbitrary form of calculating." Other disagreements around representing the realities of disabled migrants involve disputed claims about future impairment experiences. Alia's experience provides a direct example of the predictive aims of the IME and its failure to accept her impairment reality. Like Brown, Alia had a doctor who was willing to support her application and who did not feel that she would pose a 'burden' to Canada. In both cases, third-party support was articulated through the language of a capacity and impairment hierarchy, and applicants were framed as having a 'less significant' disability. However, in Alia's case, the IRCC did not believe the practitioner's claim: "[medical practitioner] said well, she has [diagnosis], she does not have significant impairments to her life […] then they [IRCC] say no, it's not enough, you have to provide more information. And so I say, 'I don't have more information'. And they wanted to know exactly what was going to happen, but [medical practitioner] say, 'we don't know, it is not something we can predict, so everything is possible'". The contested nature of the claims made by Alia's doctor reveal how the searching aims and suppositions that guide the IME process are not only structured by medicalized knowledge but by broader social values and the desire for predictive measures.

Related to these measurement practices, we must also recall Sean's warning about adult applicants who are deterred by the IME. Adult migrants with disabilities who apply for status can do so as individuals, and so the cost-benefit analyses conducted in these cases would not factor in the 'contributions' of their (non-disabled) relatives. Thus, advocacy efforts which argue that the productive potential of a disabled person's relatives must be accounted for are irrelevant to many individual applicants. This comparison between individual applicants and those who apply as family members allows us to appreciate how the slight 'advantage' that child applicants appear to have by virtue of the impact of their guardians' perceived contributions is connected to

dehumanizing discourses that view disabled migrants not as complete individuals, but as potential burdens whose 'risk' can be mitigated through the contributions of their non-disabled relatives.

In many of the examples discussed so far, dehumanization is linked to the ways in which developmental services assessments and immigration medical screening position individuals within a hierarchy of (in)capacity and (under)development. We saw that perceptions of (in)capacity relayed through developmental services assessments can lead to feelings of dehumanization and struggles around self-representation. These struggles recall historic views of people with ID as species-outsiders incapable of exercising agency and directing their own lives. It seems that excessive demand screening draws upon a similar ideological basis and invokes dehumanizing discourses that frame migrants with disabilities as undeserving 'foreign aliens' who potentially pose a burden on public resources. Participant narratives emphasize the impact of these processes, suggesting that being labelled as having an ID or as presenting an excessive demand is in itself a dehumanizing experience. In these instances, dominant understandings of who counts as human are actively negotiated by participants. As we will soon see, many participants challenged the value systems that tend to exclude migrants from notions of belonging, critiquing the medicalized assessment processes that formalize these beliefs.

Up until now it has been argued that many of the structural and cultural forces at play during participant encounters with the excessive demand regime can also be detected in the dehumanizing assessment processes that shape these experiences. Recalling Sam and Rocky's point that the SIS transforms individuals into numbers, Chester discussed the degrading experience of being 'coded' by the IRCC during what he described as a depersonalized application process that relied on numbers and prohibited the use of individual names.

Specifically, he pointed to the lack of human contact and how this generated a feeling of culpability, or "being on trial". In his words, "[i]t would be nice for the bureaucracy to have a human face to it. This was granite walls and sliding notes, and everything we had was from a number, it was a matter of numbers. A code for something. You couldn't call an officer's name. It was like you were on trial, you were being tested, and you couldn't engage with the person running the test". An inability to engage with decision-makers was also part of Alia's experience being called 'a burden' by the IRCC. Alia discussed the impact of this decision by drawing attention to the lack of detail she received from the agency and contrasting this with the heavy emotional and health-related impact the label carried: "they sent me this letter, just a few lines, that said we have assessed that with your condition you can represent a burden for Canada. That part, the burden part, I remember really well. It was so hard just to have another human being call you and your life a burden. That was a worse thing. I started crying and I couldn't stop. That was exhausting". Alia's description of having her life and personhood labelled as 'a burden' points to how the IME participates in a method of categorization premised on a dehumanizing category.

The IRCC's categorization process is as dependent upon the denigration of people with ID and the concept of incapacity as it is upon the perception that migrants are 'foreign aliens' who are undeserving of public resources. Discussing the challenges her family faced in accessing publicly funded services, Anna argued that her relative's status as a migrant with an ID who was not born in Canada should not impact their individual identity and whether they are viewed as 'worthy' of access. Suggesting that the country of one's birth is nearly random, Anna asked, "how does that make a difference about who [relative] is as a person?" Rose brought this experience of undeservedness much closer to the dehumanizing notion of 'foreign aliens' when

she discussed the matter-of-fact, yet discriminatory opinion held by Canadians who feel that her relative poses a 'drain on the system'. She described her reaction to the comments made by these seemingly friendly individuals, when they said to her "'Yeah of course, it's just a drain on the system'". Recalling this statement, Rose pointed to the role of government in perpetuating the xenophobic idea of 'keeping them out': "Can you believe it? I'm stuck [...] with these people, who were nice. I mean, this mentality people have because of a government that has perpetuated this… you hear comments like 'keep them out' and you think, how can people be like that? And then you meet them and they're lovely people." Anita also discussed public perceptions of migrants as 'burdens' and a broad culture of xenophobia, describing the number of hateful comments she has received related to her views on the excessive demand provision. She summarized these public discourses as, "we- can-barely-take-care-of-our-own kind of language". For Anita, these polarizing 'us and them' discourses relay intersectional forms of discrimination against racialized and disabled people, demonstrating "the kind of hatred that still exists against people of colour and migrants and disabled." Further comments shared by Jack, who is a person of colour, suggest that the barriers he faced in reuniting with his family undermined his sense of belonging. He stated, "it made me feel that I'm not a worthy Canadian [...] just because I was not born in this country".

Two participants in particular – Sean and Anita – drew attention to how those "not born in this country" and especially migrant workers who are people of colour, are radically objectified through their imagined labour value and the state's desire for them to contribute to Canada's economic development. Sean focused on the lack of human investment in supporting migrant workers, explaining, "it's the cheapest form of labour there is. And there's no cost to society in bringing them up… and all at the expense of other countries". Sean's comments – read

alongside Chapter Five's discussion of (neo)colonial conceptions of (under)development and existing critiques of migrant labour reviewed in Chapter One (see, for example, Bakan and Stasiulis, 1994; Arat-Koç, 1997; Tungohan, 2013; Spagnuolo, 2018) – recall another problematic dimension of capacity-oriented policies and normative understandings of 'contributions'. In the case of migrant workers, an individual's perceived capacity to contribute to Canada's economic development easily results in their overt exploitation and dehumanization as 'cheap labour' that requires no human investment or formal status. The Canadian state hopes to promote its owns development by objectifying these migrant people of colour, while racist notions of (under)development and (neo)colonial processes impacting the Global South shape decisions that can deny them formal status. These migrants are viewed as less worthy of belonging and less deserving of permanent status and the rights and benefits that come along with membership. Commenting on the situation of migrant women of colour whose children have disabilities, Anita explained, "it's exactly at the intersections of very very deeply rooted dis-ableism and deeply rooted racism and sexism".

As this dissertation has shown, intersectional and inter-related forms of racism and ableism can be linked to the inter-related concepts of (in)capacity and (under)development. Participant narratives suggest how these ideas structure assessment practices that can work against migrants of colour, disabled migrants, people with ID, and individuals who identify with more than one of these communities. Importantly, many participants also challenged dominant understandings of capacity and related economic development goals, resisting the reduction of humans to their capacity to labour in ways that are normatively considered to be valuable. Many participants also suggested alternative models of capacity and of valuation through their critique of the dehumanizing and objectifying processes involved in current assessment practices. Al and

Shiva, for example, each described how current excessive demand testing fails to capture the value or reality of the person. According to Shiva, excessive demand evaluations are "extrapolative judgments". He explained that currently, from IRCC's perspective, the ability to contribute to economic development is what determines one's value. He added that there are "three discreet measures of contributions" that include the "ability to have a job" and "ability to pay taxes". Shiva also points to an "ability to contribute to one's community" but admits "that's a lot less easy to measure". For his part, Al refers to the medical assessments that inform such judgments as "reductionist". Commenting on the assessment that led to his relative's excessive demand finding, he stated, "it's just very reductionistic these exams. It doesn't capture the value of these people".

Other participant narratives suggest how the vague possibilities contained within dominant understandings of community 'contributions' are either not factored into decision-making, or are too limiting. Discussing her relative's excessive demand assessment, Rose described an important omission and said, "there's no list of the great things [relative] does for society. That's not taken into consideration at all". Al explicitly addressed the problematic nature of the 'contribution' thesis by forwarding a more expansive view human worth. This form of valuation encompasses cultural and not simply employment-oriented contributions: "I think that the value of each person… is immeasurable, and whose to tell what contributions a person might make or not. And the contributions of people with and without disabilities, but immigrants specifically, are to enrich the country with other cultural values and other experiences, other ways of dealing with the world". Alia was equally critical of how the IRCC measures human worth, stating "it's a false understanding of what a human is. It doesn't matter what you cost […], $200, $50000, $18000, this doesn't affect your value as a human being". In our

conversation, Jack introduced the capacity-related term ‘capability’ and seemed to take issue with its application, suggesting that “medical points” was a more accurate term. Describing the medicalized ranking system used throughout the IME, he explained how panel physicians, “evaluate the medical – I don’t like to use the word capability – the medical points”. His statement suggests a refusal to associate his relative’s capacity with this numeric ranking system. Jack’s insistence on using the term “medical points” is noteworthy and suggests the possibility for alternative and non-hierarchical ways of conceptualizing capacity. Along these lines, Jack forwarded the idea that interdependency is a reality shared by many and not simply certain people with disabilities, stating “there are very few people in Canada who succeed on their own”.

Concluding Thoughts and Avenues for Future Research

The denigration of dependency and its articulation through (in)capacity hierarchies and inter-related notions of (under)development is of paramount importance to how excessive demand testing and developmental services are experienced. The above narratives provide direct examples of how individuals interact with these assessment processes and even resist their conceptual basis. In many of the above examples, responses to the documentary identities crafted through SIS and IME assessments actively shape the threat of spatial displacement, including precarious presences, forced isolation, and family separation; simultaneously, they enact modes of subjective displacement that can position people with ID and migrants with disabilities as ‘sub-human’ or ‘alien’. These findings are in keeping with spatial and subjective dimensions of displacement related to “being out of place” (Bakewell, 2011, p23), and to “service gaps” described in my previous work with El-Lahib (in press). Participant experiences further suggest that the documentary identities constructed through medicalized assessments can support claims about disability realities that have the potential to subjectively shape individuals by regulating

their opportunities to be present in Canada. This can be seen, for example, in how subjective forms of displacement promote spatial modes of displacement.

It seems then that interactions between medicalized assessments and administrative forms of decision-making can shape the distribution of public resources and along with these, impact the (non)presence and (non)citizenships of disabled people within Canadian society. The examples explored in this chapter emphasize the conceptual importance of (in)capacity and (under)development for migrants with disabilities and people with ID, further contributing to an understanding of their biopolitical function. We also saw how racialized migrant workers from countries in the Global South relate to laws and policies shaped by these inter-related ideas, which are conceptually linked to the category of ID. The range and diversity of different struggles and negotiations around (in)capacity suggest the potential for a much broader application of an analytical framework that forefronts the concept of ID. Additionally, participant insights into medicalized assessment processes create opportunities for much deeper forms of analysis.

While this chapter has introduced some of the key processes and experiences related to immigration medical screening and developmental services assessments, strategies to preserve participant anonymity within such a limited sample size have prevented the disclosure of details that are likely very important to participant identities and lived experiences. A larger sample size would facilitate an analysis of these factors, which include, but are not limited to, gender, sexuality, race, age, language, religion, impairment-specific experiences, diagnostic labels, education and occupation. Such an analysis could also include, for example, the role that an individual with an ID's specific location within the province of Ontario might play in terms of their evaluation and access to supports, or the importance of country of origin in shaping

excessive demand experiences. Recruitment efforts for future research into these issues should pay attention to the importance of representing a diversity of identities related to disability, race, sexuality, class, religion, gender, and country of origin, for example. Additionally, efforts ought to be made to balance the perspectives of people labelled with ID and migrants with disabilities, with those of relatives and individuals who work with impacted communities.

Lastly, and as mentioned at the start of this chapter, I do not discuss the results of specific excessive demand or developmental services assessments in any detail. These details could include specific wait times, medical labels, Passport funding levels, the specific rationale for excessive demand determinations and responses to this rationale, as well as the outcomes of acts of negotiation, resistance, and advocacy. Rather than presenting detailed portraits of individual participants and their unique experiences, this chapter employs generalized descriptions and has focused on collating and analyzing interview data with the goal of developing a theory of disability displacement. The overall outcome of this approach has been to highlight displacing processes and experiences that work through a governmentality of (in)capacity. The radical outsider status of many migrants and people with ID who are framed as 'alien' and 'subhuman' present case studies which allow us to situate these dynamic processes and their interactions within dominant citizenship cultures. The forms of non-citizenship documented in this chapter offer explicit examples which may aid in the process of "conceptual development and theory construction" that is so key to a grounded theory approach to interviewing (Charmaz, 2014, p87). Future interviews and a broader sample size will further test and help refine a disability displacement framework.

Chapter Eight: Conclusion

Summative Analysis

Pressure from disabled people and their organizations, along with growing recognition of the precarious forms of citizenship they experience, has continued to shape legislative efforts in Ontario and at the federal level. Beginning in 2016, for example, new Standards Development Committees related to the Accessibility for Ontarians with Disabilities Act (2005) were formed to work towards the goal of creating "An accessible Ontario by 2025" (Ontario, Standards development committee minutes; Accessibility laws).[16] Around the same time, the Government of Canada initiated a nation-wide consultation project to support the creation of the Accessible Canada Act (Bill C-81), which is currently before the Senate. Despite these recent developments, the situation of persons with ID and migrants with disabilities continues to be adversely impacted by decisions that render their status, presence, and access to rights uncertain and that place them at risk of displacement and non-citizenship. As this dissertation nears completion, Canada's excessive demand provision remains firmly in place and will likely continue to facilitate the formal exclusion of many migrants with disabilities. Meanwhile, the 2019 provincial budget for Ontario includes deep cuts to developmental services (Ontario, 2019; see Pooran Law, 16 April 2019, for a summary), the effects of which could deny individuals with ID the supports they need to enact substantive citizenship, resulting in further barriers to their belonging.

The preceding chapters demonstrate that deep forms of marginalization experienced within ID and migrant communities can be critically interpreted through a displacement framework that looks beyond official borders. In this sense, my work accords with Bakewell's (2011) expansive conception of displacement as the "self-perception of being out of place"

[16] Prior to the creation of the new Standards Development Committees, Ontario passed the Integrated Accessibility Standards in 2011 (Ontario Regulation 191/11) and convened the Customer Service Standard Committee in 2013.

(p23), lacking agency in movement, the institutionally-managed nature of this movement, and the nature of the change that the individual feels they have experienced; it also draws upon Goldring and Landolts's (2013) conception of non-citizenship as shaped by "conditionality" and related to precarious forms of presence and access that are negotiated by multiple actors. Goldring and Landolt's emphasis on "conditionality" is particularly helpful as a way of problematizing the situation of people with ID who hold formal status, but who may nevertheless experience non-citizenship. The framework developed through this dissertation helps trace the complex ways in which (non)citizenship is negotiated by documenting potentially displacing processes.

The way in which this study approaches displacement largely builds upon earlier work I completed with El-Lahib (in press), which challenges us to consider the realities of people with disabilities "who have not crossed geographic borders". Specifically, our recent book chapter, encourages displacement studies to view people with ID with permanent status as potentially experiencing displaced realities on account of their problematic relationships to home and belonging, as well as the threat or experience of institutionalization. Interviews conducted for this dissertation suggest that the risk of institutionalization, radical segregation, and other forms of spatial displacement shaped by the developmental services system do indeed continue to impact people with ID who have not crossed national borders. Participant narratives further reveal that migrants with disabilities and people with ID face unique forms of forced, coerced, or restricted movement and the risk of family separation, partly as a result of their encounters with the state and particularly with medicalized assessment regimes. These experiences are equally bound up with a subjective dimension of displacement that relates to struggles over

representational authority and specifically, in the case of migrants with disabilities and people with ID, the power to make claims about the needs of disabled people.

The framework I have begun to sketch in this dissertation marks a unique attempt to explore displacement through the lived realities of disabled people who have not left their country of origin, by bringing these realities into conversation with migrants with disabilities who experience transnational as well as translocal modes of displacement. The overall result contributes to a framework for interpreting translocal and transnational dimensions of disability displacement. The analytical model proposed is deeply intersectional in nature and attentive to how race and disability are situated within medicalized discourses and hierarchies of (in)capacity and (under)development. And while it is certainly valuable to promote a shared understanding of how medical forms of decision-making can shape spatial and subjective displacement among diverse disability communities, it is just as important that these experiences not be collapsed under a singular reading. For this reason, the framework I propose centres translocal and transnational forms of disability displacement and facilitates recognition of shared experiences among marginalized communities, but without effacing the particular, intersectional, and (neo)colonial forms of oppression they encounter.

To better account for the unique dimensions of displacement described by different participants, I focus on the social position of ID and migrant communities as well as the ideological and historical processes that have shaped them. Particular attention is given to adults with ID living in Ontario, to racialized migrant communities from the Global South, and to some of the unique factors affecting their translocal and transnational realities. To approach these realities, this study has applied a multi-layered analysis that investigates the specific assessment tools and legislative frameworks that regulate access to formal and substantive citizenship for

diverse groups. The focal point has thus been two-fold and concerned with access to developmental services for adults with ID living in Ontario, and access to permanent residency among migrants with disabilities. Specifically, I consider how Ontario's developmental services sector has implemented the Supports Intensity Scale (SIS) – a popular tool developed by the AAIDD to assess the support needs of people with ID – and how MCSS' approach to disability shapes access to Passport funding among adults with ID; and how the federal government assesses permanent residency applicants for 'excessive demand' through the requirement that migrants undergo an immigration medical exam. In addition to considering how these medicalized assessment regimes work, I also ask how they have been operationalized as biopolitical tools that regulate (non)citizenship and potentially displace disabled people.

Prior to this dissertation, the SIS and the immigration medical exam do not appear to have been studied in any detail outside of clinical settings or within any critical theoretical disciplines. In addition to addressing these research gaps, and by bringing provincial and federal assessment practices into conversation, this project seeks to contribute to the move towards "transnationalising disability studies" (Soldatic and Grech, 2014), and to broader efforts to draw translocal realities into transnational conversations (see Spagnuolo and El-Lahib, in press). Particularly, this dissertation responds to the call issued by myself and El-Lahib to consider displacement among non-migrants with ID by finding a "conceptual common ground" between their experiences and those of migrants. In an effort to locate this common ground, my analysis shows how immigration medical screening and developmental services assessments regulate various 'passports to belonging' in the form of formal and substantive citizenship.

As the ultimate articulation of citizenship, access to the Canadian passport is managed through a complex application and screening process. Similarly, the MCSS Passport program,

which provides funding for disability supports that are needed to enact substantive citizenship, is regulated through an assessment process largely centred on the SIS. To understand how these tools enable diverse forms of medical decision-making that shape (non)citizenship across jurisdictional boundaries, I consider some of the hidden assumptions they reflect and the ways in which these support dominant citizenship cultures. My findings reveal how dominant notions of (in)capacity and (in)dependence are medicalized and mobilized within a political economy that promotes a specific vision of individual and economic (under)development and that allows the possibility to punish and exclude those who fail to meet these standards. This analysis centres the concept of ID and the inter-related notions of (in)capacity and (under)development as a useful way of conceptualizing citizenship ideals and their displacing effects. Above all, this study is guided by a concern for how medicalized assessments mobilize capacity hierarchies and shape experiences of non-citizenship and displacement among people with ID and migrants with disabilities. Such a detailed examination not only shows that normative and linear understandings of (in)capacity and (under)development underpin assessment practices aimed at people with ID and migrants with disabilities, but that a radical fear of incapacity informed by intersectional factors that include both race and disability, is at the heart of dominant Canadian citizenship cultures.

As a lens of analysis, the category of ID also presents intersectional possibilities that help account for settler and other colonial processes that shape Canadian immigration. This is because the inter-related concepts of (in)capacity and (under)development have been instrumental in justifying racial hierarchies, as the body of scholarship reviewed in this study has shown. One manifestation of these dynamics, addressed by two research participants and within previous scholarly work on the topic, includes the ongoing exploitation of migrant workers who are

people of colour from the Global South. By centering ID as a lens of analysis and drawing on anti-colonial and critical race studies, this dissertation positions existing research related to migration alongside hierarchical assessments of (in)capacity and (under)development. In this regard, I draw heavily upon Chen's (2016) intersectional formulation of Down's syndrome and their broader notion of development as related to the "interarticulation of race and disability" (p236) in order to situate individual experiences within transnational and translocal processes that are shaped by a governmentality of (in)capacity.

Some of the key questions raised throughout this dissertation relate to particular barriers to belonging faced by people of colour from the Global South, migrants with ID, and non-migrants with ID. I consider how these groups are often framed as radical outsiders – particularly, as 'alien' and/or 'sub-human'. To approach these questions, I note important links between (in)capacity, racism and xenophobia, drawing closely upon constructivist critiques of the ID label. Recent histories of intelligence demonstrate that people with ID have been positioned as 'species-outsiders' and situated at the bottom of a ladder of development as a result of their assumed intellectual deficiencies (Goodey, 2016). The radical outsider status of the ID community and related efforts to undermine their agency are also connected to eugenic and positivist efforts to measure, quantify, and predict intelligence and 'incapacity'. Histories of IQ testing show how racialized communities have been subject to similar ordering devices and how forms of racism rely on hierarchies of intelligence (Singham, 2001; Mensch and Mensch, 1991). Extending this analysis, I posit that a governmentality of (in)capacity centred on linear views of (in)capacity, (under)development, and other attributes currently associated with the ID label, carries strong intersectional potential and, recalling Chen (2016), can be useful in analyzing the co-constituted nature of ID and race. Along these lines, my interpretation of current assessment

tools is largely informed by Rapley's (2004) argument that people with ID continue to be involved in interactions where they must "actively negotiate[]" key aspects of their identity (p2), and namely their "(in)capacities and (in)capabilities"(p1). My analysis of Ontario's developmental services system argues that the concept of (in)capacity, informed by normative understandings of embodiment, continues to influence hierarchical assessments of the support needs of people with ID. At the national level, I argued that excessive demand screening relies on a range of medical screening tools that reflect similar ID-related concepts and that mobilize these in screening efforts aimed at detecting potential 'burdens' on Canadian health and social services.

To appreciate the overlap between immigration medical screening and developmental services, several chapters are dedicated to an analysis of the developmental services landscape in Ontario. Chapters Three and Four argue that under the current MCSS-managed system, the obsession with ranking and ordering perceived individual deficiencies stems from medicalized views of ID and is among the many legacies of IQ-testing and ordering devices witnessed during the asylum era. Even more problematic, the clinical interest in representing perceived (in)capacities along a linear scale is often placed ahead of supporting individuals in ways that would respect their agency and self-understanding by allowing them to define the services and supports they require. Broader issues around control and regulation explored throughought these chapters also account for the Government of Ontario's failure to respond to demands for direct and individualized forms of funding and models of supported decision-making that would promote greater choice and agency among people with ID. Currently, Passport is the only program in the province that is considered a direct form of funding – although this characterization, along with the claim that Passport funding is individualized, is contested

throughout this study. Relatedly, deep tensions exist within mandates aimed at promoting the inclusion of people with ID, and within laws and practices that undermine their ability to direct their own lives. As this dissertation demonstrates, the developmental services system reflects deeply entrenched ideas around intellectual 'deficiency' that are related to collective fears of incapacity, dependency, and uselessness, and the need to govern and control these imagined aspects of human deficiency.

Chapters Three and Four also explore how decision-making around Passport funding for adults with ID, which is largely reliant upon Ontario's implementation of the SIS, involves the collection of clinically-oriented data about individual support needs that reinforces normative forms of embodiment. Over the course of these chapters, we have seen that in Ontario, this data is often considered to be accurate and is thus imbued with a predictive potential that informs decisions around funding and service allocation and along with these, individual opportunities and subjectivities. Within the evaluative practices that are funded and mandated by MCSS and implemented by the DSOs, we encounter a conceptualization of ID that is fixated on the notion of (in)capacity and (in)dependence. Relatedly, there are traces of a much broader understanding of people with ID as being 'incapable' that upholds historic trends centred on the belief that the inter-related concepts of intelligence and capacity can be reified and ranked. It is precisely these ranking and sorting practices that facilitate the carry-over of harmful effects from older and more overtly institutional policy periods, thus shaping experiences of non-citizenship through multiple modes of displacement. Through an analysis of these tends, we saw how the spatial and subjective displacement of people with ID relate to their precarious position as members of the human species – a derogatory view underlined by perceptions of capacity and intelligence as the definitional quality of being human (see Goodey, 2011). In this way, the very species-

membership of persons with ID can be risk at risk as a result of their subjugation to MCSS eligibility criteria and assessment practices that employ linear scales that reflect a governmentality of (in)capacity.

We have also seen that resulting forms of displacement suggested by interview participants are consistent with Bakewell's (2011) description of displacement as including institutionally-coerced physical movement and feeling "out of place" or unsettled. For persons with ID in Ontario, these displacing experiences can include the risk of spatial segregation, forced confinement, and the coercive acceptance of services and supports that may be inappropriate or inadequate in supporting social presence and substantive citizenship. Many of these findings are consistent with the claims forwarded in my chapter with El-Lahib (in press), which propose a conceptual common ground as the basis for improving services for non-migrant people with ID and for migrants. Importantly, many of the displacing experiences outlined in this dissertation have been suggested by my analysis of participant narratives. As my interpretation of these narratives shows, the very experience of participating in evaluative processes and documentary techniques can facilitate the re-shaping of individual subjectivities. This re-shaping occurs in ways that can threaten an individual's self-understanding and contradict self-knowledge of support needs. Underlying these evaluative structures is a specific approach to social service provision related to assumptions of incapacity.

Also at issue in this analysis is MCSS' decision to "put[] the cart before the horse", as key informants have explained, by emphasizing regulation and monitoring over individualized service-creation and funding arrangements. The current system can indeed be characterized by a governmentality of incapacity that was designed without adequate consultation with the ID community. Entrenched in this system is the SIS – an evaluative tool that has been invested in

and applied across Ontario for over a decade. However, the potential benefits of applying the SIS to the ID community requires further study, especially from non-clinical perspectives. Evidence from this dissertation, which may be one of the first studies to consider the SIS outside of a clinical context, marks an attempt to contribute to this knowledge. Specifically, participant narratives suggest how people with ID, their families, and those who work in the developmental services sector, experience assessment practices that are mandated by MCSS, pointing to potential shortcomings with these approaches.

The preceding chapters have also presented a close-reading of Ontario's Passport funding program and the model of resource allocation it enacts. The goal of this analysis is to provide a concrete example of how decisions about resource allocation can be based on certain assumptions about persons with ID and arrived at through the use of standardized tools and algorithms. What became clear over the course of this discussion is that MCSS-mandated processes and their implementation of the SIS in particular, do not necessarily measure up to policy claims around facilitating individualized funding and services. In fact, the present reality appears to conflict in many ways with official discourses of inclusion, fairness, and the imagined paradigm-shift in service provision for persons with ID that occurred through deinstitutionalization and the move away from IQ and towards adaptive function testing. A close examination of the Passport funding program has shown how medicalized and deficiency-oriented modes of decision-making can be framed as objective and articulated through algorithms. The consequences of bad decision-making in this area can place people with ID at risk of displacement and closely resemble processes and trends that occurred during more overtly institutional periods in Ontario's history. The mandated gate-keeping role played by the DSO and their use of the SIS to carry out these duties provide an entry point into the potentially

displacing effects of (trans)institutionalization that persist within this MCSS-managed system, despite the formal closure of government-run institutions for people with ID.

During interviews conducted for this study, key informants critically addressed MCSS-led reforms and the Ministry's approach to community inclusion. This study thus incorporates knowledge based on lived experiences with developmental services within a historically informed analysis of its governing legislation and key programs. We saw that even while participants felt that changes were needed around how services should be accessed in Ontario, many argued that the current system is taking the wrong approach to change. Frank, who previously worked for a DSO agency, was especially critical of the current emphasis on assessments. At one point in our interview, Frank even referred to assessors as a clique of experts ("it's like watching an elite group being created"), noting that assessor jobs pay more than most jobs in the sector, while replacing what Frank considers to be more helpful services that carry direct community benefits. Similarly, Bill, who runs a program for people with ID, claimed that assessors are the only "real winners" in this system, given the shortage of available services. His comments take issue with the emphasis on regulating access to services given that most persons with ID still remain underserviced. As a current DSO assessor, Carebear also suggested that clients are underserved as many face heavy waitlisting.

Meanwhile, on the receiving end of these policies, many persons with ID and relatives who were interviewed for this study described the potentially displacing effects of current evaluative and decision-making processes. Given the many problems within the developmental services sector suggested by interview participants, it is clear that any future development of policy and legislation would benefit from closer engagement with these communities. Relatedly, some of the issues outlined by participants convey a profound struggle over definitional and

other forms of control. Research by Carey (2009), reviewed in earlier chapters, helps us account for some of these dynamics. Carey documents the interest among professionals involved in the ID sector in retaining control through expert knowledge-claims and their professed ability to manage the lives of persons with ID, comparing 1940s and 1960s forms of professionalism to eugenicist activities before that period. According to Carey, the role played by these groups involves monitoring persons with ID, thereby "assuring the continued importance of professionals in addressing the 'problem' of mental retardation" (p104).

The desire for control that can be traced within these dynamics is also apparent in the overall design of the developmental services system. As participants suggest, MCSS was "putting the cart before the horse" by creating the DSO to regulate non-existing or inadequate services. Individual narratives further suggest that MCSS' current priority might indeed be monitoring rather than serving, and sorting rather than supporting persons with ID. Even when individuals working in this sector do wish to help, they may face structural barriers to enacting this helping role. Related to these tensions between controlling and helping, this study has traced overlapping narratives that suggest a profound tension between opportunities for rights and protection which are manifest in "policy assemblages" under the SIPPDA. Deficit-oriented views of ID, as set out in the governing legislation, are traceable throughout this sector and allow us to better account for the "policy assemblages" described by Artiles, Dorn, and Bal (2016; borrowing from Ureta, 2014). Insights drawn from histories of eugenics and anti-colonial theory support an analysis of the exclusionary effects of deficit-thinking, helping account for the non-citizenship status that can be experienced by people with ID. Notably, Ahuja's (2016) history of quarantine policies tell us that the goal of rehabilitating or curing perceived pathologies can also include the desire to 'protect' the public from certain individuals. Ahuja is arguing that the

segregation of ‘othered’ individuals into zones of exclusion where they are subjected to medicalized monitoring and interventions has largely been informed by moral judgments. His research provides a clear example of the multiple and complex functions of ‘policy assemblages’.

In Chapters Three and Four, we also considered how existing conceptions of ID, (in)capacity, and citizenship can displace disability realities in translocal contexts. Particular attention was paid to how these processes surface through (in)capacity hierarchies that structure the very service systems designed to support people with ID. The pervasive nature of systems and ideologies that designate people with ID as deficient in capacity demonstrate Carey’s (2009) point that the many forms of non-citizenship experienced by this community have become naturalized, legitimizing their exclusion and allowing their degraded status to become “widely accepted and viewed as legally justified” (p2). Chapters Five and Six shift the focus to Canada’s excessive demand provision and the immigration medical exam by demonstrating that, in strikingly similar ways, Canadian citizenship culture frames the exclusion of migrants with disabilities as a natural outcome of the immigration application process. Both the naturalized and exclusionary nature of these practices can be seen in the many screening tests that comprise the permanent residency application process and the official discourses that surround them. These methods are presented to the Canadian public and to migrant applicants as an objective means of selecting potential citizens and a fair method of regulating Canada’s health and social services that works to ‘protect’ national interests, specifically “ publicly-funded health and social services” (Government Response, 2018).

It is important to note that immigration screening practices are not without controversy. Claims to neutrality and fairness in immigration application processes have been widely

challenged by scholars and advocacy groups in relation to both race and gender (for example, Thobani 2002; MWAC Policy Submission, 2018; Walker, 2008; Tungohan, 2013; Arat-Koç, 1997; Sharma, 2006; Das Gupta, 1994). As we have seen, these practices have also been contested on disability grounds through critiques that centre their ableist dimensions, often by challenging the idea that disabled people pose a burden. It is equally important to recognize that such controversies are not unique to Canada, but are at the heart of global movements promoting the "free movement of people" (see UNESCO, 2007). Groups such as No Borders and No One is Illegal aim to conceptualize citizenship on a global scale by challenging immigration regimes and the very authority of nation states to select their own members. These movements tend to take an explicitly anti-racist and anti-capitalist approach to migration and engage around issues of illegal status, deportation, and the many injustices that compel people to migrate (See for example, No One is Illegal Ottawa, Basis of Unity).

While mindful of the global struggle for universal citizenship, Chapters Five and Six argue that the collective values shaping translocal forms of displacement are also active on a transnational scale and can be detected in evaluative practices implemented by the IRCC. The use of algorithms in immigration medical screening and the mobilization of hierarchies of (in)capacity are related trends that were addressed throughout this discussion. This analysis further reveals how a cost-benefit rationale that explicitly focuses on (in)capacity and ID-related concepts leads to overt forms of spatial displacement facilitated by medical inadmissibility assessments. In this sense, the normalization of modes of exclusion based on ID is an important topic not only for ethical reasons, but also because these values are active in broader processes that inform experiences of displacement and belonging. Given the many problems detected in evaluations of (in)capacity, reviewed in Chapters Three and Four, and the central role that this

construct plays in assessing migrants for membership, the excessive demand criteria appears to be far from neutral. Instead, this dissertation has shown that immigration medical screening puts into action the many hidden assumptions around (in)capacity, employing these in ways that mirror the developmental services system in terms of both ideology and methodology, as well as through the displacing effects that are shaped by these testing systems.

While building on earlier critiques and calls for a full repeal of Section 38(1)(c), Chapters Five and Six further demonstrate that underlying fears of underdevelopment relate to the way in which testing for ID informs more pervasive notions of (in)capacity and are instrumental in shaping access to formal and substantive citizenship for all migrants with disabilities. This discussion recalls important themes that emerged in Chapters Three and Four through a close-reading of the developmental services landscape in Ontario, which brought into focus issues of impairment hierarchies and normative, linear constructions of (in)capacity. This discussion also avoids narrowing the application and effects of these testing methods by drawing out the ways in which settler colonial and global colonial processes, particularly neocolonial relations between the Global North and Global South, inform immigration medical testing. We saw how the biopolitical strategies reviewed in the previous discussion of developmental services – specifically the application of predictive ranking techniques towards the creation of documentary identities – are also active in encounters between migrants and immigration medical officials. Similarly, an analysis of the immigration medical exam revealed that the concept of ID is central to biopower and to biopolitical operations on a global scale.

Far from being out of step with current values and thinking around disability, the excessive demand regime was framed as an accurate reflection of certain persistent aspects of problematic "policy assemblages" (Artiles, Dorn and Bal, 2016, borrowing from Ureta, 2014)

that continue shape domestic disability policy. Some of the more harmful effects of these policies crystalize around developmental services and notions of incapacity, as the example of the MCSS-managed system in Ontario has shown. Similar hierarchies of (in)capacity are active in Canada's immigration system and play a central role in shaping medical screening practices. Given that the IRCC had the opportunity to respond to evidence challenging the imagined cost savings of excessive demand policies (CIMM, 2017, p14), but chose not to accept CIMM's top recommendation to repeal the provision, this dissertation has looked beyond the stated reason – the imagined cost savings – and inquired into the hidden agendas that uphold excessive demand screening. This analysis is especially important given the lack of compelling evidence that could potentially legitimize the provision as a cost-saving measure. Overall, these chapters have considered why the excessive demand provision was not repealed and critiqued recent reforms for permitting the potential exclusion of migrants with disabilities who are assessed as being at the bottom of a hierarchy of (in)capacity. Furthermore, I suggest that new modes of critique that centre ID as a lens of analysis will help account for the ongoing exclusion of certain disabled migrants by exposing the hidden values that inform current assessment tools and practices. Specifically, to effectively challenge the excessive demand regime in a comprehensive way, this dissertation argues that we must focus on the concepts of incapacity and underdevelopment, with a close appreciation of the intersectional nature of these constructs and the (neo)colonial processes they support.

Moving Forward

The biopolitical processes at play in regulating access to opportunities for belonging among migrants with disabilities and adults with ID emphasize the importance of developing a displacement framework centred on disability experiences. This dissertation marks an attempt to

contribute to the design of such a framework and demonstrates its potential relevance in translocal as well as transnational contexts. The cornerstone of this analysis is an appreciation of how hierarchies of (in)capacity create the possibility for radical modes of exclusion – to the point where disabled people can experience non-citizenship even after they gain formal status. The involvement of 22 participants in this study means that the proposed framework has only been outlined, rather than fully developed. To expand upon this work, a more extensive interview process is required to test and further develop this mode of analysis. Future participant groups would also need to be large enough to allow for discussion of individual experiences and identities while preserving anonymity. As explained in Chapter Seven, in order to preserve the identities of participants, this study has not adequately accounted for the diverse and intersectional identities and complete experiences of people with ID, migrants with disabilities, and their relatives.

Additionally, future research would need to trace the impact of the reformed excessive demand criteria to confirm the hypothesis, presented in Chapters Five and Six, that some of the most adversely affected groups will continue to be migrants with ID and others who are assessed as being 'less capable'. These are, of course, groups who tend to be located at the bottom of impairment and development hierarchies as a result of their perceived incapacity. The ongoing impact of excessive demand criteria on people considered to have profound ID, single adult applicants with disabilities, and people of colour from the Global South, will thus need to be assessed in light of recent reforms. Similarly, at the provincial level, more comprehensive research is required into how developmental services and funding are accessed and how the Passport funding program is experienced. The impact of budget cuts as well as more positive developments, including strategies to introduce a supported decision-making framework, will

need to be factored into any future analysis of how people with ID negotiate non-citizenship. The reality of transinstitutionalization also requires further monitoring, as does the potential for transforming supported housing models by following examples set by other countries, provinces, and through innovative approaches to housing that are being practiced and piloted in some regions in Ontario. In recognizing the threat of displacement among persons with ID and migrants with disabilities, we must also consider possible responses that can support them in negotiating (non)citizenship status. In this regard, my analysis of interviews concurs with findings presented by myself and El-Lahib (in press), which suggest that (non-migrant) people with ID and migrants with disabilities experience particular settlement needs, and that efforts to improve services and supports for these communities would benefit from an approach to settlement that takes a much more expansive view of displacement.

Lastly, this study demonstrates how seemingly disparate law and policy areas are intricately connected through shared assumptions about disabled people shaped by a governmentality of (in)capacity and the risk of displacement. The goal of this study has been to explore assessment methods across two jurisdictions, asking how they shape opportunities for belonging and how these systems are experienced by people with disabilities and where relevant, their families. By outlining the potentially displacing effects of these systems, we can begin to see how (non)citizenship is experienced and negotiated in relation to disability. In this way, this dissertation aims to contribute to knowledge about dominant citizenship cultures by arguing for the importance of the concept of (in)capacity within these configurations.

A discussion of alternative modes of valuation, while well beyond the scope of this dissertation, would certainly benefit from these findings. The ways in which this dissertation addresses marginalization across multiple jurisdictions and communities will be particularly

helpful to future research that investigates social relations through an intersectional and critical citizenship lens. By centring hidden biopolitical processes and problematizing specific approaches to disability and belonging, this dissertation proposes that these conceptual underpinnings and the practices they support are more clearly revealed as a governmentality of (in)capacity. And while the mobilization of related hierarchies of (in)capacity can be traced across multiple cultural and structural formations impacting diverse communities, including people with ID and migrants with disabilities, the full extent of their influence remains to be seen. It has nevertheless become quite clear that we must challenge these value systems if we are to move beyond current practices and address long-standing issues of marginalization and exclusion.

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APPENDIX A: GLOSSARY OF ACRONYMS AND ABBREVIATIONS

APA	American Psychological Association
AAIDD	American Association of Intellectual and Developmental Disabilities
ADSS	Application for Developmental Services and Supports
CACL	Canadian Association for Community Living
CIMM	Standing Committee on Citizenship and Immigration
DANEO	Disability Advocacy Network of Eastern Ontario
DSO(s)	Developmental Services Ontario
ERDCO	Ethno-Racial Disability Coalition of Ontario
ID	Intellectual disability/intellectual disabilities
IME	Immigration Medical Exam
IRCC	Immigration, Refugees and Citizenship Canada
IRPA	Immigration and Refugee Protection Act
MCSS	Ministry of Community and Social Services
SIPDDA	Services and Supports to Support the Social Inclusion of Persons with Developmental Disabilities Act
SIS	Supports Intensity Scale – Adult Version™ and/or Supports Intensity Scale

APPENDIX B: SAMPLE INFORMED CONSENT FORM

Informed Consent Form

Study name
Beyond the Bounds of Belonging: Situating Citizenship in Local and Transnational Disability Policy Landscapes

Researchers
Researcher name: Natalie Spagnuolo
Doctoral Candidate
Graduate Program in Critical Disability Studies
Email address: [redacted]
Office phone: N/A

Purpose of the research
This project is in partial completion of a PhD in Critical Disability Studies at York University in Toronto.

The purpose of this research is to learn about the opportunities that are currently available to people with disabilities to participate in Canadian society. This project has several components: the first will explore the availability of services and the ways in which people with disabilities access and make use of existing services; the second component considers how people with disabilities are included as citizens in Canadian society. This project also seeks to learn about the history of services, laws, and policies that affect the lives of people with disabilities, across different jurisdictions.

This research focuses on the experiences of two groups:
1) People with intellectual disabilities
2) Immigrants with disabilities

The research will consist of interviews with people with intellectual disabilities and immigrants with disabilities, as well as their parents, siblings, community advocates, service providers, and employees from key organizations.

The goal of this research is to improve services and service delivery for people with disabilities and to promote opportunities for them to be fully included in Canadian society. This project gathers a variety of perspectives on existing policies and practices and offers participants the chance to share their own experiences and to help influence future policy proposals.

The results of this study will be disseminated to disability advocacy groups to help promote social change and encourage better services and laws for people with disabilities. The dissemination of this research will take place upon completion and may include use of study findings in reports, presentations, and publications

What you will be asked to do in the research
You will be asked to share your thoughts during one semi-structured interview. Interviews will loosely follow a guide to allow for flexibility in discussion and for related topics to emerge. These interviews are intended to be short (1-2 hours), but will not be caped if you wish to continue past the proposed length of time. Follow-up interviews are unlikely, but a single follow-up interview may be requested. You may be advised of this possibility and you will also be reminded that you may decline the follow-up request.

Risks and discomforts
It is possible that you may become upset during the interview as a result of the experiences you will be recalling:
Potential emotional risks will be minimized by allowing you to withdraw from the study at any time if you become uncomfortable. You may also choose not to answer specific questions that you may find uncomfortable.
In the event that the interview is emotionally upsetting for you, I will provide a list of resources for counseling or emotional support. I will provide you with this list before your leave the interview site or conclude the phone call.
Your participation in this study and your identity will be kept confidential.
For example, if you are a client, your service provider will not be informed of your participation. If you are a service provider, your employer and your clients will not be informed of your participation.
To minimize the risk of identification and to ensure anonymity, no identifying information will appear in any materials that are produced through this study.

Benefits of the research and benefits to you
This project provides you with an opportunity to influence possible policy recommendations. These recommendations may help advance the inclusion of people with disabilities in Canadian society.

Voluntary participation: Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision not to volunteer will not influence the relationship you may have with the researchers or study staff or the nature of your relationship with York University either now, or in the future.

Withdrawal from the study: You can stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researchers, York University, or any other group associated with this project. In the event you withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

Confidentiality
Confidentiality will be provided to the fullest extent possible by law.

Consent forms will be stored in a locked case in the present applicant’s home.

Potentially identifying information will be removed from transcripts. Audiofiles and transcripts will be given random identification numbers and will be password protected and stored on the present applicant's secure laptop computer. All un-identifying electronic data will be stored on the same computer.

Any written notes will be kept separate from other data and from the consent forms. Written notes will be digitized, anonymized, and then destroyed following completion of the interview.

All necessary precautions will be used to protect your privacy and confidentiality.

Only the present applicant will listen to the recorded interviews. The present applicant will transcribe the data.

All data associated with this study will be kept until December 1st, 2027, and thereafter destroyed.

Confidentiality will be provided to the fullest extent possible by law.

Questions about the research?
Questions about this project may be directed to,
The researcher:
Natalie Spagnuolo
Email: [redacted]

The researcher's supervisor:
Dr Geoffrey Reaume, supervisor
Email: [redacted]
Phone: [redacted]

The researcher's graduate program:
Graduate Program in Critical Disability Studies, York University
Email: [redacted]
Phone: [redacted]

This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, your may contact the Senior Manager and Policy Advisor for the Office of Research Ethics, [redacted] York University, telephone [redacted] or e-mail [redacted]

Legal rights and signatures:

I, _____,

consent to participate in **Beyond the Bounds of Belonging: Situating Citizenship in Local and Transnational Disability Policy Landscapes** conducted by **Natalie Spagnuolo**. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

_____ _____

Participant Signature Date

_____ _____

Principal Investigator Signature Date

Additional consent:

☐ I consent to being audio recorded.

☐ I consent to being directly quoted in the research (including in publications, reports, and presentations, for example) through the use of a pseudonym (fake name).

☐ I confirm that I am attending this interview as a support person to _____.

☐ I consent to having _____ attend this meeting as my support person.

☐ I confirm that I am legal guardian to _____ and I consent to their participation in this interview.