Social Service Accessibility in Montreal's English-Speaking Disability Community:

A Needs-Based Assessment

Aubrey Nash

Department of Integrated Studies in Education, McGill University, Montreal

June, 2019

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree

of Master of Arts, Education and Society

Table of Contents

Abstract

Health and social service systems can be difficult to traverse, especially in the stressful situations that often necessitate accessing them. In Quebec, these difficulties are exacerbated for English speaking or limited French-proficient persons. This thesis employs a needs-based assessment to explore how linguistic-based access barriers to health and social services affect Montreal's English-speaking Disability community, focusing on those with intellectual and/or developmental disabilities and their caregivers/advocates. It identifies the community's needs and proposes three key issues that result in the needs being unmet by the social service system. Specifically, the issues are (i) inaccessible information for limited French-proficient persons, as many important documents are available in only French; (ii) the primary method for bolstering language congruency between service users and providers relies on the service seeker to acquire French, which is incompatible with the lived experiences of many members of the Disability community; (iii) limited options for English services across Montreal. This thesis indicates the protection of the French language under the *Charter of the French Language* (1977) impacts the ability of the Act Respecting Health Services and Social Services (1991) to protect the rights of English-speaking Quebeckers to receive services in English. Through a human rights model of Disability and citizenship lens, it suggests that language laws can be understood and implemented to protect the Quebecois identity while ensuring active inclusion of otherwise marginalized communities in health and social service systems.

Résumé

La santé et les systèmes des services sociaux peuvent être difficile à franchir, particulièrement dans de conditions stressantes qui nécessite souvent d'y accéder. Au Québec, ces difficultés sont compliquées pour les anglophones ou les personnes avec une connaissance de la langue Française limitée. Cette thèse emploie une évaluation basée sur les besoins pour étudier l'incidence des obstacles liés à l'accès linguistique aux services de santé et aux services sociaux sur la communauté anglophone de Montréal vivant avec un handicap, concentrant sur celle ayant une déficience intellectuelle et / ou développementale et leur aidants ou avocats. Cette thèse identifie les besoins de la communauté et propose trois problèmes centraux qui entrainent des besoins non-satisfaits par le système de services sociaux. Spécifiquement, les problèmes sont (i) l'inaccessibilité d'information pour les anglophones, puisque de nombreux documents importants ne sont disponibles qu'en français ; (ii) la méthode principale pour renforcer la congruence linguistique entre les utilisateurs et fournisseurs de services dépend du demandeur de service pour acquérir un certain niveau de français, ce qui est incompatible avec les expériences vécues par de nombreux membres de la communauté des personnes handicapées ; (iii) des options limitées pour les services en anglais à Montréal. Cette thèse indique que la protection de la langue française par *la Charte de la langue française* (1977) influe sur la capacité de *la Loi sur les services de santé et les services sociaux* (1991) de protéger les droits des Québécois anglophones de recevoir des services en anglais. Au moyen d'un modèle de droits de l'homme axé sur le handicap et la citoyenneté, cette thèse suggère que les lois de la langue peuvent être comprises et appliquées pour protéger l'identité Québécoise tout en assurant l'inclusion active de communautés autrement marginalisées au sein de systèmes de santé et de services sociaux.

Acknowledgements

I gratefully acknowledge the support, commitment, and expertise of my thesis supervisor, Dr. Naomi Nichols. My development as an engaged scholar would not have been possible without Dr. Nichol’s thorough and passionate engagement with my work throughout the entirety of my time at McGill University.

The research that developed into this thesis was made possible with the financial support of the Health Care Access for Linguistic Minorities Network, a fellowship program offered by the Institute for Health and Social Policy. Thank you to Dr. Yael Peled for her feedback and encouragement.

I sincerely thank my dear friends Gabriella Volpe and her child for welcoming me into their lives. My friendship with these individuals provided invaluable insights to Montreal’s Disability community, as well as taught me to appreciate the wonder of doors.

Thank you to Danielle, Tanya, Sandra, and Harvey for their expertise, time, and participation in this research.

My appreciation to Michael Jaeggle for reading and discussing this work and to Christian Favreau for English-to-French translations. Their skill and generosity shines.

Finally, I acknowledge that this thesis was completed on unceded Indigenous lands, of which the Kanien’kehá:ka Nation is the recognized steward.

> Raising a child with special needs brings parents to their knees. The fears, anxieties, the worry, the concerns, the doubts, the panic. We get to know these feelings at their core. We face uncertainties within the diagnosis. We hand over our child to professionals with uneasiness. We search for answers and solutions and explanations and justifications. All to ease our fears.
> We are afraid.
> We are endlessly preoccupied.
> It eats away at our well-being and sometimes wears out our bodies.
> I fear the future for my son in ways most parents never have to. Knowing the unknown is coming is probably the greatest turmoil a parent has to conquer.
> So, I look for courage within the chaos of my mind with some comforting thoughts.
> (Volpe, "Restoring courage," 2018)

Introduction

It is important to me that this thesis has opened with the words of someone deeply engrained in the Disability community—a strong, passionate, and vulnerable mother—rather than with my own. It is crucial that this thesis reflects the experiences of this community as I navigate the ways in which this community has shaped me. I have been working with persons with disability[1] for most of my adult life. I've worked in schools, homes, and care facilities. I met Volpe (2018) and her son when I moved to Montreal to pursue graduate studies. I formed a strong friendship with the boy, one that has inspired this thesis. My friend is part of the English-speaking[2] Disability community in Montreal. He is loud, funny, and extremely communicative, though is non-verbal; his mother is his unwavering voice. His reality is that eventually he will need additional support that will be beyond the capacities of his mother; it is a reality for many

---

[1] Throughout this thesis, I have used what is termed *people first* language, such as "person with disability." Such a linguistic structure is typical in contemporary discourse and literature on disability. However, I acknowledge that this structure does face criticism for being grounded in the medical model of thinking (Shakespeare, 2017). Furthermore, however cumbersome the term "person with intellectual and/or developmental disabilities" is, I use this phrase in full. I worry acronyms, such as the typical "PWD" [person with disability], implicitly levels the differences between the individual experiences of having a disability.

[2] For this research, English-speaking refers to someone who is more comfortable speaking English than French, but whose first language may or may not be English.

persons with disability who will never live completely independently. The research I have completed on Montreal's disability social service system for English-speaking persons is my way of working toward assurance that my friend will continue to live a comfortable, safe, happy, and purposeful life as his support system changes to meet his needs. Having completed this research, I hope to provide insights into the realities of traversing the public disability support network that will aid families and advocates of persons with intellectual and/or developmental disabilities[3] in achieving fair access to support in a Montreal context and beyond.

This research critically examines the accessibility of social services for English-speaking persons with intellectual and/or developmental disability in Montreal. Social services refer to services that enable autonomy and integration, including but not limited to respite care,[4] work integration programs, community integration programs, socialization groups, and independent living environments. While this thesis focuses on social service provision and acquisition rather than that of health care, I understand social service access to be inalienable from matters of health. For example, long-term residential care settings provide both health care (e.g. administering of medications) and social care (e.g. life skills support and socialization opportunities). As wellness is greatly impacted by both social and health services, and, as the World Health Organization [WHO] (2009) notes, "the borderline between health care and social care varies from country to country, especially regarding social services which involve a

---

[3] The term "developmental disability" refers to disability that becomes evident during the time of development (often considered to be birth to age 18-22), while an intellectual disability may occur at any point of life, such as through a traumatic brain injury (Mason & Smith, 2005). The term 'developmental disability' frequently encompasses intellectual disability and the two terms are often used interchangeably. I use both terms throughout this thesis to account for the fact that certain groups in Disability communities define themselves as having a developmental disability, not an intellectual one.

[4] Respite care offers temporary care for a dependent person through programs such as community or work integration or residential care, providing relief for their habitual caregivers.

significant, but not dominant, health-care component" (p. 242), this thesis will discuss specific social service matters often framed within a wider discussion pertaining to health care. Furthermore, in Quebec, health care and social services are overseen by the same institutional bodies: centres intégrés de santé et de services sociaux (CISSS) [integrated health and social services centres] and centres intégrés universitaires de santé et de services sociaux (CIUSSS) [integrated university health and social services centre].

This research was provoked by the suspicion that Montreal's health and social service systems prioritize French-speakers' access to disability related social services. I understand prioritization to be more nuanced than simply providing the Quebecois population advanced access to services. In this context, prioritization occurs by assuming everyone knows French or is able to acquire the language. As a result of this assumption, those who do not meet this perquisite for care experience unmet needs. I have found that the English-speaking community often must wait years before receiving access to an English-speaking support worker who can aid them in accessing further services. While wait times for such services are also expected for the Francophone community, the language barrier that negatively impacts acquisition of a social worker is consequential only to the minority language speaker, resulting in additional expected wait times for English-speakers and limited access to social services. Prioritizing access for majority language speakers to services which impact physical, social, and mental-wellbeing impedes on the right to health for persons living with disabilities (World Health Organization, 2002).

Health and social service providers shape the meaning of Disability[5] in Quebec (as elsewhere in Canada) by creating and administering "an array of techniques for service provision, personal support, and social control" (Prince, 2009, p. 191). Persons with disability make up a structurally oppressed demographic in a society designed not for them, but for the able-bodied.[6] The level of power yielded by institutions over this systemically oppressed population must be carefully considered and institutional service providers[7] must be held accountable. At the same time, providers should work under policies that do not have the effect of privileging one group or identity over another.

With the aforementioned in mind, I have investigated the social impacts of language-based policy on English-speaking persons for whom families are seeking social services and considered their expressed life contexts in order to assess whether their needs are being met by care-providing institutions. Section fifteen (15) of the Act Respecting Health Services and Social Services (1991, chapter S-4.2) states that "English-speaking persons are entitled to receive health services and social services in the English language." Nevertheless, an English-speaking primary caregiver's ability to locate and assess the acceptability of potential programs is made difficult by the fact that many important documents are available by Santé Montreal, Montreal's health

---

[5] When I capitalize the 'd' in Disability, it is because I am referring to Disability as a unifying identity marker. When disability appears with a lower case 'd,' I am simply referring to disability as something experienced by some people; it carries no value judgement, it simply *is.*

[6] For example, wages for and hours worked by persons with disabilities in Ontario are "significantly below the provincial average for all employees" (Wilton, 2006, p. 136). Additionally, accommodation at universities often occurs only after a student self-identifies as disabled, thereby placing students with disabilities at an academic disadvantage (Hibbs & Pothier, 2006, p. 197)

[7] As this thesis considers systemic processes that impact accessibility, service providers are discussed at the institutional level rather than focussing on the individual workers.

and social service network, in French only.[8] In cases where patients and health care providers do not speak the same language, patients consistently report lower satisfaction with their care than in situations wherein a language is shared (Bowen, 2001). Dissatisfaction resulting from linguistic barriers is also apparent in information-seeking endeavors through online promotions of programs (Bowen, 2011, p. vi). In an effort to bolster language congruency, Quebec offers subsidized French language classes. The assumption of available time and cognitive resources required to succeed in these classes disregards the life contexts of Disability communities. It also allocates the onus for language congruency to the individual, rather than the service institution.

In order to comply with the Act Respecting Health Services and Social Services (1991), Montreal's health and social service institutions are categorized by languages offered. Of the five institutions, two must provide all services in English and French. This means that Montreal's English-speaking community, which makes up 15.2% of the island's population, is served by 5.9% of the health and social service institutions[9] (2016 Canadian Census Profile on Quebec Languages). While the three remaining institutions must have some programs available in English, this thesis will show that their availability is essentially tokenistic: a largely symbolic gesture toward inclusivity.

---

[8] As verified on the five centres intégrés universitaires de santé et de services sociaux websites. Chapter Five further explores this topic.

[9] I refer to the island of Montreal as simply "Montreal," though the island and the city of Montreal are actually distinct. When referring to the five CIUSSS organizations of Montreal, rather than using the French names, I simplify them and name them in English. Therefore, CIUSSS du Nord-de-l'Ile-de-Montreal is referred to as Montreal North CIUSSS, CIUSSS du Centre-Est-de-l'Ile-de-Montreal is referred to as Montreal East CIUSSS, CIUSSS du Centre-Sud de l'Ile-de-Montreal is referred to as Montreal South CIUSSS, CIUSSS du Centre-Ouest-de-l'Ile-de-Montreal is referred to as Montreal Centre-West CIUSSS, and CIUSSS de l'Ouest-de-l'Ile-de-Montreal is referred to as Montreal West CIUSSS.

While inequitable access is likely a result of a range of factors, effective communication is the principal basis for assessing accessibility, as assessments have potential to reveal the heterogeneous contexts that intersect to impact life experiences (Bowen, 2001, p. 1). Following from this, it should be noted that the aim of this research was not to compare the Anglophone system to the Francophone one, as such an analysis would inaccurately suggest Francophone communities are adequately served, while in actuality, disability services are lacking across Canada and across linguistic borders (Every Canadian Counts, 2014). Rather, the aim was to determine whether language poses an *additional* and avoidable barrier to access for minority English-speakers in Montreal, and how English minority speakers seeking services understand the relationship between their received care and their language preferences.

Study Aims

Taking all the above into consideration, this research has addressed the following inter-related questions: **(1)** How does access to social services influence the felt impacts of the prioritization of disability support services for those with intellectual and/or developmental disability and their caregivers? **(2)** With regard to linguistic barriers, what availability, accessibility, and acceptability needs *are* and *are not* being met by Anglophone disability services for the English-speaking Disability community in Montreal? I have found that members of Montreal's English-speaking Disability community feel frustrated and excluded by public social service providers. While there is awareness that the Francophone population faces access barriers as well, the linguistic-based needs and barriers are apparent for low-proficiency French-speakers.

In sum, this research considers the experiences of those often overlooked by policy actors and service providers, those hybrid persons who are, whether inadvertently or intentionally, designated to the periphery of society (Tyjewski, 2006, p. 107). These hybrid persons are the English-speakers who are also linguistic minorities; they are the linguistic minorities who are also the disabled. This research interrogates the design and implementation of language laws that not only disadvantage English-speakers, but collaterally harm members of the Disability community, underwriting the reality that "we live in a world relentlessly oriented to the able-bodied" (as cited in Devlin & Pothier, 2006, p. 13).

Theoretical Perspective

I have interpreted the needs of Montreal's English-speaking intellectual and/or developmental Disability community through a citizenship lens to best understand and analyze the relationship between rights and responsibilities, access, and belonging (Rioux & Valentine, 2006, p. 55). The notion of citizenship is grounded in a human rights approach to Disability as a conceptual framework for this research. Such an approach views Disability as a consequence of the organization of society and the relationships that therein reside. The marriage of citizenship and a human rights model of Disability directs a researcher to pay attention to how policy and law inhibit or facilitate equal participation in society (Rioux & Valentine, 2006, p. 52). Employing a citizenship lens and a human rights model has allowed me to consider laws, policies, and legal justice in my analyses. Such consideration coincides with the Supreme Court of Canada's statement that the "mere recognition of the equality rights of one group cannot, in itself, constitute a violation for the rights of another" (as cited in Devlin & Pothier, 2006, p. 11). In other words, the recognition of rights for Francophone Quebecois must not undermine the rights of English-speaking persons living in Quebec. Understood in relation to this research's aims, the rights of a linguistic community must not be allowed to disadvantage Disability communities who already face systemic societal oppression. This thesis identifies key needs of the English-speaking Disability community of Montreal and posits three issues that have resulted in these needs being unmet. These issues are (i) reduced access to information due to linguistic barriers; (ii) an approach to language congruency (i.e., intelligibility through a shared language between the service user and service provider) that is inconsiderate of the life-contexts of Disability communities; (iii) tokenistic or perfunctory rights that I attribute to practices of what Bowen (2001) terms "linguistic ghettoization"[10] (p. 4). The three identified issues each stem from linguistic elitism and general ableism through rigid implementation of protectionist language policies that starkly contrast with the Supreme Court of Canada's statement on stratification.[11]

Disability Support Service Provision Across Canada

In Canada, up to 69% of the families of persons with severe disabilities do not receive adequate support (Tétreault, Blais-Micaud, Deschênes, Beaupré, Gascon, Boucher, & Carrière, 2014, p. 272). The lack of support and long waitlists result in families experiencing both internal and external pressures, such as excess stress and economic struggles (Tétreault, et al., 2014, p. 273). As service gaps persist, informal family or charitable care is utilized to fill these gaps when possible. When such options are not possible, isolation and unmet needs ensue (Prince, 2009, p. 208). Respite care positively influences the health and wellbeing of caregivers for those with

---

[10] While this term acutely encompasses the process of restricting a group to an isolated area, I acknowledge that the region under the jurisdiction of CIUSSS West and Centre West is both affluent and is the chosen home to many Jewish residents. The comparisons between this region and a ghetto are appropriate only in the context of linguistic segregation.

[11] A recent event at a hospital in Lachute, Quebec exemplifies linguistic elitism. The hospital removed English from all signs which left community members worried that their quality of care and availability of services would be reduced for English-speakers (McKenna, 2019). In this example, the intended outcome of language laws, to recognize Quebecois culture and protect the French language from English shift, violated the rights of English-speakers.

disability, as support reduces psychological stress associated with care provision (Mullins, Aniol, Boyd, Page, & Chaney, 2002).

Those residing in Canada are fortunate to receive universal medical coverage under the Canada Health Act: “The primary objective of Canadian health care policy is to protect, promote and restore the physical and mental well-being of residents of Canada, and to facilitate reasonable access to health services without financial or other barriers” (Canada Health Act, C.6 S.3, 1984). The Canada Health Act (1984) requires that provinces “provide for insured health services on uniform terms and conditions and on a basis that does not impede or preclude, either directly or indirectly, […] reasonable access to those services by insured persons” (C.6 S.12a). As Bowen (2001) points out, however, “because access is not defined, it is not clear what would constitute reasonable access. Often, access is defined simply as the absence of explicit financial barriers (such as user fees)” (p. 16), thereby removing access from any conversation with the *Canadian Charter of Rights and Freedoms* (1982) which protects Canadians from discrimination (Section 15). If linguistic barriers precipitate a lack of access to social services which results in a loss of “life, liberty and security” (Section 7), only then can impediments to access be unlawful. However, as accessing social services is financially feasible due to Canada’s universal health care system and the *de facto* definition of access refers only to financial contexts and conceptions of life, liberty, and security that are typically not understood to be at risk (Bowen, 2001, p. 16-8). In Canada, access to health and social services is always available, though decade-long delays are often expected. The relationship between rights, health care, and under-accessible service options is a central problem for persons seeking care and support in Canada.

Disability Support Service Provision in Quebec

Quebec waitlists for disability support services are the third longest in Canada, following Ontario and British Columbia (Every Canadian Counts, 2014). Approximately 11% of Quebec's population has a moderate to severe disability and the rate of disability among children in Quebec has been steadily increasing since 2001 ("The health and wellbeing of Quebec's population," 2014). English-speaking Montreal residents with disabilities form a marginalized minority group within the dominant French-speaking society and the exclusionary, if not ableist, society at large. Options for social services for English-speakers in Quebec are limited, as most services are available exclusively in French. While under the Act Respecting Health Services and Social Services (1991), English-speaking persons are entitled to receive services in English, this right is realistically attainable only when relocating to a linguistic ghetto (that is, specific geographic locations on the island of Montreal where English services are provided), diminishing "genuine inclusiveness" and instead producing ineffective "abstract rights" (Devlin & Pothier, 2006, p. 2). Despite the difficult realities faced by many English-speaking persons in Quebec, the legislative measures in place both protect the French language and are "designed to guarantee access of the English-speaking minority linguistic community to health and social services in the English language" (Prata, 2015, p. 6). The Act Respecting Health Services and Social Services states:

> Toute personne d'expression anglaise a le droit de recevoir en langue anglaise des services de santé et des services sociaux, compte tenu de l'organisation et des ressources humaines, matérielles et financières des établissements qui dispensent ces services et dans la mesure où l'on prévoit un programme d'accès à l'article 348 [Every English-speaking person has the right to receive health services and social services in the English language, in accordance to the organization and human, material and financial

> resources of the institutions providing those services and to the extent that there is a program of access via article 348[12]]. (1991, L.R.Q., c. S-4.2, a. 15)

There is a degree of ambiguity with the Act's language which should be foregrounded: institutions must comply only to the level of their available resources. The intention of this law is to protect English-speakers. However, in practice, it protects the care providers who are able to rely on the law's phrasing if they are questioned about limited English language services. They are permitted to continue operating with programs that are not sufficiently resourced to carry out their legal mandate.

After Bill 10[13] was adopted on February 9th, 2015, the governing of Quebec's health network was reorganized, decreasing the number of health network institutions from 182 to 34 (Prata, 2015, p. 6). The much smaller network is designed to simplify service acquisition, as there is now just one point of access for each region. Montreal is divided into five regions: Montreal North, Montreal East, Montreal South, Montreal Centre-West, and Montreal West. Each of these regions has its own CIUSSS which oversees the region's various *centres local de services communautaires* (CLSC) [local community service centres] and other public health or social service related service providers. Aligning with the Act Respecting Health Services and Social Services' (1991) prescribed right to access services in English, these CIUSSS institutions are then classified as being either indicated or designated. An indicated institution is "identified in an access program as being required to offer at least one service or one service program in the English language" (Ministry of Health and Social Services [MSSS], 2006, p. 27). A designated

---

[12] My own translation.

[13] Bill 10 is otherwise known as an Act to Modify the Organization and Governance of the Health and Social Services Network, in Particular by Abolishing the Regional Agencies.

institution is “required to make the health and social services it offers accessible in the English language to English-speaking persons” (p. 27). In other words, all of the services offered at a designated institution must be made available in both English and French. A designated institution is so selected based on its status of being recognized as serving a majority of clients who speak a language other than French, typically English, though there are some institutions recognized for other languages outside of Montreal. Montreal’s indicated institutions are Montreal North CIUSSS, Montreal East CIUSSS and Montreal South CIUSSS. The islands two remaining CIUSSSs are designated institutions: Montreal Centre-West CIUSSS and Montreal West CIUSSS. These two designated institutions on the island of Montreal signal the location of a linguistic ghetto within a larger French language majority context.

Noting the harmful trend of limited access for the Disability community, the Centre for Research-Action on Race Relations (CRARR) has recently filed a “major complaint of systemic discrimination based on disability (autism) intersecting with language and social condition against an English-speaking school board” (CRARR, 2018, para. 1). The same organization has also recently intervened in what they call a case of language-based discrimination against persons with disability in Quebec, particularly in the South Shore region, an off-island suburb near Montreal (Schwartz, 2018). Such action against language discrimination reveals the prevalence of linguistic barriers against persons with disability in the Montreal area.

While the English Montreal Schoolboard is, according to CRARR, responsible for gatekeeping service acquisition based on language, Miriam Home and Services is also under scrutiny for its service provision. Miriam Home is the largest organization in Montreal offering bilingual French/English services to persons with intellectual disabilities. Exhibiting the limitation of access to respite care for English-speaking individuals, in November 2017, Miriam

Home and Services opted to tackle its long waitlist by reallocating its community integration program from their aging service users to those “transitioning from school to rehabilitation services” (Hendry, 2017). The organization will permit access to their services by prioritizing individuals based on who has “the potential to learn new skills” (Hendry, 2017). Such rationing of health care based on a priority model follows the “natural lottery” (Kenny, 1999, p. 115) of health care, which commodifies health by imbuing the service with economic, rather than ethical value (Kenny, 1999, p. 109). As the social service system in Montreal assumes service seekers speak French, so too does Miriam Home and Services assume potential for some, and therefore, inadequacy for the rest.

The Linguistic Landscape of Quebec

The *Charter of the French Language* (1977) states that Quebec’s official language is French. Quebec’s linguistic landscape is, nevertheless, varied. Noting the importance of creating equal opportunities for linguistic minorities in Canada, the federal government has recently revealed its action plan regarding official languages, which will fund organizations serving minority-language users (Crete, 2018). What follows is a brief account of Quebec’s varied linguistic landscape, as given by the 2016 Canadian Census on Quebec Languages.

In 2016 there were 8,066,560 census respondents. Half of Quebec’s population knows only French (49.9%). The other half of the population is split between being bilingual in both of Canada’s official languages (44.5%), knowing only English (4.6%), or knowing neither official language (0.9%). French is the dominant mother tongue[14] for most Quebeckers (77.1%). English

---

[14] Mother tongue is the first language acquired from birth and is generally considered to be the preferred language in stressful or emotional situations such as when seeking health or social services (Oimet, Trempe, Vissandjée, & Hemlin, 2013, p. iii). It is the terminology used by the Canadian census and is used in this thesis interchangeably with “first language.”

is the mother tongue of 7.5% of the population, while 13.2% of the population has a mother tongue that is neither English nor French. As English is a common international lingua franca, it must be noted that 628,640 people, or 7.8% of Quebec's population, speak only English or English plus a non-official language. More generally, 1,103,475 people in Quebec, or 13.7% of Quebec's population are English-speaking. While the mother tongue is neither French nor English for 13.2% of Quebeckers, only 7.3% of the population speaks a non-official language at home. These figures are indicative of Quebec's language policies which support the acquisition of French and make it difficult for one to integrate into the Quebec society without French fluency (Bowen, 2001).

Focusing on Montreal's linguistic landscape, wherein, according to data presented by Statistics Canada, more English-speakers of Quebec live than any other Quebec region, English-speakers are more highly represented. Categorizing the island of Montreal into the same regions that the five CIUSSSs follow, Montreal North is home to 21.1% English-speakers, which is 88,805 people. Montreal East, the most homogenously French region, is home to 14.9% English-speakers, or 75,135 persons. Montreal South is home to 26.6% English-speakers, or 78,410 people. The most dominantly English-speaking regions of Montreal are Montreal Centre-West and Montreal West, where 54.8% or 186,870 residents and 55.6% or 195,780 residents, respectively, speak English (2016 Canadian Census Profile on Quebec Languages). This means that there are 625,000 English-speakers on the island of Montreal, or 15.2% of the island's population speak English. Recalling that approximately 11% of the population has a disability, one expects Montreal to be home to roughly 68,750 English-speaking persons with disability.

Thesis Structure

This thesis identifies key barriers to access to social services, then provides information on causes for these barriers. The thesis concludes with my recommendations informed by the research.

Chapter One introduces different models of disability, detailing the evolution of scholarly understandings of the dimensions and constructs of disability. Chapter Two introduces notions of citizenship rights. Chapters One and Two together describe my conceptual framework. Chapter Three describes the methodology and methods employed in this research, as well as discussing the ethics of representation. Community voices are present in Chapter Four, which provides insights from interviews and observations that led to my identification of the Disability community's needs. Chapters Five and Six identify three central issues that result in the community's unmet needs. Chapter Five explores inaccessible information as a central issue negatively impacting the target community. Chapter Six explores practices of linguistic congruency and linguistic ghettoization as additional central issues affecting the community. The final chapter provides my recommendations for moving forward with equitable policies.

Chapter One: Conceptualizing Disability

This chapter explores common models of disability, culminating in the argument that the human rights model of Disability is the most beneficial to advancing the aims of my research. The human rights model of Disability states that disability is not a deficit; it is often the result of and exacerbated by societal failures to accommodate, adapt, and include somatic and intellectual differences. This model also contends that it is the right of the person with disability to seek measures that minimize the expressions of their disability, should they so choose (e.g., through medications or therapies). The human rights model of Disability also supports this research in critically examining the ways in which the Quebec social service system responds to linguistic barriers within an already marginalized community of persons with disability and their advocates.

United Nations' Reconceptualization of Disability

The United Nations adopted the Convention for the Rights of Peoples with Disability (CRPD) in 2006 after a negotiation period of four years. Unlike the previous objectifying model of disability (which emphasized treatment of a so-called impairment), it employs a model that emphasises an explicit "social development dimension," adopting "a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms" (United Nations [UN], n.d., Division for Social Policy section). The goal of the CRPD is to "fight discrimination in relation to a wide range of rights that are often not accorded to persons with disability" (Rouger, 2009, p. 40). The CRPD emphasizes that a failure to protect and uphold human rights signals neglect as well as deliberate oppression. Such an expansive focus on human rights issues for persons with disabilities offers a significant example of positive outcomes to reconceptualising disability by representing a platform for change through policy and litigation (Disability Rights International [DRI], 2014, Home section). The inclusion of these factors in Critical Disability Studies has brought about a new model of disability: the human rights model of Disability.

Historically, attempts to support persons with disability were made using the medical model of disability, which aimed to fix disability, situating the disability as an impairment within the disabled body. In response to this model, the social model of disability situates disability in society, targeting social barriers that maintain oppression against persons with disability. The social model has been widely adopted, particularly in developed nations (Shakespeare, 2017). In fact, the CRPD's shift from the medical to social model is often cited as its principal achievement, though the CRPD's human rights orientation extends beyond the social model to the human rights model (Degener, 2017, p. 42). The extension is due to the CRPD's attention to policy change grounded in "moral principles" (Degener, 2017, p. 43) and emphasis on prevention, both of which are approaches that the social model resists (Shakespeare, 2017).

Critical Disability Studies

Critical disability studies respond to "the limitations of medicality" (Meekosha & Shuttleworth, 2017, p. 177) which have led to an overuse and overabundance of institutionalization and medical intervention for persons with disability (Meekosha & Shuttleworth, 2017, p. 176-7). The goal of CDS is "to conceptualize a diversity within a radical agenda to restructure cultural meanings, social processes, and a carnally relevant politics" (Meekosha & Shuttleworth, 2017, p. 182). Stated more simply, CDS aims to critically reflect on culture, society, and politics through an interdisciplinary and inclusive intersectional approach. It does not aim to dismantle medical and social services that are interested in the treatment and prevention of disability; rather, CDS acknowledges its close relation to rehabilitation. Intersectionality, first coined by critical race theorist Kimberlé Crenshaw to discuss Black women’s experiences with employment security, has now become a means to help elucidate how forms of social subjugation overlap, compound, and intersect (West, 1995). In critical disability theory, this lens presumes a “disabled person is not only disabled, but also has a gender, class position, ethnicity, age and sexual orientation. An intersectional perspective entails analysing how these variables intersect” (Lundberg & Simonsen, 2015, p. 9). The rehabilitation sector of health care is a platform for potential change if they “more fully integrate a critique of disabling structures into their approaches” (Lundberg & Simonsen, 2015, p. 178). Accordingly, CDS calls on applied disability disciplines to draw from the work of CDS to better their practice, not to replace their conceptual orientations with a more critical one.

Previous approaches to understanding and theorizing disability have adopted frameworks such as the social constructivist model (Lundberg & Simonsen, 2015, p. 177). This work has resulted in the dichotomizing of disability that isolates the body and draws dualistic comparisons between the individual to the society and impairment to disability (Lundberg & Simonsen, 2015, p. 182). Contemporary CDS aligns with a postconventional theoretical approach which “seeks to extend and productively critique [such] modernist paradigms of disability” (Lundberg & Simonsen, 2015, p. 177). As postconventional theories correlate with a recognition of civil and human rights, it is unsurprising that CDS would employ a human rights model of Disability (Emler, Tarry, & St. James, 2007).

Social Model of Disability

Before discussing in detail the human rights model of Disability, I will address the strengths of the social model in which the human rights model grounds itself, and identify weaknesses that the human rights model addresses. Michael Oliver coined the term ‘social model of disability’ in 1983 (Shakespeare, 2017, p. 197). The social model responds to the implications of the disabling politics of the medical model: deficit-based assumptions that “disabled persons need to have shelter and welfare, and impairment can foreclose legal capacity” (Degener, 2017, p. 42). Such assumptions place human rights at great risk, though the social model targets the foundational discriminatory elements of these assumptions before the human rights model can address the politics of oppression. The social model works by distinguishing disability from impairment, where the former evokes social exclusion and the latter involves physical limitations (Shakespeare, 2017, p. 197). Such a distinction is analogous to the dichotomous structure of the constructivist model which CDS criticises.

The social model takes this thinking further, distinguishing not only disability from impairment and the social from the individual, but also the disabled person from the non-disabled one. In so doing, disabled people are understood to be explicitly oppressed by non-disabled people and their ableist society (Shakespeare, 2017, p. 198), wherein ableism refers to “the process of being defined from the outside, positioned, and placed, by a network of dominant meanings” (Young, 1990, p. 59). This simple binary is a purported strength of the social model of disability, for it presents a straightforward means to distinguish “allies from enemies” (Shakespeare, 2017, p. 198). Another strength of this model is that it has been “effective *instrumentally* in the liberation of disabled people” (Shakespeare, 2017, p. 198). Proponents of the social model implement it as a tool, rather than a theory or concept. It places responsibility on society to enact positive change towards social inclusion and equity. I hesitate to make such a distinction between engagements with theory and policy, as I believe it to be our responsibility to put theories into praxis when appropriate. That said, the social model has undoubtedly been beneficial and has paved the way for more inclusive and understanding societies. For example, Canada’s Accessibility Advisory Committee oversees issues related to accessible transportation, adapting and accommodating transit options to suit those with disability (Canadian Transportation Agency, 2017). Had the social model not highlighted the ways in which society, including public transportation systems, disable bodies through use of stairs, gaps, and unvoiced visual signals, these systems would not have changed. A final strength of the social model I will discuss is closely related to the previous point. The social model has been “effective *psychologically* in improving the self-esteem of disabled people” (Shakespeare, 2017, p. 199). The improvements result from holding society responsible for enacting change. Thereby, “the person with disability is not to blame for her inability to meaningfully participate in society” (Shakespeare, 2017, p. 199). She may be instilled with “anger and pride” (Shakespeare, 2017, p. 199) rather than self-pity.

Perhaps the most obvious issue with the social model of disability is that in its vehement demarcation between the individual and society, it implies impairment is not a problem, evinced by its rejection of medicalization through prevention, rehabilitation, or cures (Shakespeare, 2017). Certainly, the blind woman is disabled by a society that offers no Braille or audial options. However, it is her blindness that inhibits her from accessing her goal to pilot an aircraft, not the fault of a safety system that requires that pilots have perfect sight. On a similar note, another weakness of the social model is that it presupposes that people with disability are oppressed. In feminist studies, gender relations may involve oppression, but they may also empower. In the social model, oppression is an integral and inalienable component of the Disability identity. Finally, the social model imagines a barrier-free world, or as Shakespeare refers to it, a “utopia” (Shakespeare, 2017, p. 200) which places an insurmountable responsibility on society. Different people and different disabilities require different adaptations. The wheelchair user prefers ramps; the blind person with a cane prefers stairs. The student with a learning disability may require individualized lesson plans, and the student with autism may require reduced stimulation. The social model claims to be a tool rather than a theory, but when it comes to the issue of barriers, its utopian limitations mean that in reality, it can only theorize what may be an unrealizable dream. The weaknesses of the social model all involve its grounding in a differentiating view of disability and impairment. It thereby fails to account for impairment as having a hand in difficult experiences, thus creating a Disability identity that demands combative strength and anger. The passive person with disability must therefore be viewed as bowing down to an oppressive society, unable to be content in both her individual body and collective society. The social model deters the person with disability from seeking therapies to reduce the presence of disability in one's life. As this research revolves around such support services, the human rights model provides a more applicable and socially-conscious model of disability.

Normative Model of Disability

The human rights model of Disability is an evolution of the social model. It builds from the social model's work in redefining the roles of ability and disability within society and recognizes the downfalls of a medical model whose sole intention is to fix the impaired body. That said, its focus on policy, prevention, and uptake in a global frame necessitates that it be both grounded in a critical approach, while utilizing a normative lens. Brown's dissertation (2011) discusses the normative model on which the human rights model draws. It is a response to what he considers to be limitations of both the medical model and social model of disability. Brown's normative conception of disability posits that "disability is a functional impairment that adversely affects a person's vital functions for well-being compared to the relevant reference group in a specific environment" (p. 48). That is, he considers disability to be entirely context-dependent. Brown accords with the social model in distinguishing disability from impairment. However, his focus is on the status of impairment. Supposing impairment is related to normality, he argues that such a normative idea is linked to the notion of well-being. Therefore, “disabilities reduce our well-being” (Brown, 2011, p. 48). However, a process is only disabling if our welfare is at risk. To clarify, Brown argues that the medical and social models of disability ignore either the social contribution to disability, or ignore the “importance of impairment in causing disability” (p. 51), respectively. Noting the irrefutable issue of applicability of either model in his determined contradiction between lived experiences of disability and the models’ conceptualization of disability, Brown provides a third position: a normative conception wherein “disability is an interaction between both biological and social forces that undermines our basic welfare needs” (p. 51). Welfare is a crucial element of the normative model. Brown bluntly reasons that “disability is *bad* for a person” (p. 56). In this sense, welfare would be unquestionably harmed by disability. Well-being is rooted in our “personal goals,” and Brown states that disability affects our ability to achieve these goals (p. 57). For example, a person with a quadriplegic spinal cord injury cannot meet his goal to be an Olympic high jumper because such a sport involves use of nearly all muscles in the body. Such incapacity is an objective truth of his disability. Brown suggests in disability studies that we do not reject subjective disability assessments, but rather we should balance the subjective and objective “elements of well-being” (p. 61). I do not agree with all elements of the normative model, particularly for its absolutist view of disability as “bad” rather than the more nuanced view of disability as an integral aspect of one’s being in the world and a possible impediment to one’s presence within it. I do, however, see that a model which addresses impairment is necessary to fully address disability. A normative model has potential to create a foundation for policy that better provides “the care and support that people with disabilities need” (Brown, 2011, p. 85). The human rights model utilizes this practical foundation by invoking a normative framework into a justice and equity oriented objective.

Theories of Justice and Disability

Eva Feder Kittay's (2017) critiques of justice complement my use of the human rights model of Disability. In Kittay's discussion on theories of justice, she notes ways in which prominent theories exclude the person with disability, as they do not consider her to be a personhood or moral agent, that is, a "subject due justice" (p. 306). Taking issue with exclusion while recognizing the need for an inclusive understanding of justice, Kittay offers a definition of justice grounded in the idea of interdependency. Justice, she writes, "provides the *fair terms of social life given our mutual and inevitable dependency and our inextricable interdependency*" (p. 306, emphasis hers). Kittay's alternate theory incorporates two seemingly contradictory elements, inevitable dependency and inextricable interdependency, and supports the normative model's endeavour to provide the aforementioned "care and support people with disabilities need" (Brown, 2011, p. 85). The foundation for both elements of dependency is the critique of our unwavering pursuit for independence. By way of illustration, Kittay describes the relations formed in the workforce. Staff members are dependent on their bosses, entrepreneurs on their customers, etc. Particularly for those with disability, entering the workforce offers "independence from certain oppressive conditions" (Kittay, 2017, p. 307). At the same time, it does not grant total independence, as the person simply transfers dependence to a different, ideally more respectful condition (Kittay, 2017, p. 307). It is important to note here that (inter)dependency and independency are relative terms, contingent on predetermined norms, social institutions, and physical structures designed by humans. One cannot be said to *be* independent. Rather, within a particular environment and with appropriate social supports, she can *function* with relative independence (Kittay, 2017, p. 307-8). That is to say, a theory of justice which insists on independence and seeks to organize society in such a way as to avoid dependency is inherently limiting as it denies citizens the right to express their disabilities.

Kittay (2017) notes that the Disability community defines independence as including “the vast networks of assistance and provision that make modern life possible” (as cited in Davis, 2007, p. 309), meaning that with relative independence, there remain some residual dependencies. The social model emphasizes that these feelings of dependency are forced upon the body by a disabling society. The more normative nature of the human rights model instead imprints the inescapable nature of dependency onto its model, allowing for rehabilitation and support services for disability that aim to encourage the person with disability to reach their highest potential.

Kittay (2017) concisely states “we are inextricably interdependent” (p. 307); there is no situation in which we are not engaged in a social arrangement. Crucially, this is not something to be avoided. Interdependence through caring for each other and forming reciprocal relations with different people is a “fundamental reason human beings join together in social arrangements” (Kittay, 2017, p. 307). For example, caregivers to persons with disability benefit from their relationships with their clients in different ways to the persons for whom they are caring. These relationships are, nonetheless, mutually important to the client and caregiver. Whether this be a sense of purpose, financial security, or engaging with different perspectives, the caregiver benefits from this relationship. If we apply the social model’s target of independence to the caregiver/client relationship, the barrier-free environment caregivers have prepared for their clients grants the clients a greater degree of independence. However, in so doing, it renders the caregivers as invisible, thus eradicating their ability to meaningfully advocate for the Disability community and the interdependence this relation creates. The human rights model supports both the person with disability and the caregiver, understanding that this interdependent relationship is unassailable and innately human. Kittay's theory of justice, which lends itself to the human rights model of Disability, views (inter)dependency as a basis of value and connection, an opportunity to grow "empathy, sensitivity, trust, ingenuity, and creativity" (p. 310), and marks us each, regardless of ability, as distinctly human.

Human Rights Model of Disability

We now understand that the human rights model of Disability is an extension of the social model; one that accounts for prevention and rehabilitation policy due to its normative function, has realistic applications, and focuses on justice in issues of disability. The following points clarify and emphasise the benefits of the human rights model. Firstly, the human rights model has a clear concentration on the inherent and fundamental nature of human rights as a force that connects human beings. They are neither given nor removed from an individual or a community, and this moral principle is the foundation of disability policies born from the human rights model (Degener, 2017, p. 43). Morality has no place in the social model due to its understanding that society deems persons with disability as deficient—it is difference, rather than universality, that grounds the theory. This is an understanding that similarly draws from identity politics, as in the social model the person with disability must adopt an identity of someone who is oppressed or combats oppression. The human rights model carves out space for minority and cultural self-identification (Degener, 2017, p. 50), encourages an intersectional approach to identity formation and recognition, and validates empowered identities that derive from disability, such as a Deaf community identifying with their sign language. Secondly, the uptake of the social model has empowered important work in anti-discrimination policy, but has done little to recognize the need for social, economic, and cultural rights through laws on personal assistance services. Conversely, the human rights model includes these social, economic, and cultural rights, as well as civil and political rights through citizenship (Degener, 2017, p. 45). As the normative dimensions of the human rights model suggest, this model "values impairment as part of human diversity" (p. 47) and views prevention policy as a protective factor of human rights, whereas the social model "neglects the fact that disabled persons might have to deal with pain, deterioration of quality of life, and early death due to impairment and dependency" (Degener, 2017, p. 47). This is an important intervention of the human rights model of Disability, as it demands impairment be acknowledged in theories of justice. In other words, while the social model provides critical reasoning for why the vast majority of persons with disability face oppression, it is the human rights model of Disability that offers, through inclusive policy development, "a roadmap for change" (Degener, 2017, p. 54).

Conclusion

The normative and justice oriented nature of the human rights model offers an advantageous direction for critical disability studies. This thesis implements the human rights model of Disability as its conceptual framework in its exploration of the degree to which the right to citizenship is realized in all citizens, regardless of ability. Access to health, which includes all factors that impact wellness including socialization opportunities, access to work, etc., is a human right which is evaluated on the criteria of availability, accessibility, acceptability, and quality (WHO, 2002, p. 12). The English-speaking Disability community in Montreal faces policies which generate insufficient quantity of available social services in their language, and limited accessibility of services that are non-discriminate based on language and that allow ease of access to information in the English language. Therefore, the human rights model of Disability has supported this research in its efforts to advocate for the Disability community. The human rights model of Disability impels a citizenship rights-oriented investigation of policies that has the potential to make tangible change to the systemic exclusion of the community.

Chapter Two: Language and Citizenship

Achieving true equity for socially and economically disadvantaged groups is a long-term goal—one that requires a complete reworking of power structures that favour one group over all others. Ultimately, government systems and the global capitalist economic systems that fuel them must be overhauled to realize this goal. However, Prince (2009) explains that the "Canadian disability movement is neither anti-capitalist nor is it anti-globalization" (p. 182). The Disability movement criticizes unrepresentative policies that exclude and erase some under the guise of liberalism and capitalism, while working within these systems in order to achieve timely results. Framing Disability rights as a citizenship issue is a strategy that works to realign consequences of contemporary socio-economic and political systems. Such realignment understands that there are limitations to reaching an equitable status under capitalism and liberal government interests; however, it holds governments and other power structures accountable and invokes positive, attainable, and timely change for the better of otherwise disadvantaged communities. Due to the subjective nature of experiences of social inequality, measuring expressions of full citizenship is a more quantifiable and, when issues are found, a more solutions-focused approach to disability advocacy (Prince, 2009, p. 224). Above all, a citizenship framework ensures people with disabilities and their families are able to "enjoy the opportunities non-disabled Canadians expect as a *right of citizenship* [emphasis added]" (Prince, 2009, p. 47).

Language as a Symbolic Resource

Language is charged with power within the contemporary socially stratified system; it is a symbolic resource (Breton, 1984). Language, thus, helps to produce "the symbolic order" (Breton, 1984, p. 124) of society as it undergoes "allocation or re-allocation of social status or recognition among various segments of the society" (Breton, 1984, p. 124). The (symbolic) power of language (i.e. the resource) is distributed so as to construct a collective identity for citizens, thereby also generating an identity for those excluded citizens. Crucially, when language is the symbolic resource of interest, its distributor is typically the government (Breton, 1984, p. 124), evincing the need for Quebec's government to be held accountable for this level of power over whose identity is included and excluded within civil society. The debate over government intervention in language distribution has a long history in Quebec, particularly since legal measures for francization were introduced by the *Charter of the French Language* in 1977. With the *Charter* came a collective identity of the French Quebecois who defined themselves as distinct from the rest of Canada. Following the adoption of such a self-definition was the "multiplicity of symbols surrounding the rituals of public life, the functioning of institutions, and the public celebration of events, groups and individuals" (Breton, 1984, p. 125). The success of a collective Franco-Quebecois identity is grounded in its ability to recognize itself in public institutions such as governments, justice, education systems, culture, the organization of business, etc. (Breton, 1984, p. 125). Similarly, where people in Quebec do not recognize their language, culture, and experiences represented in public institutions, they may "feel that the society is not *their* society" (Breton, 1984, p. 125).

Those who fall outside of the collective identity, indeed, risk feeling excluded from the society and public life. Language is an important means to secure self-recognition in the values of public institutions as it provides a basis for defining collective identities. (Breton, 1984, p. 126). If language provides a commonality between individual and institutions, the individual's language boasts a higher social status ranking than those unrepresented. In turn, the represented language is celebrated as a collective identity marker while the unrepresented language becomes a punitive collective identity marker. Laws that symbolically or materially place one language identity above others unequivocally result in government-sanctioned status ranking of linguistic identities (Breton, 1984, p. 134). In such a situation, status groups compare their ranking to that of other status groups with awareness of the system that designates status and how status might be attained (Breton, 1984, p. 131). For those ranked highly—the Francophones in a contemporary Quebec context—the government represents their values. For those with a low ranking such as Anglophones or Allophones, the government may not be seen as adequately representing their values. As the Quebecois collective identity was formed around the protection of French language and culture from multi-cultural, multilingual, and particularly English influences, English-speakers in Quebec may now find themselves at odds with French-speakers, facing barriers posed by laws that curtail the expression of their linguistic identity.

Effects of language as a symbolic resource work against members of Montreal's English-speaking Disability community, who face various pre-established barriers such as employment insecurity and limited educational support. As this community's access to French as a resource for participating in citizenship is limited, they face additional barriers when pursuing government and institutional recognition. The pursuit of the development of their symbolic-cultural resources is often "at the cost of considerable material sacrifices, either individually or collectively" (Breton, 1984, p.137) because their oppression through ableism has already placed them at risk of economic insecurity, emotional and physical fatigue, and so on. In fact, Breton's description of society's symbolic order is fueled by a group's fear of status demotion to that of a 'second class citizen' where their perceived importance through institutional recognition is degraded. For those members of a society who already face such institutional and systemic prejudice such as those with disability, language bias that further disadvantages the symbolic resources available to this community is particularly harmful. Moreover, this explicit marginalization threatens to revoke “status rights” to participation “in the socio-political process” (Breton, 1984, p. 136), producing the “alienated person” who, much like the absent citizen, “has been estranged from, made unfriendly toward his society and the culture it carries” (Breton, 1984, p. 126). If we consider language as a symbolic resource which, when employed by institutions, has a negative impact on certain minority groups, it becomes clear that language constitutes a basis for understanding the distribution of citizenship rights and impacts on Montreal’s English-speaking Disability community.

The process of utilizing language as a symbolic resource is a process of symbolic violence which Bourdieu (1990) defines as the imposing of one group’s symbolic system onto another group. In Quebec, language is a symbolic resource or symbolic capital, as Bourdieu coins it. Under the *Charter of the French Language* (1977), French has a higher status as capital than English in cases of economic capital (e.g. more job prospects for French-speakers), social capital (e.g. easier social connections when using the dominant language of a region), and cultural capital (e.g. greater accessibility to information in French) (Bourdieu, 1990, p. 112-33). In the social service field, service providers perpetuate symbolic violence by deeming it unnecessary to acquire English language skills—an act of symbolic violence that manifests through a “gradual embodiment of social rules” (Krogh & Johnson, 2006, p. 157). The Quebec government makes no incentive for service providers to learn English, which is due to Quebec’s assertion that French is the only recognized official language of the province, as articulated in the *Charter of the French Language* (1977). French is therefore awarded a higher value of cultural capital and the continuation of its dominance is protected by social rule.

Five Elements of Citizenship

Critiquing language polices that govern the availability of social services for persons with disability benefits from a citizenship lens which identifies five elements of citizenship. Two of the five elements of citizenship relate directly to language: legal and equality rights, and democratic and political rights. These rights hold the traditional view of citizenship—membership within a state—but extend to acts of inclusion through institutions of legal systems, government branches, and disability organizations (Prince, 2009, p. 17). The linguistic-based exclusion of state membership is contrary to both citizenship principles by reducing opportunities for equality and limiting democratic participation for linguistic minorities. A third element of citizenship, discourse of citizenship, embodies the ways in which disability communities are and are not represented in policy rhetoric, and whether policy accounts for the complexities of individual needs (Prince, 2009, p. 17). Linguistic identities must be considered in such discourses and especially pertain to the unmet needs of the Disability community. The fourth element of citizenship is social entitlements, and includes access to health care, housing and income security, and social services (Prince, 2009, p. 17-8). The issue with Montreal's approach to social entitlements is that while some access is available, full and equal access is not. Geographic boundaries and limited resources in English services result in tokenistic access, where these services exist but are unattainable to many community members. The final element of citizenship is economic integration. Although economic integration is an important topic in the Disability movement, it is not well documented in my own research. Given the limited scope of my research, the topic's lack of emphasis should not be viewed as contradicting the importance of economic matters within the community.[15]

---

[15] See Charlton (2000) and Stienstra (2012) for discussion on the intersections of financial security and societal contribution. See Milne (2016) for discussion on workplace accommodation

My use of a citizenship framework to investigate linguistic barriers to social service acquisition, alongside my employment of the human rights model of Disability to consider group exclusion and human rights disruptions, is advantageous. The consolidation of these two conceptualizations supports this research in addressing the complex relationship between Disability and language and the policies that coincide with the relationship.

---

practices. See Garner (2016) for discussion on employers' roles in exclusive social organization within the workplace.

Chapter Three: Methodology

Needs-Based Assessment

This research employs a needs-based assessment methodology, wherein it identifies service deficiencies based on both expressed-needs and felt-needs. Needs-based assessments within a health care and social service context involve concepts of health and well-being status, health service utilization, health systems, and population/contextual characteristics; they aim to improve, promote, and protect the public's health and well-being (Petersen & Alexander, 2001, p. 4-5). Needs assessment studies do not focus solely on causes such as a pre-existing disability in the assessment, they also consider "the social, economic, cultural, and health care system factors" (Petersen & Alexander, 2001, p. 4) that impact health and wellbeing. This methodology thereby aligns with my use of the human rights model of Disability to determine social impacts of access barriers. Population characteristics have a reciprocal relationship with utilization of services, one that is within the scope of a needs-based assessment (Petersen & Alexander, 2001, p. 4). For example, the Disability community, which includes all those who are affected by disability, utilizes services that are available. If those services are not available for language-based reasons or otherwise, as is the case in Montreal and beyond, a population might be forced to go elsewhere to have their needs met or otherwise continue to endure unmet needs. In addition to the contextual elements that a needs-based assessment considers, including analysis of relevant policies, this methodology targets the stated needs of a community. A needs-assessment exercise suggests that an identifiable problem or need exists for the population of interest. The exercise further suggests that these needs indicate problems that have some way of finding resolution. Targeting a need in these ways is defined as a "value judgement" (Petersen & Alexander, 2001, p. 18) given the fact that needs can be subjective, disputable, relative, and unfixed. Such a reflective recognition of the individual experiencing of needs is crucial for this research with the Disability community. Just as each need or value judgement is variable and personal, experiences with disability are non-generalizable. To be certain this research successfully captures the systemic and valued factors, my approach draws from institutional ethnography. Engaging with institutional ethnography enabled me to seek to identify how experiences are conditioned by the social, institutional, and policy structures that mediate service provision in Montreal.

As a researcher, I could not present data on one person with autism spectrum disorder and claim to know anything about another autistic person. The same is true for one parent of a child with disability. These experiences are deeply personal and context-dependent. That said, this research was interested in the policies, services, and access structures that condition people's experiences as members of a Disability community and does not intend to individualize experiences. Needs are considered to arise from the life contexts of members of the community—contexts that are often shared among community members and are produced by the structures to which we are all subject. Such an assessment illuminates general patterns that are the result of shared experiences in navigating various barriers or enablers within the respite care system. Stated more emphatically, a needs-based assessment produces research that can be beneficial to the public as it delivers information on programs and policies that have impacted a community, while appreciating the individual nature of needs. This research considers emerging themes from the collection of individual experiences regarding expressed-needs and felt-needs in its endeavour to advocate for positive change for Montreal's English-speaking Disability community.

Expressed-needs are “based on an examination of clients' requests for services” (Royse, Staton-Tindall, Badger, & Webster, 2009, p. 9). As previously stated, waitlists for disability related social services are prevalent across Canada (Every Canadian Counts, 2014). Such a prevalence of deferred requests for services demonstrates the expressed interests and unmet needs of members of the Disability community and presents an area of inquiry for this research. In addition to this expressed-needs approach to the needs-based assessment methodology, a felt-needs approach enabled me to diligently avoid speaking for the other (Spivak, 1999). Though I have close relationships to persons with disability and have worked in respite care with individuals with disability for eight years in Montreal and in British Columbia, I am a (temporarily) able-bodied individual. Therefore, my position as a researcher who advocates action must also acknowledge my inherent and unavoidably restricted understanding of persons’ experiences with disabilities. Incorporating a felt-needs approach situated this research as a platform for members of the Disability community to have an opportunity to be heard. Felt-needs “is the form of needs assessment that best captures the clients' perspective” (Royse, et al. 2009, p. 10), as it places value on the emotional aspects of particular experiences that impact health and wellbeing. Specifically, a felt-needs assessment enabled this research to extend beyond an institutional analysis by examining how institutions are shaping felt needs through bearing witness to participants’ sensitive responses to institutional access barriers.

Methods

Document analysis. Expressed-needs were investigated through document analysis. The accessibility of documentation on social service waitlists and policies for disability related social services in Montreal provided key information on availability of services and visibility of the English-speaking Disability community in the running of services. The purpose was not to compare waitlist lengths and durations or quantify availability for Francophone and Anglophone/bilingual programs; rather, it was to discern whether information was as easily available for both language communities. My process was informed by participant observation, which is a method commonly used in institutional ethnography. Participant observation focuses on the micro level, or the “life world” (Smith, 2005, p. 31) of the research subject. Comparable to method acting where an actor prepares fully engages with their craft by becoming as close to the character as possible, participant observation involves the investigator engaging in practices typical of the target community in order to better understand and interpret life experiences. It draws from an emic model of ethnographic investigation which denotes “a level of description of human behavior based on categories meaningfully relevant to the people performing the behavior” (Kephart, 2006, p. 809) with limited interpretation from the outsider’s research-oriented position. Participant observation, therefore, allows the investigator to better appreciate such dimensions of the research process as “stories, […] time, motion, how ruling relations work, and particular ways for seeing the social organization” (Diamond, 2006, p. 47). By engaging in the task of searching for information related to social service acquisition myself, I grew to appreciate the complexity of such a task for caregivers. Of course, I could never purport to truly know this experience in the same way as an overworked and stressed caregiver seeking life-sustaining services for a child. I did, however, encounter feelings of frustration as I struggled to find and access valuable information. I first analyzed the public resources available on governmental websites of each CIUSSS as if I were a primary caregiver seeking information on services for my dependent. I also searched for documents available online such as financial statements and service users’ rights. These websites aim to aid individuals in locating and assessing appropriate services. When these documents are only made available in French—a common occurrence in Montreal[16]—this creates a barrier to appropriate assessment opportunities for the English-speaking Disability community and thereby exacerbates systemic accessibility barriers faced by this community.

Community Involvement

Participants. Interviews were conducted with two groups of stakeholders: caregivers and persons with disability (n=4) in order to collect data relating specifically to felt-needs as well as confirming expressed-needs collected from non-human sources. I also drew heavily from my extensive experience as a respite worker with persons with disabilities, both within and outside of Quebec. Interviews were held with community members throughout January and February, 2019. I interviewed four individuals—three females, one male. Of the three women, two were mothers and primary caregivers of children with intellectual and/or developmental disabilities or special needs.[17] The third woman was an advocate involved in securing care for a relative with special needs. The final participant was a man with special needs currently using residential care services. I acknowledge that these four individuals make up a small sample size. Although my aim was to interview ten participants, the time restraints and demanding nature of caregiving for a dependent meant securing participants was difficult.

I asked interviewees to describe their experiences seeking access to care, focusing on what they perceived to be useful tools or harmful barriers in the process of acquisition. All interviewees had basic knowledge of the French language but were more comfortable speaking English, especially when discussing support options which use specialized language. Sampling

---

[16] See Chapter Five.

[17] For many members of the Disability community, the term ‘special needs’ feels more comfortable than disability, though it is an outdated term in academic discourse. When participants identify as caring for or having special needs this term is used interchangeably with disability to better represent the participants.

for maximum diversity of experience (within the limits of a small sample size) in terms of social service access, I sought to interview people who reported a range of experiences. All participants were over the age of twenty-one, which is the maximum age a person with disability is able to attend public school. Interviews with the man with special needs who is currently accessing social services and the two caregivers of dependents accessing social services focused on their experiences of seeking and acquiring social services, as well as the ways in which interviewees' lives have changed since receiving support. One caregiver is currently receiving respite care while considering more intensive options for the future and was aware of wait-times for English services.

Due to the small target population of Montreal's English-speaking Disability community, I am able to provide only limited details of the four participants. I acknowledge that this reduces my ability to present an authentic and intersectional portrait of these individuals; however, their privacy is my priority. Without identifying who belongs to each socio-economic class, as a group, the participants' classes range from lower-middle class to upper-middle class. The following provides a brief introduction to each participant, using pseudonyms.

1. Tanya is a primary caregiver to her elementary-school-aged child with developmental delays and special needs. She is a single parent of multiple children and is white. Tanya works as a paid caregiver for individuals with disabilities, having completed a Special Care Counselling education and training program. She lives in the region of Montreal West and has limited French proficiency.
2. Danielle is a primary caregiver to her child with global developmental delay. She is a single mother of one child whom she homeschools. She has worked as a public school

teacher and currently works from home in the education sector. She is white, lives in the Montreal East region, and has limited French proficiency.

3. Sandra is an advocate for her adult relative with special needs. She became invested in her relative's care when the parents were no longer able to adequately advocate for their child. Sandra has sat on boards of directors for organizations interested in issues of disability. She sees her relative often and has spent years fighting for their rights. Sandra is fluent in French though speaks English at home, and is retired.
4. Harvey is a white man with special needs that affect his memory and intellectual functioning. He was misdiagnosed as having behavioural challenges for many years, which stunted his therapy opportunities. When he was properly diagnosed as a young man, the diagnosis was misunderstood and mistreated, resulting in him facing homelessness, precarious living situations, and incarceration. After a court order mandated that appropriate care be made available that suits his unique needs, he has found a comfortable and safe home in Montreal West. Harvey lives in a supervised residential care facility where he volunteers at the facility's in-house shop and makes music. His preferred language is English, though he is comfortable speaking French.

As a caregiver to a non-verbal person with intellectual disability, I am aware that it takes time to form a relationship with non-verbal individuals to arrive at a point where the participant's responses will be appropriately represented in the research. For this reason and due to time constraints, there were two criteria to be met for participating in this research: the ability to answer at least closed-ended yes/no questions and non-verbal but literate capacities. Accommodation allowed for answers to be responded to in writing, though this was not needed for the individual interviewed. Adaptation consisted of a reformatting of questions depending on cognitive ability, where yes/no questions were used when open format questions were inappropriate. Perry (2004) cautions that while closed-ended questions improve responsiveness, the potential for acquiescence is increased by this format, especially with participants with intellectual disability (p. 122-4). The potential for acquiescence was considered in the analysis process.

In an effort to recruit caregivers for persons with disability, and the persons with disability themselves, I posted relevant information and my contact information on public social media pages which serve persons involved in the Disability community in Montreal.

Interviews

Informal conversational interviews ranged from 15 minutes to two hours, depending on the availability and stamina of the interviewee, and were conducted in public spaces or private dwellings. Interviews with persons with disabilities and primary caregivers of the English-speaking Disability community in Montreal invited individuals to describe their experiences seeking access to services for their dependent. Participants were invited to share their experiences, comment on their needs and reflect on whether their needs were being met by the social service system in Montreal. Included were any felt responses to perceived (un)fairness in the allocation of social services in Montreal that might affect areas of their daily lives such as finances, interpersonal relationships, and personal health and wellbeing. The caregiver's perspective was crucial to this work as it informed my assessment as to which barriers influenced the individual and collective wellbeing of those who care for a person with disability. The interview with the person with special needs asked similar questions about life experiences, though these were asked in language appropriate to their discourse abilities. The framing of the interview with a person with disability depended on the participant's level of communication, which was unknown to me prior to meeting the individual. In sum, the process was accommodated and adapted to suit the individual's needs.

All interviews were audio-recorded. When interviewing persons with disability, video-recording was an option so to ensure responses were well-represented in analysis; however, the sole interviewee with disability and their guardian did not choose to partake in video-recording as the individual did not exhibit physical communicative gestures beyond what is typical of (Western) non-verbal communication.

Ethnographic Observations

I attended three public talks, events, or symposiums across Montreal that were related to different aspects of caring and planning for a person with disability. I decided to use a non-participant observational method because, as Miriam Home and Services has decided to reallocate services based on age, I hoped to understand how age influenced access to services by including interviewees who were aging with an intellectual disability or cared for a dependent with an intellectual disability over the age of forty. As I was unable to recruit interviewees with these specific experiences, I instead attended public talks that discussed such matters. While different bodies have generally defined the marker for the aging population to be sixty years and greater (>60) (Hogg, Lucchino, Wang, Janicki, & Working Group, 2000, p. 5), the parents who are often primary caregivers of persons over forty years old are, themselves, aging. It is therefore expected that they are preparing to make important decisions for their dependents for when they can no longer maintain the role of primary caregiver. Observations at the first public talk revealed the urgency of intersections of aging and disability. Observations from the second event included a presentation and discussion of possible models of socialization and integration and shared attendees' feelings of confusion, frustration, and hope among caregivers with post-school-aged dependents. Observations at a third event, a local symposium titled “Montreal Inclusion Symposium: Engage, Learn, Co-Create” held by the Friendship Circle, were more positive and action-focused, describing needs for an appropriate definition of inclusion and resolutions for making that inclusion happen. In my analysis, I interpreted dialogue observed through a needs-based lens, allowing me to understand, for example, feelings of being overwhelmed or helplessness as expressions of needs for accessible and proactive information.

Ethical Considerations

This research project passed McGill University’s Research Ethics Board III. The research involved participants with profound intellectual disabilities who are perceived as lacking capacity to provide informed consent. Ethically, these participants must be included as exclusion of the target community’s point of view would be unjustified. Studies which advocate for more inclusion of participants with intellectual disabilities in research (Arscott, Dagnan, & Kroese, 1998; Horner-Johnson & Bailey, 2013) have found that persons with such disabilities are able to adequately understand the research description when presented in a manner appropriate to the participants’ intellectual abilities. Jonathon Perry (2004) explains that difficulties in understanding risks and the voluntary nature of research can be alleviated by conveying vital information in a straight-forward manner and having a guardian/advocate present for the process (p. 117-8). That said, under Article 21 of the Civil Code of Quebec (2013), participants with intellectual disability are deemed to be incapable of providing informed consent. Therefore, this participant supplied a guardian to provide third party written consent. The guardian must be a person who generally makes decisions on behalf of the participant regarding their health, safety, and wellbeing, and, unless in exceptional cases such as institutionalization with little family contact, this person must be a close relative. While third party consent was required, the participant's assent/dissent was respected. The process of obtaining assent/dissent was carried out verbally in simple language and the potential participant had ample opportunity to ask questions. I asked them questions to ascertain they understood the details of their role in the research. (See Appendix A for Assent/Dissent form).

As one of the participants has an intellectual disability, and therefore is part of a vulnerable population as far as research is concerned, I was vigilant in ensuring that his vulnerability was not exploited by participating in this research. Griffin and Balandin (2004) elucidate that the vulnerability of persons with disability is compounded by their susceptibility to unethical research practices due to their "life circumstances, especially if they have little experience in acting as autonomous persons [by] making decisions for themselves in their own best interests" (p. 62). I selected research methods that mediated this risk. Griffin and Balandin prescribe interviews with persons with disabilities rather than about them, as a central approach to minimize risk for participants with intellectual disability (p. 77-9). Active participation is "less likely to exploit the power imbalance between researchers and participants with intellectual disabilities in the planning, conduct, and dissemination of research" (p. 78). Regarding the possibility of distress during the interview, I redirected the conversation as needed to a more "neutral or positive topic" (Perry, 2004, p. 118), and ended the interview on a positive note.

Another ethical consideration involved the risk of damaged relationships. Participants who are part of the Disability community were either accessing social disability services or their access had been deferred at the time of interaction with the research. Such a relationship between the prospective service user and service providers posed a potential risk in participating in this research. However, participants were invited to participate in the research through publically accessed social media groups related to experiences of having or advocating for persons with disability in Montreal, and, if interested, responded to the invitation privately. Recruitment through such means assured that the risk of repercussion was no more than one might expect to encounter in everyday life. All participants' privacy interests were fully respected by removing participants' identifiable information and codifying information. All information gathered from human participants was securely held in password-protected files. With these points in mind, this research was of no more than minimal risk.

Representation. I would like to expand on ethical implications to this research by introducing the notion of representation. Disability studies have benefited from the social movement, Nothing About Us Without Us (Charlton, 2000). This movement demands researchers and scholars include the Disability community in research in meaningful ways; they should be an active participant rather than objects of the research. As researchers like myself have adopted this movement into our ways of personal and professional conduct, research ethics boards have been tasked with the important duty of protecting the safety for this community that has been positioned as vulnerable by the dominant society. This section briefly details ethics boards' roles in representation and describes my own experiences with McGill's research ethics board.

Research involving disability, particularly intellectual disabilities, has a long and dark history of exploitation of this population (Beecher, 1966; Iacono, 2006). In response to such past inhumane treatment, research ethics boards have implemented rigid safeguards to protect the population from reliving past injustice (Iacono, 2006; McDonald, Conrly, Kim, LoBraico, Prather, & Olick, 2016). While safeguards are undoubtedly justified, important, and well intentioned, Iacono suggests that the nature of protection stemming from one body over another "invokes paternalistic protectionism, with a concomitant risk of non-inclusive and discriminatory decisions by institutional ethics committees" (p. 173). Such paternalism has clear implications to autonomy for those with intellectual disability. Further, Aman and Handen (2006) point out that the protectionist view assumes that even a minimal risk associated with research ought to be avoided for this allegedly vulnerable population (p. 180). An issue with my ethics application was that I was deemed to be over-selling the potential benefits to participation by stating possible long-term and non-direct benefits such as the potential for the participants' experiences to be considered in future funding and policy decision. Such long-term and non-direct benefits are common in research. Iacono (2006) suggests that benefits such as those I suggested are regularly deemed problematic by ethics boards, who tend to be more critical of non-direct benefits to persons regarded as vulnerable, often leading to exclusionary practices in research (p. 178). As researchers and advocates for the Disability community, we must verify that research participation is a positive experience, that risks and benefits are understood and consent is truly voluntary (Aman & Handen, 2006, p. 180). By limiting opportunities to participate in research, we are regulating self-government and hampering inquiry that may surface socio-political developments beneficial for people with intellectual and/or developmental disabilities.

McDonald and colleagues' (2016) work on analyzing research safeguards truly illuminates the case for inclusion. The researchers surveyed over 500 participants on the perceived safety of numerous research safeguards. 101 of those participants were adults with intellectual disability. The other stakeholders were family members of persons with intellectual disability, service providers, researchers involved in research involving persons with intellectual disability, and research ethics boards reviewers (p. 425-6). The results show that the respondents with disability perceive their participation in research as being generally safe, while other stakeholders found components of the research process to be unsafe for participants with disability (p. 433). One component with the most disparate responses was recruitment processes, particularly regarding who informs the potential participant of a research opportunity. Those with disability felt that their direct involvement with recruitment was the best assurance of safety, which counters the feedback from ethics boards reviewers (p. 430). The responses of participants with intellectual disability to the survey suggest that there is, at least, some interest in participating in research, if that research includes the demographic in respectful ways that promote "their right to self-determination" (p. 433). Indeed, Aman and Handen (2006) suggest that participants of concluded studies typically would make the decision to participate again, indicating that the experiences were non-aversive, if not enjoyable (p. 181).

We can see this sense of paternalistic protectionism in the concept of safety and risk when looking at research from different points of view. Because in Quebec persons with intellectual disability simply are not allowed to consent for themselves, we must ask if the safeguards ought to be in place to the extent that best represents the feelings of safety for those who are being protected? Or is it better to err on the side of caution and assume the neurotypical mind is better situated to assess risk? Personally, I feel conflicted when I consider this issue because I do believe disability does not equate to deficit, and researchers can work to find ways to adapt research practices to meet the needs of participants, but I also know the sordid history of exploitive research to which these risk assessment practices respond. That said, my research standpoint is such that it is the act, itself, of being critical that is imperative to being an engaged researcher. As researchers, the most important question to ask ourselves is whether ethics boards are explicitly or implicitly creating situations wherein it is easier and more feasible to exclude persons with disability from research. If so, we must critically respond with inclusion in mind.

Ethics, experience and research. Speaking more generally about the process of applying for ethics approval, as qualitative researchers we must negotiate our research in a way that is to be understood through a positivist review lens. In my ethics board application response, I was asked to provide an additional scientific review to determine the scientific validity of this research. I was told to remove my own experiences with disability from my framing of the issue and its relevance as a topic of study. A credible illustration of the invisible framing to which we must comply to pass ethics is that we must define every variable of our research but there is no space to define our own researcher ontology. When I defined disability, I did so using the generic definition used by the United Nations and in health related contexts: “a significantly reduced ability to understand new or complex information and to learn and apply new skills” (n.d.). This is not the definition I would use to talk about the people I know and love with disability, but it sufficed for the ethics boards requirements. Of course, I could have included information regarding the human rights model of Disability to which I align, but the issue is that such things are of little importance to the rigid system of ethics approval, and so the ways in which we are asked to present our proposals devalue the humanity of us as researchers as well as our research participants or subjects. Indeed, one of the first steps in pursuing research is an interaction with a structure (i.e. the informed consent process) that calls to question the autonomy of individuals by placing them in a dichotomy that assumes they are vulnerable against us ‘highly educated scholars’, and assumes that we ‘highly educated scholars’ are most successful when we work through systems rather than through compassion. As we strive to promote equal access to participation in citizenship, we find tension between this work and the paternalist protection in policy work that remains saturated in deficiency based understandings of disability.

Chapter Four: Identifying Needs through Community Voices

This chapter identifies needs of Montreal's English-speaking intellectual and/or developmental Disability community through interactions with community members. The experiences shared in interviews and public events reveal the effects of linguistic barriers on social service access. Furthermore, the stories illuminate difficulties that Disability communities face in which language is not an essential factor. These stories indicate that language poses an additional access barrier that further complicates the lives of the English-speaking Disability community. In detailing the felt impacts of prioritization in social service acquisition, this chapter draws heavily upon the five elements of citizenship: Legal and equality rights; democratic and political rights; discourse of citizenship; social entitlements; and economic integration. The experiences I relay describe either a breach in citizenship rights or a community member's efforts to protect their or their loved ones' right to active participation in citizenship.[18]

Tanya is a single mother who was living with her children in the jurisdiction of Montreal South CIUSSS when one of her children began experiencing difficulties in school and at home. Tanya's children speak only English, so she sought social services in English at her local Indicated-English CLSC. While English programs were offered at the CLSC, the child had to wait to receive an English-speaking support worker in order to obtain required services. When an English-speaking support worker was assigned to the child, they would quickly leave their position, as is, according to each of the participants in this research, a common issue in many CLSCs of Montreal.[19] The family was unable to secure a stable English-speaking support worker

---

[18] When describing experiences participants shared with me involving their dependents, I use gender-neutral language to preserve privacy of the absent individuals.

[19] One parent relayed to me a time when their child's file had been passed between three support workers in a six-month period. The parent had spoken to one over the phone and was not even aware of the others until they had already left the CLSC.

for five years of living in the CIUSSS South region. In absence of the supports the child needed, Tanya took on the role of special needs educator and counsellor for her child as well, pursuing a post-secondary education diploma in Special Needs Care and Counselling. Doing so allowed her to support her child while they waited for social services. The choice, however, put financial strain on the family while Tanya put work on hold to pursue education.

After five years of waiting, the family left Montreal South CIUSSS region and moved to Montreal West CIUSSS region. There, Tanya discovered that in all the juggling of their file from support worker to support worker, they had either been bumped from the waitlist or had not ever been officially placed on a waitlist. The child quickly began receiving services in this new neighbourhood, signifying the much shorter waitlist for English services at the designated centre. The family's earlier attempts to acquire services at the indicated centre prior to the move were unsuccessful, suggesting that the centre's linguistic categorization as indicated for both official languages is unproductive and impractical, given that it clearly lacks the capacity to provide services in English. The delay of services at the indicated centre had the potential to negatively impact the child's development and the family's well-being. Their needs were simple: access to services in the child's first language and a support worker to advocate for the family. Instead, they faced linguistic barriers to service access that contradict the Act Respecting Health Services and Social Services (1991) that outlines the right to receive services in English. The family was only able to realize their right to English services after they relocated to Montreal's English-speaking linguistic ghetto.

Identifying Needs

Through conversations with Tanya, Danielle, Sandra, and Harvey, as well as through observations at public events, I have identified five needs of Montreal's English-speaking Disability community. The three expressed needs are:

1. Access to continuous care and support via social services in a timely manner;
2. Access to social services in English, indiscriminate of location of dwelling on the island of Montreal;
3. Access to information in English on matters related to disability support and services.

The two felt needs are:

4. A wider spectrum of definitions for what constitutes disabilities and capabilities and for the updated definitions to be reflected in care options;
5. Understanding and consideration of the economic, health, and wellness effects that opportunities for subsidized support has on caregivers.

The ways in which emotions both accompany and derive from needs complicates a needs-based assessment's differentiating of felt needs from expressed needs. For example, Tanya's story demonstrates expressed needs of speedy access to services that are in English regardless of location in Montreal. These needs were expressed to Tanya's CLSC and support worker. However, Tanya also needed her CLSC and support worker to understand the financial strain that inadequate support options were putting on her and her family. Tanya's experiences with her CLSC provide insight into her expressed needs while being emotionally charged. The categorization of needs can therefore be understood as an organizational tool beneficial to researchers and policy workers rather than a ruling understanding of the presentation of needs. The remainder of this chapter will further describe the abovementioned expressed and felt needs through interactions with community voices.

Identifying Expressed Needs

The three expressed needs each involve matters of access to social services that is unaffected by where one lives or which official language one speaks. Facing limited access to information in English that might support the inclusion of a person with disability was a commonly shared experience among persons interviewed and observed for this research. The primary caregivers and advocates all cited times in which they had used alternate sources for information; they sought and found information on online forums and social media groups or otherwise used others' experiences to inform their own service acquisition endeavours, rather than consulting authorities such as social workers. Their indicated CIUSSSs did not represent their linguistic identity, instead promoting the French language, thereby encroaching upon their ability to engage with an element of citizenship: *discourse*. The requirement for alternate information resources, due to what members of the community express to be a lack of public government information in English, has resulted in experiential authority necessarily undermining the authority of social service institutions. An example of this is the surge of social media groups dedicated to the English-speaking Disability community, community workshops, and service networks that are all being implemented by community members whose life circumstances have turned them into "accidental activists" (Prince, 2009, p. 117) or advocates. Club ALink exemplifies this change in authority. The club is made up of parents of young-adult children with intellectual and/or developmental disabilities who speak English and are mostly (though not exclusively) Jewish. The club holds meetings regarding future options and possibilities for their children, such as employment and residential opportunities, and provides programs for young adults with disabilities (e.g., cooking classes). Club ALink has established itself as both a practical and online authority on acquiring social services for persons with disabilities while government institutions continue to disregard the linguistic requirements of the diverse Disability community. Club ALink's members have sought and found alternate means of engaging in full citizenship. They are counteracting the negative impacts presented by their social service institution's exclusionary practices through unrepresentative linguistic alignments.

Social media groups in Quebec and Montreal also exemplify the gains in experiential authority over institutional authority. In particular, two groups on the social media platform, Facebook, are used by parents and caregivers who share their experiences, ask and answer questions, and support one another with the difficulties of raising a child with disabilities. These groups are the Quebec Special Needs Families Support Group and the Special Needs Network of Montreal. The groups are both closed, creating a safer and more private space to discuss personal experiences and decompress by sharing challenges that often accompany attempts to navigate Quebec's social service system. For the sake of privacy, I will not detail postings to the groups. Group members' expertise in advocating for their children and supporting each other shows profound commitment to their Disability communities, whether through sharing information on caregiver tax deductions or summer respite options. These social media group postings also indicate that personal experiences do not always translate to definite answers for others in similar situations. Experiential authority is undoubtedly useful and valid but must not become a solution for the lack of institutional involvement in social service provision. If experiential authority were to be a sufficient solution, the expressed needs of the community would already be met by these hardworking accidental activists and advocates.

The expressed needs involving access to services and information remain unmet, as verified by Tanya's forced decision to move her family to an English-speaking enclave. Conversations with Tanya about her experiences before she moved, as well as with Danielle, informed me of the common and persistent miscommunications with service providers and facilitators due to language incongruency. The availability of French services and dearth of English services create different outcomes at the level of the individual family. While Tanya's family moved to the English linguistic ghetto, Danielle decided to communicate with her care team in French so to simplify the process and avoid wait times. She relayed an instance of a staff member at her local CLSC attempting to speak English over the phone. After finding this dialogue unintelligible and unproductive, Danielle felt pressured to switch to French, leaving her uncomfortable and uncertain that all information was fully conveyed and received by both parties. For Danielle and Tanya, consulting experiential authority through online forums or social clubs would not have provided the support needed. Like all members of society, these two women have the right to participate in the element of citizenship that involves *social entitlement* to social services that impact personal wellbeing, health, financial security, etc. The women, however, necessarily compromised by speaking a foreign language with care providers or relocating their family.

Conversations with Tanya and Danielle and my observations with public groups including Club ALink and the Special Needs Network of Montreal informed my identification of the three expressed needs that are not being met by social service institutions (i.e., needs specifically involving linguistic accommodation and service access). The stratification of language is apparent in Montreal's social service systems, with expressed consequences on minority groups who are underrepresented in social service institutions. Linguistic-based access barriers result in violations of human rights to choose where one lives or how one speaks and to be included in society.[20] Obstruction of human rights is likely to impact one's feelings of wellness and security within a society. The following section details the felt needs that highlight such expressions of wellbeing.

Identifying Felt Needs

The two felt needs identified in this research pertain to issues of dignity through inclusion. A common and vital theme I have noticed in my interactions with community members is a need for definitions that appropriately and thoughtfully represent disability (and Disability) in ways that promote interdependency and highlight an asset-based approach. Harvey's story of medical and therapeutic misdiagnoses and mistreatment leading to precarious living situations points to a need for more nuanced and individualized definitions of disability. Harvey's special needs are near-invisible. He is a charming, intelligent, and fiercely resourceful person who needs to be reminded of basic living skills. Put another way, Harvey is successfully autonomous when living interdependently with the care and support of others but his safety and quality of life is at risk when he is placed in an independent living setting. Before his advocate, Sandra, brought his case to court, Harvey's care team defined his disability based on what one can do weighted against what one cannot do. For example, Harvey could feed himself so was placed in an independent living unit but he would not remember to eat without prompting, so often went hungry. As independent living settings did not work for him and nothing else was available to him, Harvey experienced homelessness and was eventually incarcerated. Harvey and

---

[20] The Universal Declaration on Human Rights protects the right to choose where one lives under Articles 3 and 30, Right to Life, Liberty, Personal Security and Freedom from State or Personal Interference in the above Rights. The right to speak a language of one's choosing is protected under Article 2, Freedom from Discrimination. The right to inclusion in society is protected under Articles 22 and 27 Right to Social Security and Right to Participate in the Cultural Life of Community (UN General Assembly, 1948).

his family experienced almost thirty years of inappropriate support options for his unique needs. Only after Sandra successfully brought Harvey's case into the legal system and obtained a court mandate for appropriate care was Harvey able to find a safe home. Sandra and Harvey had to fight for access to citizenship through the element of *legal and equality rights*. Not only does Harvey's story express the need for social services to reflect more nuanced definitions of disability in their practices, it also corroborates the prioritization of care for those with higher "potential" (Hendry, 2017) or who can achieve supported independent living. The unavailability of alternate and appropriate support resulted in decades of expensive and inappropriate interventions (e.g., emergency shelter use and incarceration) and unmet needs.

Danielle, a mother of a child with special needs who similarly falls through the gaps in a generic definition of disability, felt the bureaucratic systems one faces in order to receive support, funding, or adaptive equipment was intrusive, confusing, unnecessary, or simply ethically wrong. When attempting to procure funding for adaptive equipment for her child, Danielle faced long wait times and financial barriers that stemmed from her child being too disabled for available general adaptive equipment and not disabled enough for specialized adaptive equipment. For example, her child must sit in a specific upright position to eat safely, requiring straps for the highchair. The child is, however, capable of holding them-self up on their own. Danielle explains that her child needs to be restrained when eating to decrease risk of choking as the child cannot self-regulate their movements. According to their care team, if the child can sit without support, they must do so and adaptive straps are therefore unnecessary. In fighting this decision, Danielle had to take her child to numerous in-person meetings or have home visits that involved intrusive written reports which made her feel her expertise as a caregiver and mother was not taken seriously nor valued. She has offered to pay for the equipment out-of-pocket so as to speed up the process, even though this move presents an obvious financial stress. She hoped this offer would appease the long wait for necessary safety equipment, but thus far, it has not been the case.

While Danielle's request for the specialized straps for her child's highchair was vital for the child's safety, she also explained that the straps fostered inclusion during family meals. Without the straps, she would have to feed her child in a stroller or a chair with straps that sits at near-floor level. This would mean her child would not be able to sit beside the dining table at eye level and feel included in communal eating—an act she considers to be integral to her culture. Cultural self-identification and free practice is a foundation of the human rights model of Disability which, again, considers human rights to be inherent to individuals and their communities. Danielle's culture of sharing meals with her child is thus the family's human right.

Like Disability, inclusion is a complex concept involving both individualization and universality; this complexity should be retained in its definition. Defining inclusion was the goal of Montreal's Friendship Circle symposium, which I observed. According to the symposium organizers, a universal, attentive, and appropriate definition is necessary for institutions and individuals to act as advocates rather than protectors. This is how we might inspire inclusive spaces that celebrate (inter)autonomy over mere physical access. Admittedly, the task of capturing a universal definition for inclusion is a difficult one. Inclusion is a personal and subjective experience. For one attendee of the symposium who self-identified as having autism spectrum disorder, inclusion meant allowing them to participate by quietly observing from a distance. For a person who identified as blind, it meant those with typical vision not taking sight for granted and verbally explaining visual phenomena to them. For the parent of a child with unspecified special needs, it meant initiating conversation with their child. For Danielle's child, an evolved definition of inclusion would understand that the small moments of life, such as a mother sharing a meal with her child, have the biggest impact on quality of life. The symposium concluded with the suggestion that a universal definition of inclusion is possible if that definition is uncompromisingly individualized. How this might look in practice was undetermined at the event. My own impression of individualization in definitions related to Disability is that policy cannot easily attend to the prescribed diversity, but policy workers can work to ground presumptions based on presence (assets) rather than absence (deficits). A pertinent example might be to assume the presence of hybrid individuals who are English-speaking linguistic minorities with disabilities, which would counter the ongoing erasure of such persons from policy frameworks.

If inclusion is to be an individualized practice, the inclusion of parents of children with disabilities must also be considered. There are many stories of parents feeling overlooked when they are not invited to events because of assumptions about their children (Volpe, 2018). Institutional inclusion is another pressing need for the Disability community. Danielle suggests parents can be better included as experts and purveyors of their children's interests through increased institutional proactivity. She proposes that fostering a relationship between the parent and social service provider from the moment of diagnosis will promote institutional inclusion (e.g., through provision of comprehensive information on funding sources, respite options, relevant rights, and emotional or spiritual support). Danielle believes her own experience of receiving her child's diagnosis would have been less despairing had some offer of comfort and encouragement been made. Whether it came from a trained social worker or a grandmother with a warm smile, she joked, Danielle would have benefitted from someone understanding the difficulty of receiving the news that her child would need lifelong support and reassurance that she could provide that care.

In speaking with Danielle about her experiences with receiving a diagnosis for her child and observing two public talks on parenting an older child with disabilities, there was a generally shared worry that accompanies the tendency for parents to age to a point where caregiving is no longer possible or die while being a dependent's sole carer. Providing lifelong support for a child with disability, therefore, transforms into a role of confirming that one's child will be well cared for after one can no longer sustain the role of caregiver. Interviews and observations informed me of parents' need for service providers to understand the difficulty of transitional periods and to act accordingly.

In particular, the public talk held by Club ALink was a setting for frank discussions about the impracticality of an eighty-year-old parent remaining the sole caregiver to a fifty-year-old child with disabilities. The ten-year long waitlist for a spot in a residential support centre at Miriam Home contributed to the urgency of the discussion. While the expected lifespans of persons with disabilities is far greater now than ever before (Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000), waitlists for residential care facilities have not kept pace with this demographic shift, leaving families in a state of crisis.

A saving grace discussed at Club ALink's event was that if the parents die, the adult child's file becomes a high priority and service providers will need to find a solution for their care and housing needs. This conclusion does not offer the parent comfort in knowing that their child will land in good hands; rather, the parent is merely assured the child is unlikely to end up homeless. After a lifetime of dedication to caring for a person with disabilities, this response—to guarantee service availability only in the case of the primary caregiver's death—devalues the lifework of the caregiver. It also further breaches one's citizenship right to *social entitlements* that not only involve entitlement to services, but entitlement to a sense of continuous security for both the parent and person with disability.

Danielle informed me that because institutions are incapable of providing the love and nurturing her non-verbal and high-needs child will continue to require, she intends to find other options for the child's future, even if that means, again, paying out of pocket for a more suitable care option when she is no longer able to provide the care herself. In the meantime, parents continue to seek empathetic and action-focused interventions from care providers, often by looking to various levels of government to assure their children's human rights are upheld in their absence.

I observed conversations regarding the ways in which allegiance to a particular political party shifted in response to stated recognition of the rights of the Disability community. Discussions mentioned a local politician garnering the community's support as he promised funding for residential care services to the English-speaking Disability community in Montreal Centre-West CIUSSS region. The politician then made the strategic decision to receive more votes from an alternate community by offering the funding to the higher populated Francophone community instead. With Miriam Home and Services' expected wait times exceeding ten years for residential care, it is understandable that these platform promises for funding influence people's voting practices. Such promises influence one's unimpeded participation in the *democratic and political* element of citizenship.

The Disability community has not been silent on the need for institutional intervention. This is apparent in their efforts to advocate for better understanding of the need for definitions of disabilities and inclusions that are as unique as the persons they address. It is also clear in their calls for better understanding of the various ways disability complicates living in a world oriented towards the abled. In engaging with this community, it is clear to me that not meeting their needs affects many aspects of a community member's existence. Many families, including Tanya's and Danielle's, face financial burdens from seeking alternative support options or having to leave employment to care for a dependent. Such a degree of financial strain impacts their right to the element of citizenship regarding autonomous *economic integration.* Conclusively, the fatigue from being a caregiver trying to access support while continuing with other daily duties of living is onerous. The community is experiencing negative impacts to citizenship rights due to Montreal's social service system.

Need for Citizenship

The expressed and felt needs I have identified revolve around matters of human rights. These include the right to safety (through continuous and timely acquisition of important social services), the right to choose where one lives (without feeling forced into Montreal's linguistic ghetto), the right to speak one's preferred language (without compromising support options), and the right to inclusion in society (through appropriate definitions, accommodations, and compassion). When these human rights are obstructed, a need for citizenship arises and members of the Disability community are rendered "absent citizens;" they are "socially constructed, created and reproduced through cultural beliefs, material relations, political rules, and everyday social practices" (Prince, 2009, p. 48). Constructing, creating, and reproducing citizenship impedes autonomy and contradicts the stance that rights are inherent to the individual. Similarly, the experiences community members shared with me point to the ways in which social service access intersects with the five elements of citizenship, suggesting that in Montreal's English-speaking Disability community, citizenship is stratified. The French-speaking Disability community in Montreal also faces hardships and are socially oppressed within the greater ableist society. However, when we consider that language-based needs are unique to Montreal's linguistic minority Disability community, this group is further oppressed by unequal access due to their linguistic abilities.

We can determine degrees of oppression through the exclusion of participation in citizenship by considering "matters of identity and differences, stigma, equity, segregation, and integration" (Prince, 2009, p. 69). That is, participation in citizenship reflects who belongs within a community and who does not. For example, Sandra and Harvey had to fight for their legal and equality rights in court; discourse of citizenship is reduced based on care providing institutions not representing the English-speaking population; and each community member I spoke with experienced reduced social entitlement to income security and health care, housing, and social service access. As such, the categorical need of Montreal's English-speaking Disability community discovered in this research is *the need for equitable participation in citizenship.* Prince (2009) defines the employment of citizenship in the Disability movement as the following:

> (i) It offers a normative benchmark for evaluating existing services and benefits in terms of enabling or restricting the dignity and self-determination of persons with disabilities, and thus, by extension, advocating for reforms. (ii) It places responsibility on governments to respond to claims for equal status in the democratic community by committing public resources for promoting and protecting human rights. (iii) It argues for consulting with persons with disabilities as citizens on a host of policy areas, and for supporting a vibrant network of disability organizations at the national and local levels.

> (iv) It can draw these issues to the attention of wider publics and connect them to other equality seeking groups. (p. 16-7, serialization added)

The four benefits of the relationship between Disability and citizenship Prince detailed therefore complement the findings of this research in the following ways: (i) matching the normative nature of the human rights model of Disability; (ii) holding governments and other authoritative institutions responsible; (iii) addressing the legitimacy of experiential authority and the validity of those who are formally untrained but experiential experts; (iv) considering, valuing, and disseminating the experiences of those impacted by disability through the politicizing of these experiences to invoke practical change in current liberal systems.

Politicizing citizenship. Prince (2009) refers to the relationship between political justice and disability as “politicizing citizenship” (p. 191). Sandra’s experiences exemplify the politicization of disability, and subsequently the politicizing of her citizenship, in her efforts to contest the improper care Harvey was receiving. She brought the case to court and utilized pre-established systems of justice to mobilize a critique of unequitable power relations in the health and social service system in order to get Harvey’s needs acknowledged and met. In this context, Sandra’s foray into the legal system succeeded in empowering Harvey’s citizenship.

Drawing from the human rights model of Disability, politicizing citizenship is a powerful tool for Disability advocates when they use it to hold government branches accountable, including Montreal’s CIUSSSs. When citizenship is not politicized, the imbalance of power cannot be adequately critiqued and dismantled. Equal status is imperative for active citizenship and thus the concept of politicizing citizenship contests the assignment of the Disability community to a minority (or minor) position. Or, rather, engaging equal participation in citizenship resists persons with disability *becoming minor.* JanMohamed and Lloyd explain that becoming minor is “a question of position: [it can be defined] in terms of the effects of economic exploitation, political disenfranchisement, social manipulation, and ideological domination on the cultural formation of minority subjects” (as cited in Tyjewski, 2006, p. 111). Members of the Disability community have been positioned as minorities and absent citizens by a society that ignores and excludes them from active participation in any of the five elements of citizenship. They are each in their own battle with this position, fighting against “a regime of dis-citizenship” (Devlin & Pothier, 2006, p. 1) simultaneously as individuals and community members. If there exists such a regime of dis-citizenship, so too can there exist an initiative of en-citizenship.

The five needs of Montreal’s English-speaking Disability community, made up of the three expressed needs that closely relate to matters of linguistic inclusion, and the two felt needs that call for a broader and more varied comprehension of issues related to Disability, can be conceptualized as a need for equitable participation in citizenship. Such a conceptualization encompasses the need for access unburdened by linguistic barriers as well as those needs that are of a more subjective nature. This thesis will continue by illuminating the ways in which institutional policies consider the Disability community to be those who speak French; those who do not are excluded from this community and therefore make up their own secondary and lesser group in service provision contexts. Through employing a citizenship-focused lens that is grounded in the human rights model of Disability it becomes clear that equitable access must be the responsibility of governmental bodies in order to ensure debilitating stratification does not persist. Equitable access and appropriate accountability can be accomplished by understanding that the Disability community deserves self-determination, that equal status as citizens must not be determined by linguistic abilities, that policy work must account for the complexities of the Disability community, and that all this can be done within today’s liberal governmental systems.

The following chapters of this thesis will explore reasons for the status of the Disability community's needs. I have identified three central issues that negatively impact the Disability community: inaccessible information in languages other than French, the onus for language congruency being placed on the care seeker rather than the service provider, and linguistic ghettoization practices. These issues result in unmet needs and deny community members the right to active participation in citizenship.

Chapter Five: Issue of Inaccessible Information

Considering that the CIUSSSs in Montreal are categorized as either designated or indicated to offer services in both French and English, it seems reasonable that even the indicated centres (i.e., those which predominantly, but not exclusively, serve the French-speaking population) would offer easily accessible information about their services in English, as well as French and any other language service-users require. However, as mentioned previously during an examination of Quebec's Act Respecting Health Services and Social Services (1991), institutions must only offer services to the extent that their current resources allow. Ouimet et al. (2013) make the important point that all codes of ethics for health and social service professionals in some way emphatically state that workers "must do everything in their power to provide service of the highest possible quality" (p. 26).

This chapter examines the websites of each of Montreal's CIUSSSs, coming to the conclusion that information about services in English is difficult to obtain. Vital information is often available in only French on each of the indicated CIUSSSs' websites which act as a first point of access for information on service options. The limited English information further exemplifies the ways in which low-proficiency French-speaking members of the Disability community of Montreal are overlooked as members of the Disability community and are denied equitable participation in citizenship through equal access to autonomy in care-related needs. The lack of transparency in expected wait times and related policies and procedures creates gaps in quality care that negatively impact community members, including Tanya and Danielle. This chapter elucidates the central issue responsible for the three unmet expressed needs: access to continuous care and support via social services in a timely manner; access to social services in

English, indiscriminate of location of dwelling on the island of Montreal; and, access to information in English on matters related to disability support and services.

Internet as a First Point of Access

The benefits of using the internet to access health-related information are numerous. Internet users cite such benefits as ease of access, access to a greater volume of information, anonymity, and interaction with different perspectives (McLeod, Yu, & Ingledew, 2017, p. 87). The internet's significance as a purveyor of information is apparent in contemporary Western nations such as the United States, the United Kingdom, and Canada (Kim & Kim, 2009; Murray et al, 2003; Tonsaker, 2013), where roughly 80% of patients and caregivers access the internet to research their health (McLeod, Yu, & Ingledew, 2017). The significance of the internet as arbiter of information translates to caregivers as well, who use online health related information to improve their knowledge and competence and to build a stronger relationship with their health care professional. Fostering autonomy through information and communicative relations enables caregivers' health decision making abilities (Hesse et al., 2005; Kim & Kim, 2009; Murray et al., 2003; Tonsaker, 2013) and improves the health and wellness of both the caregivers and those for whom they care (Tonsaker, 2013).

McLeod, Yu, and Ingledew (2017) investigated internet usage among a group of patients with a gynecologic cancer. They found that patients using health care services were also using the internet to seek social care specifically pertaining to emotional support and coping strategies (p. 87). Patients typically searched for information related to their diagnoses for one-hour sessions once per week (McLeod, Yu, & Ingledew, 2017, p. 88). McLeod and colleagues suggest that, while patients refer to the internet prior to contacting their physician, "this does not impact the emphasis placed on the doctor's role in prescribing treatment or their trust in their competency" (p. 85). Rather, I propose that the practice of searching for health-related content online before seeing a health care professional implies a desire for agency, as the person is able to take initiative by independently learning from readily available resources before contacting an expert. McLeod, Yu, and Ingledew's study (2017) substantiates the importance of reliable and accessible online information for health and social service seekers. When linguistic barriers impede information access, certain groups are dispossessed of their agency and independence.

When seeking reputable internet sources with important information about Quebec health and social service options, information seekers who are not fluent in French are at a disadvantage. Health and social service information seekers commonly consult institution-based websites (Tonsaker, 2013), thereby positioning Montreal's five CIUSSS websites to leverage the benefits of the internet. Many health related websites are only meaningfully accessible to those with high literacy levels (Tonsaker, 2013), typically requiring users to have a reading level of grade eleven or higher (McLeod, Yu, & Ingledew, 2017), requiring more proficiency in second language speakers than might be expected for daily functioning. As support options for disability often use specialized language, high literacy expectations, especially when information is not available in an information seeker's first language, pose a barrier to information access. Literacy levels can be a result of many variables, including education, (dis)ability, and linguistic fluency. Chiu and her colleagues' research (2009) on the effectiveness of internet support systems for Chinese Canadian caregivers shows that online interventions are especially helpful for immigrants to Canada but can be particularly difficult to navigate for this demographic, unless they are appropriately implemented with fair access in mind (e.g., addressing the difficulty of typing in Chinese on English computers). Chiu and colleagues' research suggests that institutions and organizations must plan for literacy inconsistencies to provide equal access to their important online material. Below, I detail data acquired through participant observation which signals that Montreal's CIUSSS websites do not plan for a diverse user base, and thus do not foster fair access.

An Active Offer of Services

The Office of the Commissioner of Official Languages [OCOL] defines an active offer as a commitment to a "culture of respect, a culture of excellence" (2019); it is an "open invitation" to use either of Canada's official languages, French or English, when interacting with a federal governmental service. An active offer is therefore understood as a demonstration of respect and manifestation of a "virtuous cycle" (OCOL, 2019, I Make an Active Offer section). The OCOL states that "without a bilingual greeting, clients are less inclined to request service in the official language of their choice" and employees begin to believe there is no need for the offering of services in both official languages (Creating a Virtuous Cycle section), thus fortifying the aforementioned social rule through symbolic violence. Granted, with the passing of the *Charter of the French Language* (1977), Quebec's only official language is French, meaning the active offer is neither mandated nor expected in contemporary Quebec culture. However, the descriptors used by the OCOL, namely, "respect," "excellence," "open invitation," and "virtuous," suggest a culture of inclusion and *discourse of citizenship* through representation is the goal of the active offer.

Prata (2015) advocates that organizations within the health and social service system of Quebec ought to be "providing information in English and in the appropriate other languages using, for example, signage, websites, translated documents, telephone tree options, kiosks, and community-focused outreach" (p. 18). The offer of English services must be "visible, audible and accessible all along the continuum of care" (Prata, 2015, p. 18). An active offer of services model in Quebec would reallocate responsibility to safeguard adequate communication from the client to the service provider, and would work to balance the stratification of linguistic identities, where Francophones hold more power than Anglophones, who hold more power than Allophones.

The following section will analyze each CIUSSS website as a first point of access for service seekers, describing the ways in which they do not provide an active offer of services, and thus, do not promote participation in citizenship through an inclusive environment.

Visiting Service Websites

Prata (2015) explains in her Language Access Policy Guide that various vital health and social service related documents should be available in English as well as French, regardless of the overarching provincial language policies. These documents are crucial to the health, safety, and autonomy of service seekers. In addition to health and diagnosis-related information beyond the scope of this thesis, documents include consent and complaint forms, written notices of rights, advisories of language assistance services, and contact information (p. 16). Prata's Policy Guide advances policy development through what Prince (2009) terms "community—public service engagement" (p. 169), a strategy that involves advocates engaging with public servants, such as service providers, by offering advice, monitoring progress, and holding these bodies accountable (p. 169). Of the five CIUSSSs of Montreal, only the two designated centres' websites are available with an English option, though even in these cases, not all vital documents are available in both English and French. The three CIUSSSs with indicated services provide no English information.

Availability of "Language Access Policy Guide" required forms.

Complaint forms. In order to fill out a complaint file online or view information regarding filing or reviewing a complaint at any of the five CIUSSSs, I used the search tool bar for “complaint” at the two designated centres’ websites, and “plainte” at the other three centres’ websites. Montreal West and Centre West CIUSSSs, the two designated centres, provided concise English and French information. Montreal South CIUSSS and Montreal East CIUSSS were more difficult, as I had to first navigate a website in French only, search for a term in a language foreign to me, then scan the results in French for a link to an English form regarding complaints. Fortunately, such a link does exist for these two CIUSSSs. The same cannot be said for Montreal North CIUSSS, where no English information on complaints is available, thereby infracting Prata’s (2015) Language Access Policy Guide suggestions.

Notice of rights. Notices of rights are available online at each CIUSSS, in different capacities. Montreal West CIUSSS posts their list of rights under the service quality section, making it easily identifiable and accessible to Anglophones and Francophones. Montreal North CIUSSS lists user rights in the same way as Montreal West’s; however, it only provides information in French. Montreal South CIUSSS also provides a list of user rights in French only, which is made even more difficult for an English-speaker to locate, as it is not clearly listed under any section, though is searchable with the keyword “droits,” leading to a page not easily accessible any other way. Again, one must be computer savvy and know the correct keywords to search in order to find this information. Searching for user rights on Montreal East’s CIUSSS’s website led me to a PowerPoint slideshow in French only. Finally, Montreal Centre-West CIUSSS reworked their website as of January 2019. User rights are no longer listed. However, they provide two documents in both French and English on their code of ethics, which does mention users' rights. Regrettably, this information is now presented in a more convoluted way, as ethics are the choice of an organization, not to be confused with the rights of a service user.

None of the three indicated CIUSSSs provide information on user rights in English. This omission is particularly disappointing as one of the rights of users is to "receive services in English, in accordance with the government's access program" (CIUSSS Ouest, Your Rights as a User section). The government's access program is what distinguishes Montreal West and Centre-West CIUSSSs as designated centres, and the remaining three CIUSSSs as indicated, meaning they must have some programs available in English. The users of those English programs have no means to be informed about their rights unless they look to the documents put forward by other centres, creating uncertainty for the service user. Again, this is in conflict with Prata's (2015) Guidelines.

Language assistive services. The website for the Ministry for Health and Social Services includes information for translators through the Banque interrégionale d'interprètes. They offer services in approximately fifty languages, working on request. While I was unable to find information on any of the CIUSSS websites regarding language assistance services, Montreal East CIUSSS does provide a document (East Island Network for English Language Services, 2015) on English services in the region, "Health and Social Service Resources for English-Speaking Communities in the East End of Montreal." This is a useful resource with contact information for numerous services offered in English for what they refer to as "four development sectors: youth, seniors, intellectual deficiency [sic] and mental health" (East Island Network, 2015, Profile section, para. 2). It should be noted that the document linked on the CIUSSS site is not the most up to date report published by the East Island Network for English Language Services; a more recent 2018 version is available on the organization's own website. It should also be mentioned that the more recent version indicates that there are now less English services available than in 2015. (The reduction of English options was also mentioned in interviews and community discussions that contribute to this research.) The list of English services published by the network is not the language adaptation and assistance Prata (2015) recommends, as it does not work to reallocate responsibility from the client to the service provider. Rather, the client is still tasked with seeking options outside of their CIUSSS's CLSCs. The presence of the document does, however, indicate that Montreal East CIUSSS is aware of the "overlooked" English-speaking community within its jurisdiction (East Island Network, 2015, profile section, para. 1).

Availability of additional vital documents. The documents deemed vital by Prata's Language Access Policy Guide (2015) are often not available in both official languages on each CIUSSS website. This section identifies additional documents that I understand to be vital to the adequate assessment of services, which is an important component to appropriate accessibility of services. The six documents I have identified are the Access Plan, approval report, glossary of definitions, annual report, management report, and financial statement. Each of these documents are intended to assist service users in making informed decisions about their care or the care of their dependent. They give information on plans for the future of the centres and reports of past work to identify successes and problem areas. Additionally, they allow for comparisons to be made between different care options based on funding and general approval ratings, and provide key definitions that allow the documents to be fully understood. They each correspond to participation in citizenship through the fostering of appropriate interdependency and autonomy of care decisions.

Access plans. The Access Plan (also referred to as the action plan and plan d'access) is a document detailing goals for accessibility for persons with disabilities at each of the CIUSSSs, save Montreal Centre-West, which does not seem to have such a document (or does not make it accessible to the public). The Access Plan is part of Quebec legislation (RSQ, ch. E-20.1) that passed in 2004 and applies to public bodies and private agencies including all networks of provincial governmental departments. These organizations must produce for the Office des personnes handicapées du Québec a plan of access report, detailing equal access and inclusion of persons with disability for their organization[21] (Prince, 2009, p. 233). Perhaps the most regrettable of all the documents discussed in this chapter is this one, for it is available only in French, even at the designated English centre (that has one available). The Access Plan is put together specifically for each CIUSSS, meaning its information is especially relevant to service users; it is not generic policy mandated by a government. These plans involve creating accessible websites, mention language obstacles, and each have central goals of making programs accessible and inclusive. None of them, however, mention the English-speaking community or aim to create an active offer of services for this demographic. Those with low French proficiency cannot access the Access Plan's important care-related information with the same ease as a French-speaker, indicating the preferential treatment of Francophones in health and social services.

Reports. Approval reports, annual reports, and management reports deal with similar subject matter. Approval reports describe the general approval ratings of services, annual reports

---

[21] Montreal North CIUSSS published their plan d'action à l'égard des personnes handicapées in February 2017. The remaining plans are intended to span across various stated timelines. Montreal East CIUSSS's plan of access spans from 2018-2020, as does Montreal South CIUSSS's, and Montreal West's plan of access covers 2016-2018.

examine complaints and how they were dealt with, and management reports focus more generally on the organization of the centres and their services. Each CIUSSS does not have all three reports available online. The reports they have, however, are all available only in French.

Glossary. The glossary of key definitions was published by the Ministère de la Santé et des Services Sociaux and includes only French terms commonly used in the Act Respecting Health Services and Social Services (1991). According to Montreal West CIUSSS's website, "the glossary also reflects the changes made to the Act to modify the organization and governance of the health and social services network, including the types of institutions, missions, and territorial divisions and services networks" (Publications section, 2019). This suggests that the glossary provides crucial information for the comprehension of recent changes made to service provision and for understanding other important documents related to care. The glossary is available in only French.

Financial statements. Funding is an important part of assessing quality of care. Financial statements can provide crucial information on the realities of care, such as documenting overspending or underfunding compared to other programs. Montreal South CIUSSS has not published their financial report since the 2014-2015 period. Each of the other four CIUSSSs have up to date published financial reports. They are all available only in French. These documents were especially difficult to navigate, as they abbreviate French terms, inviting uncertainty for those with low French language proficiency and those with limited knowledge of technical health and social service related terminology.[22] The CIUSSSs provide different programs depending on needs and funding available, meaning that a comparative analysis of the financial

---

[22] In analyzing these documents, I searched for the term "déficience intellectuelle" [intellectual disability] and found it abbreviated to "DI." I then searched for "trouble du spectre autisme" and "trouble du spectre autistique" [autism spectrum disorder] and found it abbreviated to "TSA."

statements of each CIUSSS is not the most fruitful method of analysis.[23] The most important message provided by the process of acquiring financial information on the centres is that, again, this task is designed with the Francophone in mind, overlooking the possibility that an English-speaker might wish to gain such information.

Access to Information

It is reasonable to expect that the health care organizations in question do not make all vital documents available online, particularly those involving the internal workings of the organization. However, public sector health care services such as the CIUSSSs are covered under the Act Respecting Access to Documents Held by Public Bodies and the Protection of Personal Information, adopted in 1982 (Éducaloi, 2019, Access to Documents of Public Bodies section). In order to gain access to information held by these public bodies, I sent each CIUSSS a formal request asking for three items to be released: (1) Waitlist policies for social services for adults with intellectual and/or developmental disabilities; (2) Average wait times for access to each social service offered at the CIUSSS's centres for adults with intellectual and/or developmental disabilities; (3) The most recent completed annual budget report that includes information on social services for adults with intellectual and/or developmental disabilities. While the information requested would be useful for this research, my primary reason for these requests was to identify areas of linguistic-based difficulties in communications.

I sent a written request in English for the three items via email on October 24th, 2018. I used information on where to send the requests found on the website for the Commission d'accès à l'information. I received receipt of the requests from Montreal West, North, East, and South

---

[23] Though financial comparisons are not the focus of this research, I have created a table detailing CIUSSS funding of family support initiatives by the four CIUSSSs with published financial statements to simplify the process for those interested. (See Appendix B.)

CIUSSSs within one week. Montreal Centre-West CIUSSS's receipt arrived on December 13th, 2018. Montreal West and South CIUSSSs responded in English, Montreal East and North CIUSSSs responded in French, and Montreal Centre-West CIUSSS responded in both English and French.[24]

Montreal East CIUSSS. Montreal East CIUSSS responded to the request in French. The body of the email explained their decisions to provide access. Regarding the request for waitlist policies, they informed me that no such policy on waitlists exist for their organization. In contradiction to that statement, in their response to my second request (for information on expected waitlist times), they explained that they have no accurate data on average waiting times ["nous n'avons pas de données précises sur le temps d'attente moyen pour les services psychosociaux pour cette clientele"]. However, they do assess the priority level of each client and provide service according to three levels of priority outlined by each centre locaux de services communautaires [CLSC]. An urgent case is seen to in less than 72 hours, a high priority case is given maximum one month waiting time, and a moderate case waits for a maximum of 360 days. The CLSC priority levels are in place for medical issues and referrals ("les services psychosociaux"), rather than social services such as community integration or residential care. For this reason, these figures do not adequately represent the realities of wait times for the Disability community. Lastly, in response to my final request, Montreal East CIUSSS does not hold financial information on separate services; it provides only global budget reports. Again, this information was all conveyed in French only.

---

[24] According to section 47 of the Act Respecting Access to Documents held by Public Bodies and the Protection of Personal Information (1982), public bodies have twenty days to respond following the receipt of a request. They are, however, entitled to an additional ten days, so long as written notice of this delay is provided (R.L.R.Q., c. A-2.1, the "Act"). All five organizations informed me that they will be taking the ten-day extension.

Montreal North CIUSSS. Montreal North CIUSSS responded to my requests with only one document: the plan d'accès. As previously mentioned, this document is made available in only French. In their message they also informed me that they have no waitlists policies nor any information on average wait times for services. This information was relayed to me by email in French.

Montreal South CIUSSS. Montreal South CIUSSS responded to my requests in intelligible though non-fluent English, referring me to documents attached in the email that included information on my requested items. Each attached document was in French. They provided me with a single figure for their annual budget for their DI-TSA [intellectual disability and autism spectrum disorder] program.[25] They also provided their plan d'accès from 2008. While no policies for wait times seem to be in place, Montreal South CIUSSS has detailed information on users of their services, including waitlists. The Centre de Réadaptation en Déficience Intellectuelle et Trouble du Spectre de l'Autisme (CRDITSA), which offers services to persons with intellectual and/or developmental disabilities, has 1356 persons waiting to access a first service. 969 people are waiting for an integration or adaptation service. Eighty-six of these people are waiting to access a community integration service, 224 are waiting to access a work integration program, and 181 people are waiting to access a residential integration service. (See Appendix C for the complete data on Montreal South CIUSSS waitlists.) It is crucial for an organization to have information on their wait time numbers, as Montreal South CIUSSS does. Only with a clear understanding of these numbers can one comprehend the urgency of the situation. Montreal South CIUSSS provided concise information on budgets and wait times, showing that they understand the Disability community has unique needs from other service

---

[25] $174,876,706 for the 2019 fiscal year.

users within their organization, and that a global policy or budget report does not appropriately detail these needs.

Montreal West CIUSSS and Centre-West CIUSSS. The two designated English centres have yet to provide responses to my requests. As it is my right as a citizen to access these public documents, there are options for me to follow up legally to access documents. The reasoning behind my request for document access, as stated above, is to analyze the channels of communication and identify areas where access barriers impact care seekers' efforts to assess their options for social service support. In the case of the two designated centres, lack of response presents a barrier to information access.

Information Access via Telephone

As searching for information online or contacting the institutions via email provided limited results, I telephoned various CLSC offices. I focused on the CLSCs that are categorized as indicated, in an effort to conclude whether their categorization is practical or tokenistic. The indicated centres I spoke with had CLSCs that were mandated to have reception, assessment, guidance, and referral options in English, as well as each offering at least one program for persons with intellectual and/or developmental disabilities.[26] Each CLSC listed stated that services are offered in French and English ("Les services sont offerts en français et en anglais"). Contact information for each CLSC was available in only French, contravening Prata's Access Guide (2015). I telephoned a total of twelve CLSCs and concluded that the bilingual services mandated by the indicated category are not realized.

---

[26] The CLSCs are mandated by the Secrétariat à l'accès aux services en langue anglaise and the Secrétariat à l'accès pour les communautés culturelles, which support and advises on service accessibility for English-speakers.

Montreal East CIUSSS. I telephoned seven CLSCs in the Montreal East CIUSSS region. Each call was answered by an automated directory that provided no English option. The automated reception seemed to indicate that, though the CLSCs are said to provide bilingual services, I would not be accommodated given my linguistic abilities.

Montreal North CIUSSS. Calls to any CLSC in Montreal North CIUSSS region are first directed by the centre, which has an option for English service on their automated directory. The first time I called I spoke to a receptionist who could not understand me when I asked for information on services for an adult with autism. The receptionist told me they could not understand then spoke in French, which I did not understand. I repeated the word autism and adult again, which they repeated back to me in French, signaling I was understood. I was then transferred to someone else (unspecified role/department) who, after I restated my request, transferred me again. The next person (unspecified role/department) answered in French, I repeated my request but was hung up on before I could finish speaking. Thinking perhaps the hang-up was an accident, I called back. The same receptionist answered, recognized me, and told me they would transfer me elsewhere. The person to whom I was transferred admitted they did not speak English then transferred me to the Mental Health Service Centre. The person who answered this call informed me that this was not the place to find information on disability services and they provided me with the phone number for the CIUSSS North again. These phone calls to the CIUSSS North suggest that the indicated centre is poorly equipped to adequately serve the English-speaking community. My experience with these calls corroborate Danielle’s experiences of feeling as though she must switch to French, regardless of her low proficiency, in order to proceed with the information exchange.

South Montreal CIUSSS. I telephoned two of the six CLSCs of CIUSSS South that offer English services. In these conversations, language congruency was not a problem. Both receptionists were fluent in English and I felt comfortable making my request. It seems, however, that CLSCs of the CISSSS South will provide no information without first meeting with a social worker. There are no appointments for these meetings, only walk-ins are permitted for first appointments. The receptionist could provide no information on expected wait times or even which services are available at the CLSC for English-speaking clients. Fulltime caregivers' time is scarce, making unscheduled appointments difficult. Tanya's story suggests that English-speaking social workers and services are limited in CIUSSS South, implying that there would be no guarantee of a timely meeting. Furthermore, this chapter indicates CIUSSS online resources provide much information that is only accessible if one speaks French. For those who cannot access the information, phoning one's local CLSC with relatively simple questions would be a valuable alternative information resource. Of the twelve CLSCs I telephoned, I was unable to obtain any information on services, including exactly what is offered by the CLSC, steps one must take to access services, or expected wait times for services.

The various CIUSSS interactions, whether by email or over the phone, illuminated a major concern regarding the lack of policies on waitlist procedures. Many of the parents and persons with disabilities I have spoken with have similar experiences of uncertainty regarding waiting for services. Tanya waited five years before finding out she was not on a waitlist after all that time. Danielle waited for adaptive equipment for their child before realizing their request had not been approved with no notice given to them. There is precedence for the lack of transparency regarding waitlists for intellectual and developmental services in Canada. In 2011, British Columbia's Community disability service providing institution (Community Living

British Columbia) refused to comply with document access requests (British Columbia Government and Services Employees' Union [BCGEU], 2011). After five months, the government shared their waitlist statistics because, according to the BCGEU, "it was forced to" (2011, para. 2). Once the statistics were shared, the BCGEU, CLBC, and the deputy minister published instructive reports resulting in the Government of British Columbia pledging $40 million to CLBC[27] (BCGEU, 2011; CTV News Vancouver, 2011; Deputy Minister, 2011). British Columbia's example provides an astute lesson for Quebec on the importance of waitlist transparency.

Policies regarding waitlists might require providers to update clients every three months and to keep records of who is waiting for what services so to identify problem areas. It is evident from the real experiences of members of Montreal's Disability community that some policy intervention is necessary. As for the released documentation all being in French, I was expecting this to be so because the *Charter of the French Language* (1977) enacts that internal communications must be in French. The *Charter* does not, however, declare a prohibition against providing services in English nor an evident reason for their current unavailability (Ouimet et al. 2013). The availability of website documents, internal documents, and communication exchanges in both official languages is a simple and valuable means to provide an active offer of services. Equal opportunities for information access is also a vital tool for meeting community members' needs. Feeling that one's linguistic identity is represented in institutions would suggest

---

[27] The Deputy Minister's Review of Community Living British Columbia revealed four concerns on the organization's operations: overlooked school to post-school transitioning into CLBC-funded services; staffed residential facility closures without alternative options available; inadequate inclusion of families and caregivers in conversations about the direction of the CLBC; and poorly managed internal organization that led to inaccurate information regarding the number of people not able to access services (Deputy Minister, 2011).

that the institutions value diverse identities and promote active participation in all elements of citizenship.

Chapter Six: Issues of Language Congruency and Linguistic Ghettoization Practices

The final two of the three central issues that negatively impact Montreal's English-speaking Disability community, that of the allocation of onus for language congruency and linguistic ghettoization practices, are discussed in this chapter. The issue of language congruency implicates the issue of linguistic ghettoization: If language congruency is impossible between the care seeker and provider, relocating to a linguistic ghetto might be the only option. Language policies have a cataclysmic relationship with the ruling Act Respecting Health Services and Social Services (1991) which, again, states that "the Québec network is required to provide services in English to anglophones and adapt its services to the needs of the members of cultural communities" (Ouimet, Trempe, Vissandjée, & Hemlin, 2013). This chapter explores this relationship by describing the ways in which language laws account for users' rights laid out by the aforementioned Act (1991), while employment of the Act must also comply to the protectionism of language dictated by the *Charter of the French Language*[28] (1977). The relationship between language policies and the Act is based on the exclusion of minority groups from visions of equal access: service providers need not hire sufficient numbers of English-speaking staff or spend time and money on translating important documents into languages other than French. Institutions must comply with their indicated status as laid out by their plans of access only to the level attainable by the *current resources* of each institution. As exhibited in

---

[28] I have consulted research on linguistic barriers completed within the last forty years in Canada. This wide temporal window coincides with changes to Disability rights and scholarship brought on by the passage of the 1977 Canadian Human Rights Act. The *Canadian Charter of Rights and Freedoms* of 1982 extended the Act and made way for the 1986 Canadian Employment Equity Act. This duration represents a time period of great momentum for Disability rights. However, a window of limited advancement exists between this time and the United Nation's replacement of the medical model of disability in 2006 (Rioux & Valentine, 2006, p. 60-1).

the previous chapter, service provision institutions are not compelled to increase their resources to meet their clients' needs. Equal access, however, can be construed in different ways, where service providers can claim impartiality through the models of equality: equal treatment and equal opportunity. Conversely, the ideal well-being model of equality intends to facilitate meaningful inclusion and participation (Rioux & Valentine, 2006).

Comprehension of the linguistic, socio-economic, cultural, and racial diversity of Disability communities in Montreal has potential to bolster the meeting of the two felt needs identified in this thesis: a wider spectrum of definitions for what constitutes disabilities and capability and for the updated definitions to be reflected in care options; and understanding and consideration of the economic, health, and wellness effects that opportunities for subsidized support have on caregivers.

Issue of Onus for Language Congruency

Quebec's dominant method for bolstering language congruency between care provider and seeker is to offer subsidised courses in the majority language of the region, French. In fact, Quebec's new premier was voted in on a platform that would require newcomers to take a French language test, stating that for "greater success in the integration of immigrants, it will be mandatory for any newcomer wanting a Selection Certificate to learn French" (Coalition Avenir Quebec, 2018). Such a stance on immigrant autonomy disregards the fact that many immigrants in Canada do not speak an official language even after many years in this country (Bowen, 2001, p. 5), which is due to a number of reasons including disability and education. Stevens (1993) and Jackson (1998) found that immigrants who do not learn an official language are more commonly mothers of dependents, the undereducated, the elderly, or those with mental health issues. The four characteristics are overrepresented in determining who has unmet needs for health services

(Bowen, 2001, p. 5). Certainly, these identity categories provide justifiable reasons, also, for non-immigrant low-proficiency French-speakers not to acquire French. Furthermore, the basic conversational skills needed for day-to-day life are inadequate when dealing with health-related events (Bowen, 2001, p. 5), meaning that even those with basic skills in an official language face linguistic barriers in a health care system that expects the client to adapt to the institution.

Just as caregivers, the undereducated, elderly, and those with disabilities show high levels of unmet health needs, an Ontario based study (1995) by Majumdar, Browne, and Roberts found that, in English-dominant settings, those who are non-white English-speakers are underrepresented in homecare services. The researchers grouped clients of homecare services into ethnic categories: white English-speaking, white non-English-speaking, visible minority, Francophone, Indigenous, and Hispanic. They found that 88.3% of clients were white Anglophones, while only 11.7% were from “multicultural groups.” At the time of the study, 24% of the region was multicultural, signifying an overrepresentation of white English-speakers accessing services. What these examples of the negative effects of misplaced onus for language congruency show is that marginalized minority groups’ rights are jeopardized by this approach. Assuming that *anyone,* including persons with disabilities and primary caregivers, can take time away from their work or family duties, has the intellectual capacity to learn a language, or is comfortable assimilating to the social rule exemplifies a view of equality that is tarnished by its reliance on assumptions: the equal treatment model. In Quebec, the equal treatment model is based on a comprehension of equality that disadvantages the English-speaking Disability community by failing to recognize that services and information are “being accessed by a diverse population” (Rioux & Valentine, 2006, p. 54). The equal treatment model coincides with the need for diverse definitions of disabilities and capabilities, as the need for a wider spectrum of definitions is unmet due to the assumptions on which the equal treatment model relies.

A more judicious method for increasing language congruency between care provider and seeker is to offer courses for health care providers to learn minority languages. In 2007, Quebec invested about $1.6 million to teach Francophone health professionals English (Ouimet et al., 2013, p. v). There is an issue with this educational system, nevertheless, as there are few assessment measures available to assess a professional's actual proficiency in English if it is not their first language (Ouimet et al., 2013, p. 1). In fact, this problem persists across Canada, as "there are no nationally accepted standards regarding qualifications and assessment measures for bilingual staff" (Prata, 2015, p. 12). With no standards in place, researchers have illustrated risks of false fluency, wherein providers attempt to communicate with a patient in a language in which they have only limited proficiency. False fluency risks dangerous miscommunications between the provider and seeker (Bowen, 2001, p. 4). While there are clear issues with this method of confirming adequate communication between care provider and seeker, this method does not rely on assimilation or acculturation. In fact, Ouimet et al. (2013) consider the onus for mutual understanding to be an issue of ethical practice. They state that health care professionals should "not only make every possible effort to speak the language of users" but should confirm "mutual understanding in cases where they are not proficient in the users' language" (p. 26).

Issue of Linguistic Ghettoization Practices

The above section reveals how allocating the care seeker with the onus for language congruency between herself and the care provider is a risky practice with vulnerable populations bearing the consequences. Bowen (2001) identifies "negative effects of language barriers on a range of services" (p. iii) including hospital care, speech and occupational therapy, home care, and support for caregivers. Patient satisfaction is the most prominent measure of the effectiveness of communication between client and health care provider (Kaplan, Greenfield, & Ware, 1989). Research shows that "individuals who do not share a common language with their providers [are] less satisfied with their care" (Bowen, 2001, p. 75). In fact, researchers have concluded that the percentage of a setting's dominant-language speakers who reported their care experience as more than adequate was twice as high as non-dominant language speaking patients (Hu & Covell, 1986). Tang (1999) states that Canadian government reports corroborate the satisfaction discrepancies between linguistic minorities and dominant language speakers, indicating that patients who do not speak one of Canada's official languages receive a lower standard of care.[29] Patients who do not speak French or English are more likely to "receive less protection in terms of ethical standards" (Bowen, 2001, p. 79). Ethical care practices are in place with the intention to protect and support the most vulnerable of persons, often those whose reduced autonomy limits the degree to which they can hold their care providers accountable.

Désy's Quebec based report (2010) linked "quality of communication [to] delivery of care"[30] (as cited in Ouimet et al., 2013, p. 25). Désy promotes the notion that equitable health care access refers to such principles as the right for those with special needs to access required

---

[29] In a disability context, it must be noted that approval, satisfaction, or ethical care ratings necessarily reflect approval within a lacking system, as quality and availability of care for persons with disability across Canada is inadequate. Approval reports only reveal the perspectives of those who have accessed services, while the many people on waitlists or who have been denied access are excluded. For those who do not speak French in Quebec, approval ratings may evaluate someone who does not know whether they were mistreated, as user rights are difficult to access in a language other than French.

[30] A 1986 study in British Columbia similarly characterizes the link between communication and care. It found that capacities for communication with elderly patients in long-term care facilities affected the standard of care. The researchers divided patients into three categories: Canadian born, United Kingdom born, and those born in non-English-speaking countries. Communication levels dropped between the care provider and the non-English-speaking patient (Jones & Amelsvoort Jones).

special services and the right for limited French-proficiency clients to access quality care (Désy, 2010). Service providers and policy workers can interpret Désy's notions as an equality of opportunity model that reflects the aforementioned equal treatment model of equality, given that service provision institutions do acknowledge that English-speakers have the right to English services. The equality of opportunity model presumes equality can be achieved by providing opportunities (Rioux & Valentine, 2006, p. 54). For example, the Act Respecting Health Services and Social Services (1991) mandates that English-speakers have the opportunity to receive English services. The mandate to provide English services does not include time-limitations for receiving those services, often resulting in unreasonable wait times for a person's situation. Otherwise, individuals may choose to exercise this right by moving to Montreal's linguistic ghetto to receive services at a designated English centre, as Tanya did for her family. Again, there are many situations that might render this option impossible for a person with disability (e.g., reduced transit options, financial insecurity, proximity to support network). While the rights for accessing required specialized services and quality care are available through opportunities presented by indicated and designated programs, the person with disability may experience an inability to travel or long wait periods, making it impossible for them to actualize their rights. Therefore, the oversights that easily accompany an equality of opportunity model risk continued exclusion. Crucially, as the human rights model of Disability states that rights are inherent—they can be neither given nor taken from a person or community—the practice of linguistic ghettoization that maintains that persons must choose to relocate in order to experience access to disability services is a violation of their human rights.

Language congruency methods that inaccurately assume all Quebec residents have the means to acquire the French language lead to the frustration which Tanya experienced when relocating her family. The relationship between these two events, the false assumption (that all Quebec residents can access French language instruction) and the subsequent decision to relocate, result in unmet needs. Specifically, the relationship between service providers' assumptions and the service seekers' response impacts the need for what I identified as understanding and consideration of the economic, health, and wellness effects that opportunities for subsidized support has on caregivers. If caregivers and those with disabilities are not provided with support, they face serious hardships. In attempting to avoid such hardships, they may feel obliged to take extreme measures, such as paying out of pocket for what they have the right to obtain, as Danielle has considered, or moving one's family, as in Tanya's case. With consideration of the benefits care has on their clients, institutions will understand that their practices of language congruency and linguistic ghettoization are causing more issues than they are solving. Such consideration and understanding would have to follow the model of equality that holds well-being as the main objective, rather than the equal treatment model or model of equal opportunity that diminish diversity of life contexts (Rioux & Valentine, 2006). The well-being model expresses that all persons "are entitled to consideration and respect as equals, and have the right to participate in the social and economic life of society" (Rioux & Valentine, 2006, p. 54).

Intersections of Policy and Identity in Canada

Discussion in this chapter so far has detailed two issues that result in continued unmet needs for Montreal's English-speaking Disability community. It has also argued that the two issues are enmeshed, as the prevalence of one exacerbates the other. I now suggest that these issues exist because of a wider societal problem of Quebec that involves protectionism of a language rather than guardianship of citizens. Meeting the need for active participation in citizenship is hampered by policies that disregard or actively dissuade acknowledgement of diversity among stakeholders. English-speaking Quebeckers and English-speaking members of Montreal's Disability community are often overlooked hybrid identities. Further, Allophones and non-white members of the local Disability community face additional oppressive systems such as discriminatory immigration policies. This final section details issues that impact the ways in which service-providing institutions might meet the Disability community's need for equitable participation in citizenship.

Quebec has gone to great lengths to preserve the French language in Canada, particularly through the 1977 *Charter of the French Language* which asserts that "French is the official language of Quebec" (Chapter C- 11- S.1). As this thesis shows, the protection of the French language in Quebec poses challenges to Anglophones in the region. It must also be acknowledged that the protection of the French language also serves to protect the Quebecois culture, which is intricately tied to the language. The notion that the French language is tied to culture is supported by the preamble to the *Charter of the French Language*, which states that "the French language, the distinctive language of a people that is in the majority French-speaking, is the instrument by which that people has articulated its identity" (Chapter C-11). This shows that the Quebec government endows the French language with social status through *The Charter*'s prescribed symbolic order.

Quebec's linguistic landscape, and associated language policies, are complex, as the French language is dominant, protected, and of cultural importance to the Quebecois people, while English is a minority language of the region, though it is globally dominant. When considering the Quebecois culture as removed from the cultures of English-speaking Quebec residents, it is important not to distinguish experiences of Montreal's Disability community in an unbridled fashion; experiences of caregivers of persons with disabilities and the individuals are more common than distinct. The Disability movement fosters “a sense of common belonging” (Prince, 2009, p. 63) rather than highlights differences within the community. However, the fact is that this specific English-speaking community has multiple organizations, issues, and perspectives (p. 191) that are affected by policies and services that favour French-speakers in Quebec.

Status of French in North America. The *Charter of the French Language* (1977) is an effort to combat language shift. Language shift occurs when people begin to use a language other than their first language as their primary language, usually for political or economic reasons such as ongoing colonialism (Holmes, 2013). For French-speakers west of Quebec in Canada, approximately three quarters of this demographic will shift to speaking English at home by the age of fifty (Sabourin & Belanger, 2015, p. 738). Considering the status of French in Canada, where French is an official language, it seems there is justification for the legal protection of the French language in Quebec. It is, however, important to make clear that while French speakers in Canada outside Quebec might be in some danger of shifting to English, —that is, unilingual French-speakers become bilingual French-English-speakers, and eventually, become unilingual English-speakers—French is in no way an endangered language. Similarly, while English-speakers in the officially French-speaking province of Quebec are minority language speakers, their language is in no danger of extinction (Wardhaugh & Fuller, 2015). With neither French nor English being endangered, especially within Canada, the focus of protection should be on the speaker and their culture rather than on the status of the language itself. This is especially true when considering that marginalized Disability community members are subject to further oppression due to the misguided protection of language over the protection of individuals.

Immigration and language. An expectation for someone to assimilate to the dominant culture is problematic on many levels.[31] Immigration policies reinforce adversarial practices wherein various facets of society, including the health and social service sector, allot citizenship based on linguistic abilities. The four interviewees in this research and a large majority of the attendees at public talks I attended as an observer were all white and were all fluent in English. While they are linguistic minorities and experience diminished Quebec citizenship, they are otherwise privileged by their whiteness, citizenship, and fluency in a globally powerful language. As difficult as acquiring access to social services is for White-Anglophones, immigrants who are persons of colour and/or are not fully fluent in either French or English face greater hardships in participating in citizenship.

According to the 2006 Canadian census, China is now the number one source country for immigrants to Canada (Statistics Canada, 2006). In Quebec, the top three source countries were all French-speaking (Algeria, France, and Morocco, respectively), with China being the fourth source country, signifying that the language policies in Quebec influence immigration patterns in Canada. Further, in 2001, 85% of Chinese immigrants in Canada could converse in at least one official language. 78% of the 85% who acquired an official language could speak English, 1% could speak French, and the remaining 6% could speak English and French (Conrick & Donovan, 2010, p. 335). Conrick and Donovan (2010) question whether Quebec language policies go so far as to deter rather than merely influence Chinese immigrants from settling in Quebec, as Chinese immigrants in Quebec make up over 6% of the population, but only 1%

---

[31] The controversy around Bill 21, An Act Respecting the Laicity of the State, exemplifies the challenging nature of mandated assimilation in contemporary Quebec. It obligates cultural assimilation through religious neutrality. The Bill was presented in March 2019 and passed in June 2019 under the Coalition Avenir Quebec political party (National Assembly of Quebec, 2019).

speak French (p. 335-6). Immigration policy in Quebec highly values French as a symbolic resource. In fact, Quebec disadvantages applicants who cannot speak French more severely than the federal system disadvantage applicants who cannot speak either official language. This means a prospective immigrant with knowledge only of, for example, Chinese languages has a greater chance of immigrating to provinces other than Quebec (p. 337).

In addition to Chinese persons living in Canada being more comfortable speaking English than French, REISA, the East Island Network for English Language Services (2018), has identified Latino, Indian, Pakistani, Polish, and Italian communities as commonly preferring services to be available in English rather than French (Profile section).

Canadian integration policies attempt to accommodate all cultures and traditions and encourage the retention of a non-official language. Conversely, in Quebec, adoption of the French language is emphasized:

> "Pour les personnes immigrantes, la langue française est un instrument essentiel de communication avec les autres citoyens; elle contribue à rompre leur isolement et à accroître leur autonomie" [For immigrants, the French language is an *essential* instrument of communication with other citizens; it helps to break their *isolation* and increase their *independence*]. (as cited in Conrick & Donovan, 2010, p. 341, emphasis added)

This suggests that without French proficiency, citizenship (through inclusion rather than *isolation* and *independence* rather than subjection) is not guaranteed. That is, French language proficiency is an *essential* prerequisite to citizenship.

I have previously mentioned two models of language congruency between health professionals and care seekers, noting that Quebec tends to use a model that relies on the limited French-proficient person to learn French. It is now clear that such a model is rooted in this immigrant integration (or assimilation) policy, which is itself rooted in a protectionism of the French language. As we know that French is not an endangered language, and the Quebecois culture is well protected under these policies, we must question who bears the impact of these systems of acculturation. Resoundingly, the answer is the communities who face such underlying oppression as racism or ableism in addition to these linguistic barriers. Furthermore, ableism in immigration law goes beyond linguistic barriers; in some cases, disability is "explicitly considered a legitimate reason for denying an applicant admission to Canada" (Devlin & Pothier, 2006, p. 17). A person with a disability who does not speak French faces a seemingly insurmountable level of discrimination when attempting to relocate to Quebec.

Language and culture. Language revitalization scholarship, particularly with a focus on Indigeneity, has unambiguously supported the idea that language and culture are linked. Language researchers Pine and Turin (2017) explain that "language is so heavily intertwined with cultural knowledge and political identity that [it serves to indicate] a community's vitality and social well-being" (Summary, para. 3). Henze and Davis (1999), (and later Neegan, 2005, p. 9) clarify language's relationship to culture and identity using the notion of worldview (p. 3). Fishman (1996) notes that due to language and culture's "deictic relationship," language represents culture for both the speaker and the "outsider" (p. 72). These authors each suggest that language is more than a communicative tool; rather, it is integral to culture and identity and encountering alternate worldviews.

The French language is undoubtedly integral to the Quebecois culture and identity, as described in *The Charter of the French Language* (1977). Interpretations of *The Charter* in contemporary policies prioritize the Quebecois culture over the cultures and languages of non-French-speakers who live in Quebec. The 2016 Canadian census shows that 10.4% of the population of Quebec most often speaks English and a non-official language or only English at home (Statistics Canada, 2016). This figure denotes a significant proportion of Quebeckers who are challenged by policies that inhibit their inclusion in society. Certainly, without Quebec’s policies of language protection, a shift to English is likely. Quebec has produced an immigration prioritization system that advantages French-speakers, particularly (white) European French-speakers, thus limiting the number of Allophones or Anglophones that enter the province. However, immigrants who come to Quebec arrive with fully formed identities and cultures shaped by their home country.[32] Similarly, English-speaking parents of children with disabilities have their own linguistic identities, which care providers should accommodate to provide the best care possible. Such a need for appropriate support from institutions validates the aforementioned cataclysmic relationship between language laws and the Health Services and Social Services Act (1991), wherein linguistic policies must protect the individual speaker who is seeking social services. Nevertheless, these policies remain focused on protecting the language, thereby benefiting French-speakers and prompting the social service sector to follow suit by considering the needs of French-speakers as the default for the Disability community. Stated more emphatically, assumptions that French is a prerequisite for citizenship in Quebec are resulting in what this research suggests to be a reduced active participation in citizenship for Montreal’s English-speaking Disability community.

---

[32] While outside the purview of this research, it should nevertheless be noted that Indigenous Peoples of Canada, including Quebec, were subject to an educational system that forced them to learn English, and should now be supported in relearning their ancestral languages rather than an additional colonial one (Battiste, 2005).

Conclusion: Recommendations

Throughout this thesis I have shown that Montreal's English-speaking intellectual and/or developmental Disability community faces additional barriers to social service access due to their status as linguistic minorities. I have employed a citizenship lens, informed by the human rights model of Disability, to guide this needs-based assessment. The five unmet needs I have identified led me to distinguish three key issues that have resulted in the unmet needs. The needs, again, are: (i) access to continuous care and support via social services in a timely manner; (ii) access to social services in English, indiscriminate of location of dwelling on the island of Montreal; (iii) access to information in English on matters related to disability support and services; (iv) a wider spectrum of definitions for what constitutes disabilities and capabilities and for the updated definitions to be reflected in care options; (v) understanding and consideration of the economic, health, and wellness effects that opportunities for subsidized support has on caregivers. I understand the systemic non-meeting of these needs to culminate in the categorical need for equitable participation in citizenship. The three key issues I consider to be largely responsible for this outcome are: (i) inaccessible information in languages other than French; (ii) the onus for language congruency being placed on care seekers rather than care providers; (iii) linguistic ghettoization practices. In identifying community needs and reasons for them being unmet, I have considered how access to social services influences the felt impacts of the prioritization of disability support services. A lack of self-recognition in institutional settings, due to linguistic prioritization of French, impacts the Disability community's wellbeing and produces linguistic barriers. These barriers are fortified by institutional policies' interpretations of the relationship between *The Charter of the French Language* (1977) and the Act Respecting Health Services and Social Services (1991).

This final chapter will conclude this thesis by offering my recommendations for working toward dismantling the additional barriers English-speaking members of the Disability community face. In so doing, it offers means for garnering a more inclusive social service network for all members of Disability communities in Montreal. Recommendations begin by tackling specific needs this thesis has identified. I then propose institutional changes that target the systemic concerns that result in the prioritization of social services for French-speakers and accompanying withholding of citizenship rights.

Recommendation One: Institutional Investments

Prioritization of French-speakers' social service access occurs in Montreal due to false assumptions of a homogenous French-speaking population that provokes an equal treatment model for handling diversity. When linguistic diversity is considered, an assumed universal ability to learn French provokes an equal opportunity model via offers of subsidized French courses. The negative consequences of such models are apparent in the expressed needs of the hybrid community members—the English-speaking intellectual and/or developmental Disability community. This research has revealed that French is often necessary to assess the acceptability of services through internet reports, to access services such as adaptive equipment, and to take the first steps in determining availability of services through document access requests. As such, my first recommendation is for care providing institutions to invest in translations of documents and to acquire and retain bilingual and multilingual staff at various levels of the institution (e.g., liaisons/receptionists and social workers). Given that all programs must be available in English at designated centres and some programs must be available at indicated centres, all CIUSSSs should require sufficient English-speaking staff and bilingual documentation. The Act Respecting Health Services and Social Services (1991) supports compliance with this recommendation, as accessing English services is a protected right. *The Charter of the French Language* (1977) allows the intervention of English, so long as French remains prominent. This is acceptable, as French-speakers are the majority demographic of Montreal. Adhering to my recommendation would not impinge upon the Quebecois culture; it will empower linguistic minorities' self-recognition within this Quebecois culture.

Accountability policies are also necessary for standardizing bilingual fluency of care providers. Accountability in this area will minimize the risk of false fluency, as experienced by Danielle in unintelligible telephone conversations. Institutions can secure adequate human resources for providing English services by encouraging care providers to participate in English-language classes. Doing so will appropriately allocate onus for language congruency to the care provider. Furthermore, holding CIUSSSs accountable for providing English services will minimize instances wherein individuals feel they must relocate in order to access the services to which they are entitled. If indicated centres verily provide the services they are meant to, designated centres will not offer the sole option for some people. Linguistic ghettoization practices will therefore be obsolete. Institutional investments will foster attainment of social entitlements, and thus, participation in citizenship.

Policy and procedural change is necessary in order for institutions to be held accountable for securing representation of their English-speaking clients in their practices. Currently, institutions must only provide English services to the extent that their human, material, and financial resources allow. Entitlement to English services must be a priority when institutions consider their own available resources, which they do yearly in annual reports. Publishing wait times and continually updating individual service seekers' timelines would aid institutions in pinpointing areas of need for resources. Accountability requires the CIUSSSs to adopt transparency practices. Admittedly, institutional investments toward transparency within today's capitalist system are only a feasible recommendation if benefits extend to the care providing institutions as well as service users. Bowen (2001) explains that providing fair and equal access to care services benefits a number of stakeholders. The patients and clients benefit from improved diagnoses and higher satisfaction. Care providers benefit from reduced frustration and risk of malpractice, while administrators avoid liability and increase their efficiency. More generally, with equitable access, the health care and social service system will see improved health outcomes and society will benefit from increased overall health and productivity for all citizens (p. 95).

Guaranteeing universal access to services will alleviate various difficult experiences resulting from inaccessible services. For example, caregivers' financial strains would be reduced if a mother like Danielle did not have to be with her child fulltime. The health and wellness impacts that accompany caregivers' juggling of numerous roles, as Tanya has done, would be appeased. Those in similar situations to Harvey would not experience the risks to personal safety caused by insufficient care options. Finally, Sandra and other advocates could focus on positive aspects of their relationships, rather than the worries and frustrations that accompany attempting to access the social service system on behalf of someone with a disability. That said, simply recommending that services be available, wait times be shorter, and institutions be more compassionate is infeasible without a plan. The following recommendations, for community consultations and implementation of intersectional policy frameworks, call for an ideology shift that allows for new conceptualizations of expertise, inclusion, and relationships between policy and citizenship. These recommendations are in no way ground-breaking. In fact, Disability communities have appealed for their enactments at least since the Nothing About Us Without Us movement (Charlton, 2000). What this means is that in my inclusion of these recommendations, I acknowledge that more experienced individuals have called for the same interventions.

Recommendation Two: Consultations

A goal of the Disability movement is to increase instances of consultations with communities and to treat community members' opinions and experiences with dignity. In fact, due to the necessitated accidental activists who are caregivers with limited support options, Montreal already participates in intra-community engagement which involves multiple organizations working and consulting within the Disability movement (Prince, 2009, p. 159). The involvement of non-governmental organizations is apparent in the various workshops, symposiums, and online and in-person support groups within the Disability community. However, Montreal's version of intra-community engagement is limited to the non-profit and grassroots sectors with little involvement of government and public disability-related organizations. Intra-community engagement must be more proactive in its consultations. Affiliates and locals must share information, engage in conversations on policies, and collaborate with the various sectors of the Disability community (Prince, 2009, p. 159). Engagement enables and empowers the Disability movement to enact change at the governmental level as decision-makers hear and value their opinions.

Only through meaningful consultations with Montreal's Disability communities can institutions understand the effects care and support has on individuals and begin to satisfy this need. Throughout this research, I have revaluated my own conceptions of what inclusion and Disability mean by speaking with and listening to persons with disabilities and their caregivers. Prince (2009) refers to a "significant gap […] between the rhetoric of inclusion and the lived realities for many persons with disabilities" (p. 225). The gap between rhetoric and reality is understood and mended through consultations that value the expertise of community members. Consulting with Montreal's English-speaking intellectual and/or developmental Disability community will make this overlooked demographic visible to institutions and decision-makers. It is an act of inclusion that promotes citizenship through the right to state membership.

Recommendation Three: Intersectional Policy Work

Disability is neither static nor is it an intra-sectional experience. People with disabilities are susceptible to experiences of various forms of oppression and stigma, as are many abled persons. In a duo-lingual setting such as Montreal, language-based stigma is a risk for hybrid persons who are both linguistic minorities and persons with disabilities (and any other identity characteristic that experiences marginalization). Unfortunately, this risk is furthered by language policies that affect explicit disability related policies including the Act Respecting Health Services and Social Services (1991). I recommend an intersectional approach to policy analysis and implementation to combat risks of further marginalization.

An intersectional-based policy analysis framework captures and responds "to the multi-level interacting of social locations, forces, factors and power structures that shape and influence human life and health" (Hankivsky et al., 2014, p. 1). This work is accomplished by analyzing policy with the intention of illuminating "how policy constructs individuals' and groups' relative power and privileges vis-à-vis their socio-economic political status, health and well-being" (Hankivsky et al., 2014, p. 1-2). This research has considered language to be a symbolic resource that the Quebec government uses to empower French-speakers and disempower others, so to protect the status of the Quebecois culture. Policy substantiates such stratification, and therefore, an intersectional-based policy analysis framework attends to the resulting disadvantaging of low-proficiency French-speakers in social services. An intersectional framework also complements the human rights model of Disability which is interested in how policies and laws influence equal participation in society (Rioux & Valentine, 2006, p. 52).

I suggest that an intersectional approach to policy work incorporates a human rights model of Disability approach in order to appropriately represent the unique needs of Disability communities. Doing so will support citizenship practices by identifying gaps in policies and legislations that specifically exclude persons with disability. It also provides initiatives that reflect “the human rights and fundamental freedoms and the needs of persons with disabilities” (Prince, 2009, p. 100).

The purposes of such a focused approach are to facilitate inclusion of persons with disability in policy and program planning and implementation and to increase awareness of disability issues in policy and governmental circles (Prince, 2009, p. 100). These purposes complement my recommendation for consultations, suggesting Anglophone and Allophone representation and self-recognition in the social service system is consequential. A human rights model of Disability also aids in identifying issues negatively impacting the wellbeing of persons with disability and in assessing likely impacts of all proposed implications. Attentive identification of issues will assure that initiatives are truly accessible and that they will not negatively affect anyone beyond their intended scope (Prince, 2009, p. 100). Identifying impacts and defining intended affected persons is crucial in future policy work. Currently, Quebec’s language laws intend to protect the French language and Quebecois culture, though it is not clearly understood who is impacted by such protection and what those impacts do to one’s wellbeing. This research has shown that Montreal’s English-speaking intellectual and/or developmental Disability community experiences disadvantages due to by policies and procedures that have not appropriately considered the communities’ presence or their needs.

In employing an intersectional policy analysis framework, policy workers must ask questions and be ready to learn from Disability community members. Hankivsky and colleagues (2014) categorize questions within the analysis framework as either descriptive or transformative. Descriptive questions “generate critical background information about policy problems” (p. 3). Transformative questions identify alternative policy response and solutions “specifically aimed at social and structural change that reduce inequities and promote social justice” (p. 3). In tandem, these question categories enable the advocate to consider and critique systems of social stratification (Prince, 2009, p. 214). Descriptive questions that confront feelings of exclusion and inclusion, personal definitions of such exclusion and inclusion, as well as of disabilities and capabilities, and experiences that are the result of access or barriers to social services will further convey the community’s needs. Transformative questions regarding racism, linguistic elitism, classism, educationism, ableism, etc., will illuminate the state’s role in the production of barriers to access and citizenship. While policy analysis focusing on ableism address a significant adversity encountered by people with disabilities, it should not obviate the other factors that exclude this group from society and lead to the phenomenon of unmet needs. Once policy workers comprehend the depth of needs—whether or not they are met—they can mediate the felt impacts of prioritizing disability support services based on linguistic abilities. Intersectionality affirms that human lives cannot be reduced to single characteristics and policies must not prioritize one element of a person (Hankivsky et al., 2014, p. 2). Similarly, intersectionality applied to policies pertaining to people with disabilities recognizes that people with disabilities are more complex than the categories used to describe them suggest. We must therefore understand community members’ unique needs and required measures to address these needs as complex.

Conclusion

While the research involved in this thesis is confined to a Quebec and especially Montreal context, its work can be applied to other regions governed by linguistic hierarchies. The minority French-speaking population of Ontario, for example, is being made invisible by their political government, led by Doug Ford, who is considering reducing funding and services for this community (Rieti, 2018), as well as for disability support services. There is also a great need for intersectional work with a Disability focus to investigate intersections of language, ability, and race/ethnicity, especially in Quebec where, as detailed in this thesis, immigration laws disadvantage non-French-speakers and particularly advantage white French-speakers hoping to immigrate to Quebec. Access to vital social services is a right of all persons residing in Canada and, through socially conscious research and advocacy, we can ascertain that this right remains inherent to all.

Language laws that prioritize French-speakers undermine the rights of Montreal's hybrid identities: The English-speaking intellectual and/or developmental Disability community. Society is organized on the biased assumption that everyone is able-bodied and Quebec public services assume everyone can speak fluent French. Both these false assumptions result in exclusion, unmet needs, and reduced participation in citizenship. As we continue to work toward dismantling barriers to access of social services and we fight for a social rule that equally values all citizens, I offer Volpe's (2018) words to close this thesis. Let her affirmations remind us of the trust, courage, and commitment that accompanies interdependency, and let us act accordingly.

> Even though there are things in life I cannot control, I commit to letting go.
> I surrender my fears, anxieties, and worries.
> I trust that what will come is for my higher good, and for my child's well-being.

I trust the professionals placed in our path.
I trust that the intentions of others are for my child's well-being.
I ask for guidance within my fears.
I listen for answers in nature, in people's words, and within my own heart.
I am courageous. My child is courageous.
No matter what happens, I know I will be OK.
No matter what happens, my child will be OK.
No matter what happens, it will all be OK. (Volpe, "Restoring courage")

References

Act Respecting Health Services and Social Services, Lois et Règlements du Quebec (1991, c. S-4.2). Retrieved from the Légis Quebec website: http://legisquebec.gouv.qc.ca/en/ShowDoc/cs/S-4.2

Arscott, K., Dagnan, D., & Kroese, B. S. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 11.* 77-83. doi:10.1111/j.1468-3148.1998.tb00035.x

Battiste, M. (2005). Post-colonial remedies for protecting Indigenous knowledge and heritage. *Teaching as Activism: Equity Meets Environmentalism.* P. Tripp & L. Muzzin (Eds.). 221-232. McGill-Queen's University Press.

BC Government. (2011). Improving services to people with developmental disabilities. *Deputy Minister's review of Community Living British Columbia.* Retrieved from https://communitylivingaction.files.wordpress.com/2012/01/bcgov-deputyministerreport-011912.pdf

Beecher, H. (1966). Ethics and clinical research. *New England Journal of Medicine, (274)*, 1354–1360.

Bourdieu, P. (1990). *The logic of practice.* Cambridge, UK: Polity Press.

Bowen, S. (2001). *Language barriers in access to health care.* Health Canada: Ottawa. Retrieved from Government of Canada website: https://www.canada.ca/content/dam/hc-sc/migration/hc-sc/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2001-lang-acces/2001-lang-acces-eng.pdf

Breton, R. (1984). The production and allocation of symbolic resources: An analysis of the linguistic and ethnocultural fields in Canada. Canadian Review of Sociology/Revue

Canadienne de Sociologie, 21(2), 123-144.

Brown, J. M. (2011). *Disability: A normative evaluation.* Retrieved from ProQuest Dissertations and Theses Global. 3450668

Canada Health Act (1984), C. 6. Retrieved from https://laws-lois.justice.gc.ca/eng/acts/c-6/FullText.html

Canadian Transport Agency (2017). Accessibility advisory committee. *Government of Canada.* Retrieved from https://otc-cta.gc.ca/eng/accessibility-advisory-committee

Carmichael, K. & Gudmestad, A. (2018). Language death and subject expression: First-person-singular subjects in a declining dialect of Louisiana French. *Journal of French Language Studies,* 1-25. doi: 10.1017/S0959269518000236

Chan, J. B., & Sigafoos, J. (2000). A review of child and family characteristics related to the use of respite care in developmental disability services. *Child and Youth Care Forum, 29*(1). Retrieved from https://link-springer-com.proxy3.library.mcgill.ca/content/pdf/10.1023%2FA%3A1009420206722.pdf

Charlton, J. (2000). *Nothing about us without us: Disability oppression and empowerment*. Berekely: University of California Press

Charter of the French Language, Lois et Règlements du Quebec (1977, c. 11). Retrieved from the Légis Quebec website: http://www.legisquebec.gouv.qc.ca/en/pdf/cs/C-11.pdf

Chiu, T., Marziali, E., Colantonio, A., Carswell, A., Gruneir, M., Tang, M., & Eysenbach, G. (2009). Internet-based caregiver support for Chinese Canadians taking care of a family member with Alzheimer disease and related dementia. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement, 28*(4), 323-336.

CIUSSS Centre-Ouest [Integrated Health and Social Services University Network for West-Central Montreal]. (2019). Retrieved from https://www.ciussswestcentral.ca/

CIUSSS Est [Centre Intégré Universitaire de Santé et de Services Sociaux de l'Est-de-l'Île-de-Montréal]. (2019). Retrieved from https://ciusss-estmtl.gouv.qc.ca/

CIUSSS Nord [Centre Intégré Universitaire de Santé et de Services Sociaux du Nord-de-l'Île-de-Montréal]. (2019). Retrived from https://ciusss-nordmtl.gouv.qc.ca/accueil/

CIUSSS Ouest [Centre Intégré Universitaire de Santé et de Services Sociaux de l'Ouest-de-l'Île-de-Montréal]. (2019). Retrived from https://ciusss-ouestmtl.gouv.qc.ca/en/home/

CIUSSS Sud [Centre Intégré Universitaire de Santé et de Services Sociaux du Centre-Sud- de-l'Île-de-Montréal]. (2019). Retrived from https://ciusss-centresudmtl.gouv.qc.ca/accueil/

Coalition Avenir Quebec (2018). Identity and culture: 100% Francization. Retrieved from https://coalitionavenirquebec.org/en/blog/enjeux/identity-and-culture/

Community Health and Social Services Network. (2018). *2017-2018 Annual Report.* Retrieved from http://chssn.org/wp-content/uploads/2014/11/CHSSN-Annual-Report-2017-2018_eng.pdf

Conrick, M. & Donvan, P. (2010). Immigration and language policy and planning in Quebec and Canada: Language learning and integration. *Journal of Multilingual and Multicultural Development 31*(4), 331-345. doi: 10.1080/01434632.2010.497215

Cowen, P. S., & Reed, D. A. (2002). Effects of respite care for children with developmental disabilities: Evaluation of an intervention for at risk families. *Public Health Nursing, 19*(4), 272-283. doi:10.1046/j.1525-1446.2002.19407.x

CRARR [Centre for Research-Action on Race Relations]. (2018, July 8). We are happy to report that we will file this week a major complaint of systemic discrimination based on disability (autism) intersecting with language and social condition against an English-speaking school board. The case is of major importance for English-speaking [Facebook status update]. Retrieved from https://www.facebook.com/Center-for-Research-Action-on-Race-Relations-CRARR-258996297500425/

Crete, M. (2018, March 28). Liberals promise historic investment as official languages action plan unveiled. *Canadian Broadcasting Corporation.* Retrieved from http://www.cbc.ca/news/politics/official-languages-plan-joly-1.4596687

Davis, L. J. (2007). Dependency and justice: A review of Martha Nussbaum's frontiers of justice. *Journal of Literary Disability, 1*(2). doi: 10.3828/jlcds.1.2.2

Degener, T. (2017). A new human rights model of Disability. In V. D. Fina, R. Cera, and G. Palmisano (Eds.), *The United Nations Conference on the Rights of Persons with Disabilities: A commentary,* 41-59. Cham, Switzerland: Springer. Retrieved from https://link-springer-com.proxy3.library.mcgill.ca/book/10.1007/978-3-319-43790-3#toc

Désy, M. (2010). Qu'est ce que l'accessiblité culturelle et linguistique des services? Proposition de réponse. Les services sociaux et de santé en contexte pluriethnique, Éditions Saint-Martin.

Devlin, R. & Pothier, D. (2006). Introduction: Toward a critical theory of dis-citizenship. In D. Pothier & R. Devlin (Eds.), *Critical disability theory: Essays in philosophy, politics, policy, and law* (pp. 1-24). Vancouver: University of British Columbia Press.

Diamond, T. (2006). "Where did you get the fur coat, Fern?" Participant observation in institutional ethnography. In D. Smith (Ed.), *Institutional Ethnography as Practice* (pp. 37-50). Lahnman, Maryland: Rowman and Littlefield Publishers, Incorporated.

Disability Rights International [DRI], 2014. Retrieved from https://www.driadvocacy.org

East Island Network for English Language Services, The [REISA]. (2018). St-Leonard, QC. Retrieved from https://www.reisa.ca/health-and-social-service-resources-for-english-speaking-communities-in-the-east-end-of-montreal-2/

Emler, N., Tarry, H., & St. James, A. (2007). Post-conventional moral reasoning and reputation. *Journal of Research in Personality, 41*(1), 76-89. https://doi.org/10.1016/j.jrp.2006.02.003

Every Canadian Counts. (2014). *Cross-province/territory data on developmental disability.* Retrieved from http://everycanadiancounts.com/wp-content/uploads/2014/11/DevelopmentalDisability_DataComparisonChart(2014-05-01).pdf

Fishman, J. (1996). What do you lose when you lose your language? In G. Cantoni (Ed), *Stabilizing Indigenous Languages.* Flagstaff, Ariz: Northern Arizona University. 80-91.

Garner, T. (2016). The social model and challenges. Personal collection of T. Garner. Simon Fraser University, Burnaby, British Columbia.

Griffin, T., & Balandin, S. (2004). Ethical research involving people with intellectual disabilities. In E. Emerson, C. Hatton, T. Thomson, & T. R. Parmenter (Eds.), *The international handbook of applied research in intellectual disabilities* (pp. 61-82). West Sussex, England: John Wiley and Sons Limited.

Hankivsky, O., Grace, D., Hunting, G., Giesbrecht, M., Fridkin, A., Rudrum, S., . . . Clark, N. (2014). An intersectionality-based policy analysis framework: Critical reflections on a methodology for advancing equity. *International Journal for Equity in Health, 13*(1).

Hendry, L. (2017, November 27). Outcry over service cuts for severely disabled ‘unreasonable,’ says health authority senior manager. *Canadian Broadcasting Corporation.* Retrieved from http://www.cbc.ca/news/canada/montreal/outcry-over-service-cuts-for-severely-disabled-unreasonable-says-health-authority-senior-manager-1.4418696

Henze, R., & Davis, K. (1999). Introduction: Authenticity and identity: Lessons from Indigenous language education. *Anthropology and Education Quarterly, 30,* 3-21.

Hesse, B., Nelson, D., Kreps, G., Croyle, R., Arora, N., Rimer, B., & Viswanath, K. (2005). Trust and sources of health information: The impact of the internet and its implications for health care providers: Findings from the first health information national trends survey. *Archives of Internal Medicine, 165*(22), 2618-24.

Hibbs, T. & Pothier, D. (2006). Post-secondary education and disabled students: Mining a level playing field or playing in a minefield? In D. Pothier & R. Devlin (Eds.), *Critical disability theory: Essays in philosophy, politics, policy, and law* (pp. 195-219). Vancouver: University of British Columbia Press.

Hogg, J., Lucchino, R., Wang, K., Janicki, M.P., & Working Group. (2000). *Healthy Ageing - Adults with Intellectual Disabilites: Ageing and Social Policy.* Geneva, Switzerland: World Health Organization. Retrieved from http://www.who.int/mental_health/media/en/23.pdf

Holmes, J. (2013). *An introduction to sociolinguistics* (4th ed.). New York: Routledge.

Hu, D. J. & Covell, R. M. (1986). Health care usage by Hispanic outpatients as function of primary language. *Western Journal of Medicine, 144,* 490-493.

Iacono, T. (2006). Ethical challenges and complexities of including people with intellectual disability as participants in research. *Journal of Intellectual and Developmental Disability, 31*(3), 173-179. doi:10.1080/13668250600876392

Jackson, C. (1998). Medical interpretation: An essential service for non-English-speaking immigrants. In S. Loue (Ed.), *Handbook of Immigrant Health* (pp. 61-79). New York: Plenum.

Jones, D. C. & Amelsvoort Jones, G. M. (1986). Communication patterns between nursing staff and the ethnic elderly in a long-term care facility. *Journal of Advanced Nursing, 11,* 265-272.

Kaplan, S. H., Greenfield, S., & Ware, J. E. (1989). Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Medcare, 27.* S110-S127.

Kenny, N. (1999). Ethical dilemmas in the current health care environment. In Saul J., Cruess R., Rae B., Kenny N., & Deber R. (Authors) & Somerville M. (Ed.), Do we care?: Renewing Canada's commitment to health (pp. 109-117). McGill-Queen's University Press. Retrieved from http://www.jstor.org.proxy3.library.mcgill.ca/stable/j.ctt80txq.16

Kephart, R. (2006). Emics. In H. J. Birx (Ed.), Encyclopedia of anthropology (pp. 809-810). Thousand Oaks, CA: SAGE Publications, Inc. doi: 10.4135/9781412952453.n279

Kim, J., & Kim, S. (2009). Physicians' perception of the effects of internet health information on the doctor-patient relationship. *Informatics for Health & Social Care, 34*(3), 136-48. doi:10.1080/17538150903102422

Kittay, E. F. (2017). Centering justice on dependency and recovering freedom. In L. J. Davis (Ed.), *The disability studies reader* (pp. 305-10). New York: Routledge.

Krogh, K. & Johnson, J. (2006). A life without living: Challenging medical and economic reductionism in home support policy for people with disabilities. In D. Pothier & R. Devlin (Eds.), *Critical disability theory: Essays in philosophy, politics, policy, and law* (pp. 151-179). Vancouver: University of British Columbia Press.

Lundberg, C. & Simonsen, E. (2015). Disability in court: Intersectionality and rule of law. *Scandinavian Journal of Disability Research, 17*(1), 7-22. doi: 10.1080/15017419.2015.1069048

Majumdar, B., Browne, G., & Roberts, J. (1995). The prevelance of multicultural groups receiving in-home service from three community agencies in southern Ontario: Implication for cultural sensitivity training. *Canadian Journal of Public Health, 86,* 206-211.

Manderson, L. & Warren, N. (2013). "Caring for" and "caring about": Embedded interdependence and quality of life. In *Reframing Disability and Quality of Life* (11). Retrieved from https://link-springer-com.proxy3.library.mcgill.ca/content/pdf/bfm%3A978-94-007-3018-2%2F1.pdf

McDonald, K. E., Conroy, N. E., Kim, C. I., LoBraico, E. J., Prather, E. M., & Olick, R. S. (2016). Is safety in the eye of the beholder? Safeguards in research with adults with intellectual disability. *Journal of Empirical Research on Human Research Ethics, 11*(5), 424-438. doi:10.1177/1556264616651182

McKenna, K. (2019, January 9). Anglo advocates vexed by decision to remove English from Lachute hospital signs. *Canadian Broadcasting Corporation.* Retrieved from https://www.cbc.ca/news/canada/montreal/anglo-advocates-vexed-by-decision-to-remove-english-from-lachute-hospital-signs-1.4972442

McLeod, J., Yu, I., & Ingledew, P. A. (2016). Peering into the deep: Characterizing the internet search patterns of patients with gynecologic cancers. *Journal of Cancer Education, 32,* 85-90. doi: 10.1007/s13187-016-1002-9

Meekosha, H., & Shuttleworth, R. (2017). What's so "critical" about critical disability studies? In L. J. Davis (Ed.), *The Disability Studies Reader* (pp. 175-94). New York: Routledge.

Milne, Kendra. (2016). Accommodation. Disability Rights [Interview]. Personal Collection of T. Garner. Simon Fraser University, Burnaby, British Columbia.

Mullins, L. L., Aniol, K., Boyd, M. L., Page, M. C., & Chaney, J. M. (2002). Psychological distress in parents of children with developmental disabilities: A longitudinal study. *Children's Services: Social Policy, Research, and Practice, 5*(2), 123-138. https://doi-org.proxy3.library.mcgill.ca/10.1207/S15326918CS0502_06

Murray, E., Lo, B., Pollack, L., Donelan, K., Catania, J., White, M., Zapert, K., & Turner, R. (2003). The impact of health information on the internet on the physician-patient relationship: Patient perceptions. *Archives of Internal Medicine, 163*(14), 1727-34.

National Assembly of Quebec (2019). Bill 21: An act respecting the laicity of the State. Quebec: Quebec Official Publisher. Retrieved from http://www2.publicationsduquebec.gouv.qc.ca/dynamicSearch/telecharge.php?type=5&file=2019C12A.PDF

Neegan, E. (2005). Excuse me: Who are the first peoples of Canada? A historical analysis of Aboriginal education in Canada then and now. *International Journal of Inclusive Education, 9,* 3-15.

Office of the Commissioner of Official Languages [OCOL]. (2019). Active offer: A culture of respect, a culture of excellence. Retrieved from: https://www.clo-ocol.gc.ca/en/resources/public-servants/active-offer-tool

Oliver, M. (1990). The politics of disablement – New social movements. *The Politics of Disablement.* 112-131.

Ouimet, A. M., Trempe, N., Vissandjée, B., Hemlin, I. (2013). Language as a determinant of health status and service quality: Language adaptation in health care and health services: Issues and strategies. *Institut National de Santé Publique du Quebec.* Retrieved from https://www.inspq.qc.ca/pdf/publications/1697_AdapLinguisSoinsServicesSante_VA.pdf

Patja, K., Iivanainen, M., Vesala, H., Oksanen, H., & Ruoppila, I. (2000). Life expectancy of people with intellectual disability: A 35-year follow-up study. *Journal of Intellectual Disability Research, 44*(5), 591-599. doi:10.1046/j.1365-2788.2000.00280.x

Perry, J. (2004). Interviewing people with intellectual disabilities. In E. Emerson, C. Hatton, T. Thomson, & T. R. Parmenter (Eds.), *The international handbook of applied research in intellectual disabilities* (pp. 114-131). West Sussex, England: John Wiley and Sons Limited.

Petersen, D. J., & Alexander, G. R. (2001). *Needs assessment in public health: A practical guide for students and professionals.* New York: Kluwer Academic.

Pine, A., & Turin, M. (2017). Language revitalization. Oxford Research Encyclopedias: Linguistics. Retrieved from http://linguistics.oxfordre.com/view/10.1093/acrefore/9780199384655.001.0001/acrefore-9780199384655-e-8

Prata, G. (2015). *Language access policy: Planning and implementation guide.* Jeffrey Hale -

Saint Brigid's Institute. Retrieved from http://chssn.org/wp-content/uploads/2014/11/JHSB_guide_05b.pdf

Prince, M. J. (2009). *Absent citizens: Disability politics and policy in Canada.* Toronto, ON: University of Toronto Press.

Rieti, J. (23 November, 2018). Ford government backtracks on some cuts affecting Ontario francophones. *Canadian Broadcasting Corporation.* Retrieved from https://www.cbc.ca/news/canada/toronto/doug-ford-francophone-cuts-1.4919026

Rioux, M. H. & Valentine, F. (2006). Does theory matter? Exploring the nexus between disability, human rights, and public policy. In D. Pothier & R. Devlin (Eds.), *Critical disability theory: Essays in philosophy, politics, policy, and law* (pp. 47-69). Vancouver: University of British Columbia Press.

Rouger, T. (2009). The impact of international human rights law on the national laws of Ethiopia from a gender rights and disability rights perspective. In L. Swartz and M. MacLachlan (Eds.), *Disability and international development: Towards inclusive global health,* 31-49. New York: Springer. Retrieved from https://link-springer-com.proxy3.library.mcgill.ca/book/10.1007/978-0-387-93840-0#toc

Royse, D., Staton-Tindall, M., Badger, K., & Webster, M. (2009). *Needs assessment.* New York, NY: Oxford University Press.

Sabourin, P. & Belanger A. (2015). The dynamics of language shift in Canada (P. Reeve Trans.). *Population, 70,* 727-757.

Schwartz, S. (2018, May 27). Autistic man on South Shore being denied English services, family says. *Montreal Gazette.* Retrieved from https://montrealgazette.com/news/local-news/autistic-man-on-south-shore-being-denied-english-services-family-says

Shakespeare, T. (2017). The social model of disability. In L. J. Davis (Ed.), *The disability studies reader* (5th ed.) (pp. 195-204). New York: Routledge.

Sienstra, D. (2012). *About Canada: Disability rights.* Nova Scotia: Fernwood Publishing.

Smith, D. (2005). *Institutional ethnography: A sociology for people.* Walnut Creek, CA: AltaMira Press.

Spivak, G. C. (1999). Can the subaltern speak? In V. B. Leitch, W. E. Cain, L. Finke, B. Johnson, J. McGowan, T. D. Sarpley-Whiting, & J. J. Williams (Eds.), *The Norton Anthology of theory and criticism* (2nd ed). New York, NY: W. W. Norton & Company.

Statistics Canada (2006). 2006 census of population: Census metropolitan area and residual for province or territory of residence 1 year ago (49), Immigrant status and period of immigration (9), Place of birth (33), Age groups (17B) and Sex (3) for the population aged 1 year and over of Canada, provinces, territories and census metropolitan areas, 2006 census - 20% sample data. Statistics Canada Catalogue no. 97-556-XCB2006018. Retrieved from https://www12.statcan.gc.ca/census-recensement/2006/

Statistics Canada (2016). 2016 census of population: Citizenship (5), Place of birth (272), Immigrant status and period of immigration (11), Age (12) and Sex (3) for the population in private households of Canada, provinces and territories, census metropolitan areas and census agglomerations, 2016 Census - 25% Sample Data. Statistics Canada Catalogue no. 98-400-X2016184. Retrieved from https://www12.statcan.gc.ca/census-recensement/2016/

Stevens, S. B. (1993). *Community based programs for a multicultural society: A guidebook for service providers.* Winnipeg: Planned Parenthood Manitoba.

Tang, S. Y. (1999). Interpreter services in health care: Policy recommendations for health care agencies. *Journal of Nursing Administration, 29,* 23-29.

Tétreault, S., Blais-Michaud, S., Deschênes, P. M., Beaupré, P., Gascon, H., Boucher, N., & Carrière, M. (2014). How to support families of children with disabilities? An exploratory study of social support services. *Child and Family Social Work, 19*(3), 272-282. doi:10.1111/j.1365-2206.2012.00898.x

Tremblay, S. (2011). Standards for culturally and linguistically appropriate services in health: An exploratory study of American standards. *For linguistically and culturally adapted health services: Linguistic accessibility is a determinant of the quality and security of health services.* Retrieved from https://santefrancais.ca/wp-content/uploads/Normes-sommaire-ex--cutif-EN.pdf

Tyjewski, C. (2006). Ghosts in the machine: Civil rights laws and the hybrid "invisible other." In D. Pothier & R. Devlin (Eds.), *Critical disability theory: Essays in philosophy, politics, policy, and law* (pp. 106-127). Vancouver: University of British Columbia Press.

United Nations [UN] (n.d.). Convention on the rights of persons with disabilities (CRPD). *Division for Social Policy and Development Disability.* Retrieved from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Volpe, G. (2018, October 3). Restoring courage, overcoming parental fears [Blog post]. Retrieved from http://www.gabriellavolpe.com/day-3-restoring-courage-overcoming-parental-fears/

Wardhaugh, R. & Fuller, J. M. (2015). *An introduction to sociolinguistics* (7th ed.). West Sussex, UK: John Wiley and Sons, Incorporated.

West, C. (1995). *Critical race theory: The key writings that formed the movement* (K. Crenshaw, N. Gotanda, G. Peller, & K. Thomas, Eds.). New York: New Press.

Wilton, R. D. (2006). Working at the margins: Disabled people and the growth of precarious employment. In D. Pothier & R. Devlin (Eds.), *Critical disability theory: Essays in philosophy, politics, policy, and law* (pp. 129-150). Vancouver: University of British Columbia Press.

World Health Organization [WHO]. (2002). *The World Health Report 2002: Reducing risks, promoting healthy life.* Geneva: World Health Organization.

World Health Organization [WHO]. (2002). *Patient safety: WHO guidelines on hand hygiene in health care.* Geneva: World Health Organization. Retrieved from: https://apps.who.int/iris/bitstream/handle/10665/44102/9789241597906_eng.pdf;jsessionid=C7B748DCB0593CCDF9E02100E10F8C8C?sequence=1

World Health Organization [WHO]. (2018). Definition: intellectual disability. *Health Topics.* Retrieved from http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability

Young, I. R. (1990). *Justice and the politics of difference.* Princeton: Princeton University Press.

Appendix A:

Verbal Assent/Dissent Script

I would like to speak with you about your experiences with accessing social services such as _____ (your community program; your work program, etc).

This is for research that I will write about for my thesis at McGill University.

I won't include your name or any identifiable features about you in my report.

I will record sounds and video during our conversation, but only I will ever listen to or watch them.

You can only talk with me if you want to, and if you change your mind you can stop our conversation at any time. We'll talk for maximum thirty minutes.

Do you have any questions for me?

Would you like me to explain what we're doing again?

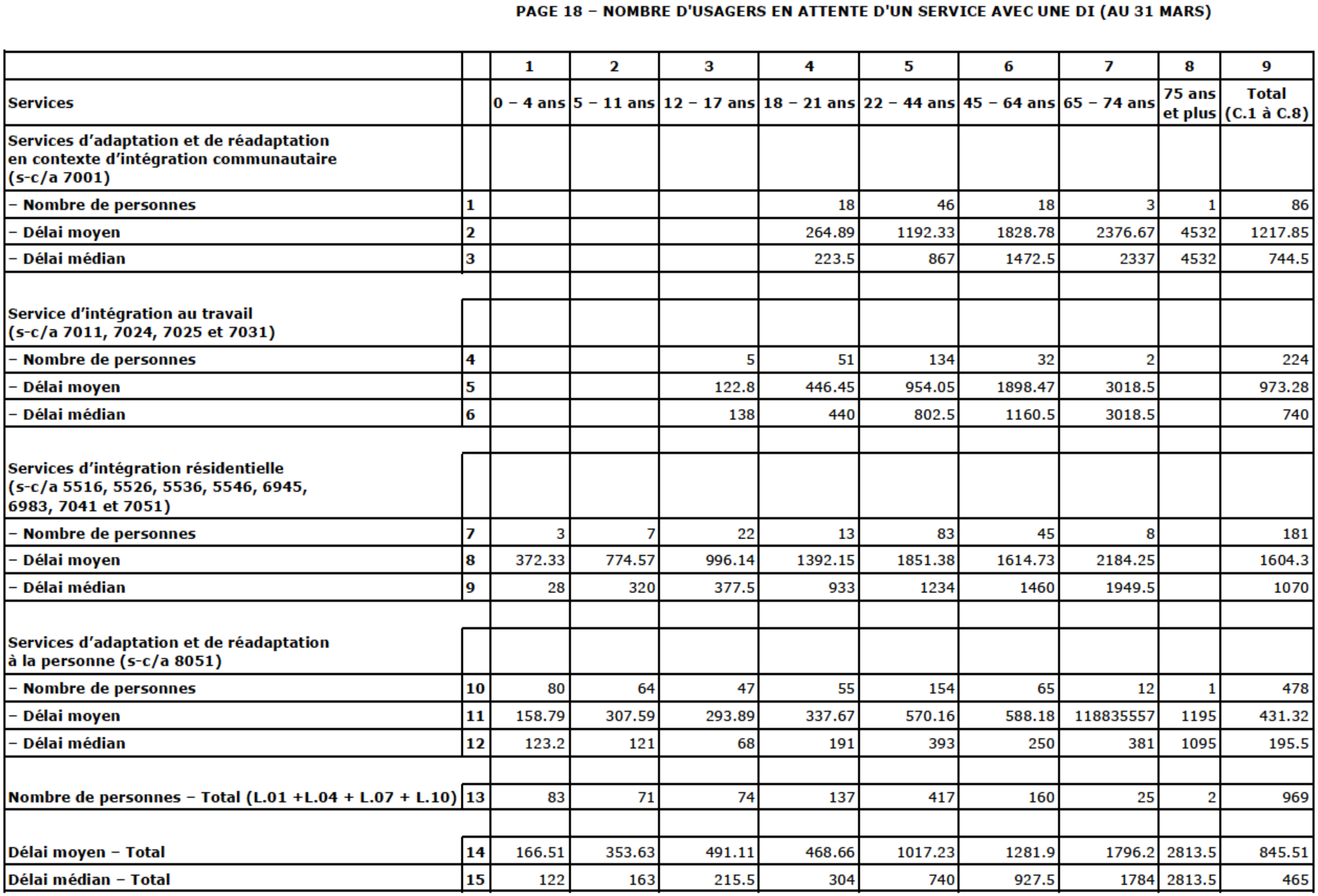
Can you explain what we're doing today to _____ (your caregiver/parent/me/etc.)

Is it okay with you if we have the conversation now?

Appendix B: CIUSSS Funding

	CIUSSS NORTH	CIUSSS EAST	CIUSSS WEST	CIUSSS CENTRE-WEST
FAMILY SUPPORT				
DIRECT CHARGES				
SERVICES BOUGHT PREVIOUS				
SERVICES BOUGHT CURRENT				
SUPPLIES PREVIOUS		$429.00		
SUPPLIES CURRENT				
DIRECT SUPPORT PREVIOUS	$933,685.00	$953,641.00	$770,742.00	$631,960.00
DIRECT SUPPORT CURRENT	$901,613.00	$1,053,658.00	$783,028.00	$622,796.00
TOTAL DIRECT CHARGES PREVIOUS	$933,685.00	$954,070.00	$770,742.00	$631,960.00
TOTAL DIRECT CHARGES CURRENT	$901,613.00	$1,053,658.00	$783,028.00	$622,796.00
DEDUCTIONS				
SALE OF SERVICES PREVIOUS				
SALE OF SERVICES CURRENT				
RECOVERY PREVIOUS	$15,661.00	$1,269.00	$33,268.00	
RECOVERY CURRENT	$11,511.00	$6,444.00	$32,556.00	
TOTAL DEDUCTIONS PREVIOUS	$15,661.00	$1,269.00	$33,268.00	
TOTAL DEDUCTIONS CURRENT	$11,511.00	$6,444.00	$32,556.00	
NET DIRECT COSTS PREVIOUS	$918,024.00	$952,801.00	$737,474.00	$631,960.00
NET DIRECT COSTS CURRENT	$890,102.00	$1,047,214.00	$750,472.00	$622,796.00
USERS PREVIOUS	476	572	459	361
USERS CURRENT	493	573	482	326
COST EACH USER PREVIOUS	$1,928.62	$1,665.74	$1,606.70	$1,750.58
COST EACH USER CURRENT	$1,805.42	$1,827.60	$1,557.00	$1,910.42

Appendix C: CIUSSS South Wait Times



PAGE 18 – NOMBRE D'USAGERS EN ATTENTE D'UN SERVICE AVEC UNE DI (AU 31 MARS)

		1	2	3	4	5	6	7	8	9
Services		**0 – 4 ans**	**5 – 11 ans**	**12 – 17 ans**	**18 – 21 ans**	**22 – 44 ans**	**45 – 64 ans**	**65 – 74 ans**	**75 ans et plus**	**Total (C.1 à C.8)**
Services d'adaptation et de réadaptation en contexte d'intégration communautaire (s-c/a 7001)										
– Nombre de personnes	**1**				18	46	18	3	1	86
– Délai moyen	**2**				264.89	1192.33	1828.78	2376.67	4532	1217.85
– Délai médian	**3**				223.5	867	1472.5	2337	4532	744.5
Service d'intégration au travail (s-c/a 7011, 7024, 7025 et 7031)										
– Nombre de personnes	**4**			5	51	134	32	2		224
– Délai moyen	**5**			122.8	446.45	954.05	1898.47	3018.5		973.28
– Délai médian	**6**			138	440	802.5	1160.5	3018.5		740
Services d'intégration résidentielle (s-c/a 5516, 5526, 5536, 5546, 6945, 6983, 7041 et 7051)										
– Nombre de personnes	**7**	3	7	22	13	83	45	8		181
– Délai moyen	**8**	372.33	774.57	996.14	1392.15	1851.38	1614.73	2184.25		1604.3
– Délai médian	**9**	28	320	377.5	933	1234	1460	1949.5		1070
Services d'adaptation et de réadaptation à la personne (s-c/a 8051)										
– Nombre de personnes	**10**	80	64	47	55	154	65	12	1	478
– Délai moyen	**11**	158.79	307.59	293.89	337.67	570.16	588.18	118835557	1195	431.32
– Délai médian	**12**	123.2	121	68	191	393	250	381	1095	195.5
Nombre de personnes – Total (L.01 +L.04 + L.07 + L.10)	**13**	83	71	74	137	417	160	25	2	969
Délai moyen – Total	**14**	166.51	353.63	491.11	468.66	1017.23	1281.9	1796.2	2813.5	845.51
Délai médian – Total	**15**	122	163	215.5	304	740	927.5	1784	2813.5	465