

Rouler/Wheeling Montréal:  
Moving through, Resisting and Belonging in an Ableist City

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## ABSTRACT

### **Rouler/Wheeling Montréal: Moving through, Resisting and Belonging in an Ableist City**

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**Concordia University, 2018**

Despite the growing literature on walking practices, mobile methods, differential mobilities and mobility justice, little is known about what it means to move through cities using a wheelchair. While other mobilities researchers engage with wheeling – for example, those studying cycling – I offer a new perspective on a type of wheeling that has been historically ignored and devalued. At a time when cities are taking actions to build more walkable environments, understanding the experiences of disabled people is critical. As a researcher using a motorized wheelchair, I explore what it means to conduct wheeling interviews, instead of “traditional” walking interviews, with 15 disabled Montrealers. The interviews are recorded on a GoPro camera, mounted on my wheelchair and theirs – for interviewees who had one. One participant walks with the assistance of a dog and another uses a white cane. The mobile methodology developed in this research builds on Arseli Dokumaci’s (2013; 2014a; 2014b; 2018) research on disability as a method and the affordances of the everyday as well as on my own activist research on ableism at the Mobile Media Lab at Concordia University. Through the wheeling interviews in different Montréal’s boroughs, I examine participants’ everyday mobilities and two different dimensions of participants’ sense of belonging: their belonging in Montréal disability communities and their belonging in the city. I analyze participant’s experiences mainly through critical disability studies, mobility studies and oral history. Participants’ stories show that their right to the city and their capacity to move through it are severely compromised because ableism is embedded in Montréal’s built environment and culture. Yet few participants question their belonging in the city or proudly declare their attachment to the city. The lack of vocabulary in French for talking about ableism makes it difficult to discuss sense of belonging from a critical perspective. Furthermore, disabled Montrealers are not all equal in the face of the ableist city’s barriers. Those who experience several types of discrimination – for example racism and ableism – are more likely to face obstacles and to question their sense of belonging. I conclude the thesis by proposing 51 actions to build an anti-ableist city.

*Keywords:* ableism, disability, wheeling, sense of belonging, right to the city, accessibility, everyday mobilities, intersectionality, oral history, mobile methods, Montréal.

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## Epigram

*Taking up space as a disabled person is always revolutionary.*

—Sandy Ho, Asian-American disability community-organizer and activist, August 1, 2018

## Introduction

### *My journey as a disabled activist and researcher*

For the past 16 years, my wheelchair and I have covered thousands of kilometers in Montréal. When I moved to Montréal in 2002, I started to wheel from my home to many of my destinations out of necessity. All of Montréal's métro stations were inaccessible. About half of the bus fleet was accessible, and ramps were poorly reliable. And Transport adapté (adapted transit or TA for the insiders<sup>1</sup>) was extremely restrictive and simply did not meet my needs. Over time, wheeling became my favourite mode of transportation in the city. It turned out to be the most reliable, efficient and safe way to go to most of the places I needed and wanted to go to all year around, even if Montréal's winters certainly made everything more complicated. Over the years, I have gotten to know by heart most of the cracks of the city's numerous sidewalks and bike paths, and adopted favourite routes to reach different destinations. It is through wheeling that I became familiar with the neighbourhoods around me. I know the city from a sidewalk perspective—I do not have access to most places, in many cases because of a single step, but I know where they are and what they look like from the outside. The emotions I have felt and carried with me while wheeling the city have shaped who I am today. What started as a simply practical choice—getting around of the city because I had to—developed into a mobile practice with its own politics, which I have come to write about in my doctoral thesis. My lived experiences of wheeling Montréal are, therefore, central to this thesis.

As a disabled woman, I am particularly inspired and influenced by the work of critical disability studies scholars, feminists and oral historians who have insisted on the necessity for scholars to position themselves in relation to their research and have critiqued the concept of objectivity in social sciences. Donna Haraway (1988) argues that “Feminist objectivity is about limited location and situated knowledge, not about transcendence and splitting of subject and object. It allows us to become answerable for what we learn how to see.” (p. 583) I therefore chose to use autoethnography as a method throughout my thesis. This is why I am making explicit my own perspectives on the issues I am writing about.

As Joëlle Rouleau explains in her doctoral thesis, which uses autoethnography as method, “il ne s'agit pas d'une recherche sur moi (autobiographique), mais plutôt d'une recherche *à partir*

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<sup>1</sup> Most participants used the acronym TA to talk about Transport adapté. This acronym is used by many whether they communicate in French or English.

*de moi.*” (Rouleau, 2015, p. 4) Ardra L. Cole and J. Gary Knowles (2001) state that autoethnography “uses the self as a starting or vantage point from which to explore broader sociocultural elements, issues, or constructs.” (p. 16) “One way to unpack our researcher baggage [...] is to write what we call a personal history account in which we examine the path taken to a research project,” they write (*Ibid.*, p.49). For example, the fact that I am a disabled researcher writing on disability issues matters. It gives me invaluable insights into ableism (Dreger, 2004; O’Toole, 2013). For feminist disability studies scholar Rosemarie Garland-Thomson (2005), who identifies as a disabled feminist, “situated theory offers a feminist disability epistemology that protests the disability system.” (p. 1569) By weaving my own personal stories in my thesis, I aim to do exactly that—protest the dominant ableist narratives on disability and offer counter-narratives in response. This decision is not apolitical. It is a statement about a world that too often undervalues lived experiences and the knowledge of disabled people. Karen Mogendorff (2013), herself a disabled researcher, explains that there are risks associated with weaving lived experiences in academic research for emerging disabled scholars. She writes:

Incorporating one’s own lived experiences in research implies a blurring of boundaries between the private, the professional, and the public. [...] Because of the low status of disabled people and of experiential knowledge, disclosure of own experiences with disability may negatively influence young disabled researchers’ careers.

Grada Kilomba’s performance *Decolonizing Knowledge* (2008) presents a powerful critique of traditional knowledge production. Her words resonate strongly with me. She writes:

When they speak, it is scientific;  
when we speak, it is unscientific.  
When they speak, it is universal;  
when we speak, it is specific.  
When they speak, it is objective;  
when we speak, it is subjective.  
When they speak, it is neutral;  
when we speak, it is personal.  
When they speak, it is rational;  
when we speak, it is emotional.  
When they speak, it is impartial;  
when we speak, it is partial.  
They have facts, we have opinions.  
They have knowledges, we have experiences.

I have been extremely privileged to be surrounded by a committee who has encouraged me to use my personal experiences as a powerful source of knowledge. This is precisely one of the main

areas of expertise of my supervisor, professor Steven High. My committee's support has made it possible for me to feel confident about putting pieces of lives in my thesis.

In the next pages, I share some key moments of my life that have brought me here. In doing so, I unpack my research and activist baggage. It is important to note, however, that I have chosen not to concentrate on my lived experiences in my introduction, but to write about them throughout the thesis. This overview of my journey, as a disabled researcher and activist, is therefore enriched in the following chapters.

*A story always starts before it can be told.*

—Sara Ahmed, feminist writer and independent scholar, 2017

I remember that when I was a kid, strangers would often ask my mother how old I was. They asked that question because my body was different from the bodies they were used to seeing. I was visibly disabled, and visibly disabled kids could not be found on every street corner. In fact, I do not recall seeing kids like me outside of rehabilitation centres and hospitals. Most of the time, my mother would tell those strangers to ask the question directly to me because I was able to give them an answer. I hated these encounters, right to the depth of my soul. I remember one in particular, when a woman asked me if I was born with a disability or if something had happened to me. I do not think I was much older than eight, and I vividly remember her question striking me as ridiculous. I probably could not help myself, and just rolled my eyes. “Évidemment que je suis née handicapée! Tu penses que j’ai rapetissé dans la sécheuse?”, I wanted to reply. However, I was a (too) polite child, already used to invasive questions and uninvited stares, so I just told her that I was indeed born this way. Luckily, these encounters did not reflect what my everyday life was like. Maybe this is why they bothered me so much. They were disturbing interruptions to my easy, happy childhood.

I grew up in the most loving family in a small Québec village called Lemieux, about 150 kilometres northeast of Montréal. When my parents signed me up for kindergarten, the school board told them that I should go to a special school for disabled kids. My parents refused and I started kindergarten at the regular local school in Daveluyville, a small town close to Lemieux.<sup>2</sup> A few weeks after the beginning of classes, I met with the school's child psychologist. He asked

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<sup>2</sup> In 1991, a year after I started kindergarten, 64% of kids with physical disabilities were included in mainstream classrooms (Duval, Gauthier & Tardif, 1995, p. 31). I have friends of my age with disabilities similar to mine who were excluded from these classrooms. Their parents had to fight to have them included.

me to do puzzles that I considered extremely easy. I quickly understood that he wanted to evaluate my intellectual abilities because I was physically different. I was insulted. I already knew how to write my name and where the main Québec cities were on a map. It was my first and last appointment with him. I went through the mainstream educational system from kindergarten to high school without any issues. I was never bullied, had many friends and got good grades. In short, I fit within the traditional education system. In terms of physical mobility, in addition to using a walker at home, which I still use today, I started using a manual chair at age five, just as I started school. I got my first electric wheelchair in the first year of high school. Even though I did have one major surgery when I was four and regular doctor appointments, physiotherapy and occupational therapy, I was able to carry on with my daily life without any significant health issues. Having spent the first 16 years of my life surrounded exclusively by able-bodied people, I did not identify as disabled. Aside from my disability, my family and I had many privileges in terms of race, sex, class and language. We were a traditional nuclear family, we were white and middle-class, and we spoke French like the overwhelming majority of people in Lemieux and its surroundings. I must admit I absolutely believed that my family embodied the definition of “normal”!

A major turning point in my life was when I was 17 years old and moved to Montréal to start CÉGEP. Many of the short stories woven into my thesis happened at that time of my life and in the years that followed. That is the time when I faced ableism on an everyday basis without knowing it even existed. It is also the time when I met some disabled people but still did not yet understand the power of disability solidarity and had little interest in establishing relationships with them. For many years, I tried my best to navigate Montréal and its many obstacles. During my first six years in the city, I was able to count on the precious support of my parents. My mother moved to Montréal to help me in my everyday life. For example, she had an adapted van and often drove me to school and several other places, providing me with a necessary escape from the failures and limits of Transport adapté. It saved me an incredible amount of time and energy. In 2007, I got my undergraduate degree in political science and international relations. Like most of my colleagues at UQÀM at the time, I thought neoliberalism was hurting people all around the globe, and the wars in Afghanistan and Iraq were wrong. I dreamed of a career covering international politics. During summers, I worked for disability organizations in Montréal, which focused on local issues, and slowly, without really realizing it, I started doing research on disability.

In 2008, I left for Toronto to start a master's in Critical Disability Studies at York University. Professor and psychiatric survivor Geoffrey Reaume (2014), who was one of my professors, describes this interdisciplinary field as follows:

Critical disability studies view disability as both a lived reality in which the experiences of people with disabilities are central to interpreting their place in the world, and as a social and political definition based on societal power relations. Emerging from the activism of disabled people in the 1970s, this area of study involves both academics and activists representing multiple disciplines and perspectives. It challenges approaches that pathologize physical, mental and sensory difference as being in need of correction, and instead advocates for both accommodation and equality for disabled people in all areas of life. Critical disability studies seek to change conventional notions of disabled people as pitiable, tragic victims who should adjust to the world around them. (p. 1248)

In Toronto, my perspectives on the world, and on my own everyday life, changed very fast and radically. I made disabled friends who I became close with for the first time of my life. I discovered disability solidarity and complicity. My interest in politics and social change did not wane, but instead fuelled my new passion for disability politics. The concept of ableism became central to my critical thinking. Disabled academic Fiona Kumari Campbell (2017) defines ableism as:

a system of causal relations about the order of life that produces processes and systems of entitlement and exclusion. This causality fosters conditions of microaggression, internalized ableism and, in their jostling, notions of (un)encumbrance. A system of dividing practices, ableism institutes the reification and classification of populations. Ableist systems involve the differentiation, ranking, negation, notification and prioritization of sentient life.

Intersectional social justice engineer, attorney and artist Talila A. Lewis (talilalewis, 2017) argues that definitions of ableism should include a critique of at least another system of oppression such as racism. Lewis claims that ableism is:

a system that places value on people's bodies and minds based on societally constructed notions of normalcy, intelligence and excellence. These societally constructed notions of normalcy, intelligence and excellence are deeply rooted in eugenics, anti-Blackness and capitalism. (Bi: Notes for a Bisexual Revolution, 2018)

The more I learned about disability from a critical perspective, the more I reconsidered some things I had taken for granted. One of these things was my own sense of belonging in Montréal. Elspeth Probyn (1996) argues that "If you have to think about belonging, perhaps you are already outside."(p. 8) I sometimes felt like I had been on the outside for a long time without realizing it. "A story always starts before it can be told", writes Sara Ahmed (2017). After writing

papers on issues happening in foreign countries in which I was completely absent within the text, I started to write about issues I had personally experienced. Erasing or distancing myself from the issues I was writing about became impossible. While working on my Masters thesis on the history of the hegemony of stairs in the Montréal métro system, I was confronted with the absence of written literature on Québec's disability issues. I realized that what had been written on Québec history almost completely ignored disabled people. I had no other choice but to find first-person accounts and to interview disabled people to write my thesis.

As soon as I moved back to Montréal after completing my Masters, I got involved in disability activism. With three other disabled Montrealers, I co-founded the Regroupement des activistes pour l'inclusion au Québec (RAPLIQ), a non-profit disability rights organization. Unlike most established disability organizations, we did not have any funding. We relied on our own personal resources. For example, instead of having an office and working together in the same physical space, we worked from our respective homes and communicated by email. We quickly noticed that even though the use of mobile and social media was on the rise, the Québec disability rights movement had not made much use of these technologies to bring disability issues to the attention of the public and the media. Moreover, traditional media coverage was regularly disappointing. Francophone media were never as present as Anglophone media at our actions. Through my interactions with journalists, I realized that many journalists had limited understanding of disability issues and ableist language was the norm. For example, on numerous occasions, I was described as being "wheelchair-bound." Journalists were often working on tight deadlines and did not have time to dig into the complexity of our stories. Making our own videos turned out to be a strategy to gain media coverage, share stories ignored by the media and produce more representative stories countering ableist discourses. In the first year of RAPLIQ's existence, I made a number of videos on various issues, with the assistance of my filmmaker friend Joëlle Rouleau. At the time, I needed Joëlle to make films for three main reasons: I did not own any filming equipment; that kind of equipment was too heavy for me to carry alone; and I did not have her filmmaking skills. To shoot footage from my perspective, we tried to attach her camera to my wheelchair. However, the camera could not absorb the constant impact the uneven sidewalks had on my wheelchair. The footage was unsteady and shaky, and the risk of the camera falling off my wheelchair and breaking was too great. Regulations prevented us from using our bulky equipment to film in spaces like the métro. It was clear that I needed to get a smaller device

for shooting videos. When my flip phone contract came to an end in August 2011, I decided to get my first smartphone.

My smartphone became an essential weapon of resistance in my activist toolkit. Whenever I encountered obstacles – often when navigating Montréal buses – I just had to take my phone out and start filming. However, filming in cold weather was difficult, as my fingers would freeze after only a few minutes. The stability of the image was also an ongoing issue, as I was often in motion when filming. Wheeling on uneven sidewalks and streets made it almost impossible to shoot videos that did not feel like a rollercoaster for the viewers. In 2012, I bought a GoPro camera to address some of these issues. GoPro cameras are miniature high-definition cameras that can be mounted to a body part or a device. *Crippling the Landscape 1: Quebec City*, my first mobile documentary, was shot entirely with my GoPro camera, without someone else's technical assistance. The documentary chronicles a five-kilometre journey from Université Laval to the Sainte-Foy train station in Quebec City. As I wended my way to the train station, I was exposed to moments of danger. There were no accessible buses or taxis. At some intersections, I was unable to reach the pedestrian crossing button. The number of obstacles was overwhelming. In turning the viewer's gaze towards Quebec City's ableist landscape, I aimed to undermine the power structures that contribute to reinforcing the normalcy of the inaccessible public infrastructure.

As RAPLIQ was fighting its first battles mostly on the stage of municipal politics, I started a PhD in Humanities at Concordia University. My co-advisor, professor Kim Sawchuk, introduced me to the Concordia University-based Mobile Media Lab. I got involved in multiple projects on disability, mobility and media making. In most of these projects, I worked in collaboration with other disabled Montrealers. In 2014, I participated in the foundation of the Critical Disability Studies Working Group (CDSWG) at Concordia University. Our group consisted of professors, graduate and undergraduate students, artists, activists and community members. We met regularly to talk about different disability and accessibility issues and to present our work. For two years, as the co-coordinator of the CDSWG, I organized meetings and multiple events with my colleagues. Our biggest event was the organization of the Québec's first Critical Disability Studies Symposium (Desjardins, 2016). Together, we built a home for critical disability studies at Concordia. Our existence created a well of enthusiasm at the university and beyond. Throughout my doctoral studies, I have had the opportunity to travel and present my

work in multiple conferences. At these conferences, I met numerous academics, artists and activities from different countries. During my studies, I remained involved as a disability activist after leaving RAPLIQ in 2004. I co-founded the Facebook group Transport mésadapté in 2013 and the non-profit organization Québec accessible two years later.

Before moving on, I want to recognize the challenges that face disabled academics, which did not come up in my story because I have been surrounded by incredible people and always had the precious support of my family and friends. In their article on ableism in academia in the United Kingdom, Nicole Brown and Jennifer Leigh (2018) ask “Where are the disabled and ill academics?” (p. 985) They report that even though 16% of working-age adults and nearly 13% of undergraduate students are disabled, only 3,9% of academics identify as disabled (*Ibid.*). Even though I have not been able to find equivalent statistics in Québec, I would suggest that the representation of disabled people is not much better in Québec universities. On many occasions, I have found myself to be the only visibly disabled people at academic events. I remember my surprise when at an international disability and accessibility conference gathering Francophone researchers and community members, I was one of the few disabled researchers in the programme. Disabled people were a minority even where they should be expected to be more numerous. Furthermore, with the exception of my master’s in critical Disability Studies at York University, I have never had a professor who identified as disabled. Ableism in academia has been pointed out as a major problem for disabled people aspiring to work as academics (Chouinard, 1995; O’Toole, 2013; Mogendorff, 2013). Inaccessible working environments, refusal of disability accommodations and ableist attitudes from colleagues and administrators are among the obstacles faced by disabled researchers. These obstacles are more pervasive for those experiencing multiple systems of oppression.

Considering the poor representation of disabled people in academia, Corbett O’Toole (2013) calls upon academics in the field of disability studies to disclose their relationship with disability. “The statement ‘I am disabled’ is complete and does not necessitate an impairment discussion,” she sums up. O’Toole argues that identifying publicly as a disabled researcher “challenge[s] the shame typically associated with identifying with disabled people.” Furthermore, she suggests that it helps to find a community who can provide “invaluable support and strategies.” O’Toole indicates whether or not the scholars and activists she cites in her work are

disabled. For my thesis, I have decided to indicate when the person I quote is disabled. However, I am aware that for many people I cited, I do not know whether or not they are disabled.

This short overview of my personal, academic and activist journey shows how my research and community engagement overlap and intertwine. Unsurprisingly, from the very beginning of my PhD, I have intended to work on a research project that would be meaningful for the Montréal disability community. My community. As a disabled person, I regularly receive invitations to participate in research projects. I only very rarely agree to participate. Over time, I got tired of giving my time to projects that seemed to have no positive impact. My close friends who are disabled have shared similar feelings. Considering this, I am particularly aware that my research needs to make a difference.

#### *What this research is about*

At the beginning of my research, I read a paper by Tovi Fenster entitled “The Right o the Gendered City: Different Formations of Belonging in Everyday Life”. Fenster critiques the notion of the right to the city developed by philosopher Henri Lefebvre. She argues that his conceptualization ignored patriarchal power relations and therefore could not reflect the everyday experiences of women in cities. In her article, she claims that women’s right to the city—and therefore their right to belong in the city—is compromised because of these patriarchal power relations. I immediately thought that a similar analysis could apply to disabled people. In order to understand their right to the city and their sense of belonging, an analysis of ableist power relations is in order.

I have known from the very beginning that I wanted to conduct interviews with disabled Montrealers. I thought that it would be interesting to interview people in other cities. I had three cities in mind, on two continents no less! Luckily, my supervisor, Dr. Steven High, quickly advised me that this was too tall an order. He told me that two cities would be quite a bit of work already. I chose to go to New York City. I was interested in that city because I knew that while it still had many obstacles in the built environment and public transportation, much like Montréal, but that its culture, in terms of disability policies and disability communities, was very different. In the previous months, I had the opportunity to meet Dr. Faye Ginsburg, who teaches at New York University, in Montréal. I contacted Professor Ginsburg and she generously agreed to support me during my research stint in New York. I spent the months of October and November 2014 in the Big Apple. I had access to an office space at the university and was given the chance

to meet with many professors, students, activists and community members. A few days after my arrival in NYC, I set up a research blog, which I titled “Wheeling New York City.” One of the objectives of the blog was to help me take the time to document and reflect on my experiences in NYC. Over the course of two months, I posted 32 entries, including eight videos I made using either my iPhone or my GoPro camera. I met 16 disabled New Yorkers for interviews and conducted eight wheeling interviews in the city. When I started writing my thesis after conducting interviews in Montréal the following year, I made the difficult decision to concentrate my thesis on the wheeling interviews that took place in Montréal. That does not mean that what I did in NYC did not have an impact on my research. On the contrary, the work I did in NYC has been extremely important to develop my method. For example, it was there that I assessed which filming equipment did not work and which worked better. The discussions I had with disabled New Yorkers strengthened my motivation to write about wheeling. Being in NYC gave me the necessary tools to reflect on my own wheeling practice. In NYC, the things that I would take for granted in Montréal did not apply. I did not have my landmarks. I did not know the pedestrian culture. I was not an expert on the (in)accessibility of the public transit system. Somehow, I had to re-learn how to wheel and get around the city. I was forced to pay attention to the little details. I believe this made me a better researcher in Montréal. It gave me the distance that is necessary to see things that, over time, I had come to take for granted in Montréal.

This research takes its roots in my interest for disability rights, wheeling, storytelling and media making and in the many gaps in the literature I have identified during my academic journey. I am interested in disabled Montrealers’ everyday mobilities and in their sense of belonging in the city. I analyze participant’s experiences mainly through critical disability studies, mobility studies and oral history. From August to November 2015, I interviewed 15 disabled Montrealers—13 of whom used a mobility aid. Even though my main interest was wheeling, I thought it would be interesting to talk to people with different disabilities as it would give me insight into other perspectives. The interviews were recorded on a GoPro camera, mounted on my wheelchair and theirs—if they had one. Using public transit and my wheelchair, I travelled a total of 319.87 kilometres—including the distance between my house and the places where I met the participants. I wheeled 195.67 of these kilometres—greater than the distance between Montréal and Ottawa.

My research raises several questions and has many objectives. While some of them were already on my mind prior to conducting the wheeling interviews, others emerged through the research and writing process. One question arose as soon as I started getting ready to conduct my first wheeling interviews in New York City. Since I was experiencing numerous technical and methodological challenges, the question “What does it mean to conduct walking interviews when you do not walk the way society expects you to?” quickly became central to my research. The methodological aspect of my project therefore turned out to be more important than I anticipated. One goal of my research is to contribute to the growing literature on mobile methods that embrace disability instead of erasing or overcoming it. Even though I initially planned to focus on participants’ sense of belonging, I realized, quite early in the research process, that how participants embodied the mobile practice of wheeling—moving using a wheelchair—was highly relevant to my project. Before being about participants’ sense of belonging in the city, my thesis seeks to offer a new perspective on a type of wheeling that has been historically ignored and devalued, and to document the everyday mobilities of Montrealers wheeling the city. It is through their everyday mobilities that I was able to approach the complex issue of belonging. Considering that previous research in mobility studies indicates that mobility is a “resource distributed unequally among social groups” (Frith, 2012, p. 134) that creates “different scales of belonging,” (Fallov, Jørgensen & Knudsen, 2013, p. 483) does it mean that disabled Montrealers who have more mobility options, by owning a car for example, have a stronger sense of belonging in Montreal than those who have fewer options? Can some disabled Montrealers exercise their right to the city more easily than others? Another important aspect of my research is that it participates in the development of critical disability studies in a Francophone context and tells stories that are still not easily accessible. The subjectivities of participants are not a weakness of my research, but rather a strength, which I chose to place at the forefront, in order to highlight the diversity and complexities of disabled Montrealers’ lives. This is particularly needed because statistics available on disabled Montrealers are limited and do not capture these complexities. “Sharing one’s story is one of the ways that social movements and communities come together, forging new bonds of friendship or identification and reinforcing old ones,” writes Steven High (2014, p. 35). By telling these stories and writing this thesis, I aim to support disabled Montrealers in their quest for an anti-ableist city.

### *Why this thesis matters*

Understanding the context in which my research project took place is fundamental to understand why my thesis is both an academic and activist contribution. Even though this is something that will be covered throughout the following chapters, I want to highlight key elements such as the continued marginalization of disabled people, the lack of critical perspectives on disability in various fields, the need for more stories to document the lived experiences of disabled people, the increased political role played by cities and their commitment for more walkable cities and, finally, the particularities of conducting such a research project in Montréal.

Despite the fact that disabled activists and academics and their allies have been working for the right to live in dignity for disabled people and have fought against discrimination in the past number of decades, disabled people continue to be marginalized. Disabled geographer Vera Chouinard (2009) argues that disabled Canadians experience “shadow citizenship.” They are legally citizens but are not treated as such. Disability is also largely perceived and portrayed as intrinsically negative. “Mainstream cultural maps continue to relegate disabled people to the periphery of human value and worth,” writes neurodivergent mestiza and activist scholar Sara M. Acevedo (2018, p. 220). In Western popular culture, disability is often portrayed as a fate worse than death. Mobility aids such as wheelchairs and scooters are still regularly considered entrapment tools instead of liberating ones. This is reflected in the language used to talk about wheelchair users. They are presented as being “confined in” or “bound to” their wheelchair. Wheelchairs are often used to scare able-bodied people and convince them to adopt safe and healthy lifestyles (Ladau, 2014a) and to advocate for safer working conditions (Parent & Veilleux, 2015). Contrary to other mobility devices with wheels such as cars and bicycles, wheelchairs are seen as unwanted means of mobility. Andrew Power (2016), citing Mimi Sheller, argues that “automobiles endow their owners/drivers with significations such as being ‘competent, powerful, able and sexually desirable’.” (Sheller, 2004, p. 225) In contrast, users of wheelchairs—understood as another travel modality—are perceived as “incompetent, powerless, disabled, and asexual.” (p. 282) The British-American romantic drama film *Me Before You*, a 2016 box office hit, is a great example of an ableist media representation of disability. The story focuses on a disabled man, a motorized wheelchair user, who has everything he needs to be happy but is encouraged and supported to seek assisted suicide because of his disability. In other words, he is better off dead than disabled. This storyline has echoes in the real world. In fact,

some jurisdictions have legalized assisted suicide or euthanasia for disabled people and such requests are highly mediatized.<sup>3</sup>

In many cases, disability marginalization goes unnoticed and is depoliticized, as it is embedded in several everyday practices and spaces. The omnipresence of stairs and steps in urban landscapes is testament to that erasure. Jos Boys (2017) argues:

disability has somehow remained consistently stuck in a non-historical, atheoretical and – most crucially—*seriously underexplored* category in relationship to building design practices. It is invisible in both avant-garde and mainstream architectural theories and discourses, just as it is a persistent absence in critical and cultural theory (Davis, 2002; Davidson, 2008). Perhaps this illustrates just how deeply disability remains widely avoided, compared to other disadvantage identities. Unlike gender, race or sexuality then—and the feminist, post-colonial and queer studies which underpin associated scholarship and debate—it seems that we assume ‘disability’ to be unable to bring any kind of criticality or creativity to the discipline of architecture. (p. 1)

Boys’ words are relevant to many academic fields. Even though the interdisciplinary field of critical disability studies is dynamic and has developed in various locations, disability is still not recognized as a phenomenon that can and should be analyzed critically in many circles, even in some of the most progressive ones. A critical understanding of disability brings new perspectives on various issues that may seem completely unrelated at first sight. For example, disabled historian Catherine Kudlick (2003) claims that disability “reveals and constructs notions of citizenship, human difference, social values, sexuality, and the complex relationship between the biological and social worlds.” (para. 50) In short, research possibilities abound.

To fight against the marginalization and the stigmatization experienced by disabled people, it is often argued that more research and more stories on their everyday experiences are needed. In a report on the implementation of the United Nations Convention on the Rights of Persons with Disabilities in Canada, the Canada Human Rights Commission (2015) states that “additional research needs to be done in order to better understand the experiences and impacts of discrimination on the lives of persons with disabilities.” (p. 27) One recurrent issue is that stories on disability issues are told by non-disabled person and often promote ableist values. “We, as people with disability, rarely get to tell our own stories,” claims late disability rights activist,

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<sup>3</sup> In Québec, medical aid in dying is legal for the terminally ill. However, many argue that it should also be available to people identified as being severely disabled, even when they are not terminally ill (Bachand, 2017; Boisvert, 2018; Université de Saint-Boniface, 2018; Villedieu, 2016).

comedian and journalist Stella Young (2013). Jacynthe Ouellette, a participant with whom I wheeled, has told me that she has had frustrating experiences when being interviewed by non-disabled journalists. She recalls that in an interview, a journalist asked her what her dream job would be if she was not disabled. The question upset Jacynthe. She explains:

Je fais déjà ma job de rêve! On peut-tu considérer qu'on fait quand même nos jobs de rêve tsé? Tsé j'aurais pu répondre: astronaute. Mais eux, ils auraient retenu « ah, elle aurait aimé ça être astronaute, mais elle ne peut pas car elle est en fauteuil ». Alors que la réalité, c'est que je peux pas car je suis fucking nulle en maths pis en sciences.

Critical perspectives on disability change how research projects are conducted and how stories are told.

Many of the issues that are discussed in my thesis fall within municipal jurisdiction. My research takes place at a time when cities are gaining power and recognition in the world's politics. Michele Acuto (2017), professor of Diplomacy and Urban Theory at University College London, writes:

Over the past two years, urban issues—from sustainability in the built environment, to inequality in cities—have become an international priority. Cities, in turn, are taking on a more important role in global politics; the growth of city diplomacy has forged hundreds of city networks and thousands of transnational initiatives.

For instance, many cities around the world are working together on environmental action to address climate change (Roberts, Iveson & Schultz, 2018). Initiatives to reduce the use of automobiles and increase the use of public transit and other sustainable means of transportation, such as cycling and walking, are multiplying. For many experts and citizens, the viability and sustainability of cities hinges on better walking and cycling infrastructures. For instance, U.S. writer Adam Gopnik (2011) insists on the importance of pedestrians in Montréal's city life. He argues that they are “the city's red blood cell, without whom the city pales and sickens and dies of anemia.” (p. 191) Furthermore, Montréal is likely to obtain even more powers since the adoption of the *Loi sur la métropole* by the Québec government in 2017. The law must be understood in the context of the international movement for greater collaboration between cities to work on global issues. It recognizes Montréal as Québec's metropolis and aims to increase the city's autonomy and powers. It also provides that the Québec government must commit to take into consideration Montréal's particularities in the development of every law, policy and program concerning the city (Radio-Canada, 2017c).

Finally, I want to stress the importance of conducting this project in Montréal (Tiohtià :ke), built on unceded Kanien'keha:ka (Mohawk) territory, which is currently the metropolis of the province of Québec and the second largest city in Canada. The city enjoys an enviable reputation worldwide. In 2017, it was named the world's best city for students (Bruemmer, 2017). Another study ranks Montréal as the healthiest city in North America (Pilon, 2018). And the list goes on. Montréal is also known for its walkability and its efforts to make the city more bicycle-friendly—for a North American city (Babin, 2016). “Copious bike lanes, expanded sidewalks and more park land have greatly reduced traffic in the neighbourhood and created one of Canada's most livable urban environments,” CNN reporter Joe Yogerst writes about Plateau-Mont-Royal (2017). In short, Montréal certainly makes many city lovers jealous. However, disabled people's exclusion, which is embedded in Montréal's built environment and culture, is generally evacuated from these narratives about Montréal, told by non-disabled people.

When I started working on my research project, Montréal was gearing up to celebrate its 375<sup>th</sup> anniversary. I wrote most of my thesis during the year of celebrations, in 2017. The celebrations that were supposed to make Montrealers proud of their city turned out to be criticized for the striking lack of representation of Indigenous and racialized people. Community organizations and activists reacted strongly. “La réalité autochtone avait été oubliée de la programmation,” Marie-Josée Parent, co-president of the Montreal Aboriginal Network, told Radio-Canada (Radio-Canada, 2017b). In a video promoting the 375th anniversary celebrations featuring a great number of Québec artists, people of color were nowhere to be found (Normandin, 2017). Numerous critiques forced the organizing to commit to making corrections and producing a video that was more representative of the Montréal population. What completely slipped under the radar was the absence of disabled people from the promotional campaign for the festivities. I am not aware of any events that specifically address disability issues in Montréal or the contribution of disabled people to the city's history. This is not for a lack of issues or content. Even though discrimination based on disability is not an isolated phenomenon, as can be seen in the number of complaints received by the Québec Human Rights Commission every year, and even though Montréal is home to numerous disability rights organizations, disability remains particularly depoliticized in the city. I argue that the gap in the development of critical disability studies between Francophones and Anglophones may explain, at least in part, this depoliticization.

Disabled scholar Patrick Fougeyrollas, who taught at Université Laval and is one of the most known Francophone academics working on disability issues, writes:

Cette accession académique d'un nouveau champ de savoirs n'a trouvé ni légitimité ni reconnaissance universitaire en milieu francophone jusqu'à aujourd'hui. Cela constitue un indicateur navrant de l'invisibilité des enjeux politiques, théoriques conjugués aux transformations sociétales associées au phénomène du handicap et à la force très largement dominante de l'interprétation biomédicale et psychologique du handicap perçu comme un problème individuel relié à la santé et à la protection sociale. (2010, p. 23)

One of the consequences of this situation is the lack of language in French to identify the oppression experienced by disabled people (Parent, 2017). When I started writing my thesis, I chose to keep Francophone participants' stories in French but to write my analysis in English. That decision made sense in that almost all of my references were in that language. However, I am delighted to say that, in the past few years, the movement for the development of critical disability studies in Francophone communities has grown significantly. If I were to start writing my thesis today, I would definitely write it in French.

#### *Structure of the thesis*

My thesis is divided in six chapters. Each chapter begins with a personal reflection in relation to the issues discussed in the pages that follow. These personal reflections are not presented in chronological order, and some were written prior to the start of my doctoral studies. A map including the itineraries and key moments of wheeling interviews is [available online](#).<sup>4</sup> (see Appendix B) These key moments are represented either by a written quote, a photo or a video clip taken during the wheeling interviews. Links to these moments are included in the written thesis. The written reflections and videos I made in NYC are available at <http://mia.mobilities.ca/wheeling-ny-city-blog/>.

My thesis starts with an overview of the growing literature on walking practices, mobile methods and differential mobilities and the intersections between mobilities research and critical disability studies. I highlight the predominance of the non-disabled perspectives in mobilities research. Building on Arseli Dokumaci's work on disability as method (2013; 2018), I explore the making of the wheeling interview, the mobile methodology I have developed with disabled participants as a disabled researcher using a motorized wheelchair, by sharing some of the challenges we encountered. One of the objectives of this chapter is to situate wheeling, the act of

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<sup>4</sup> I used the data collected through the MapMyMap app to draw these maps.

moving using a wheelchair, as a mobile practice in its own right. In Chapter 2, I present the 15 Montrealers with whom I have wheeled through individual profiles. These profiles provide information about who they are, the relationship I have with them and the context of the wheeling interview. In the introduction of that chapter, I explain why the inherent subjectivities of oral history interviews are essential to my research. Not only do participants' subjectivities tell us about their personal lives, but even more importantly, they tell us about the city. I reflect on my position as a Francophone activist and researcher who learned to think critically about disability in English and conducted this research project in a predominantly Francophone context. The stories told by the participants were influenced by my presence and my own politics. Chapter 3 offers an overview of the historical context behind participants' stories and investigates one issue faced by most participants to provide an insight into Québec's disability politics. The first part of the chapter focuses on some of the key moments of the Québec disability rights movement since the 1950s. I pay particular attention to the Montréal movement and its more recent tensions between what I call traditional disability rights organizations and new disability activism initiatives on social media. In the second part, I examine the politics of obtaining a mobility aid in Québec. In doing so, I point to the fact that disability issues vary from one political context, hence the importance of conducting critical disability studies research in different parts of the world. I argue that obtaining a mobility aid in Québec involves navigating a complex process shaped by the rehabilitation industry and its health care professionals, government policy, ableism, the built environment and the individuals' own personal stories.

In the two following chapters, I document and analyze some of the most popular themes of the wheeling interviews regarding what it means for the participants to get around Montréal. These two chapters demonstrate how ableism is embedded in Montréal's built environment and culture. Chapter 4 draws attention to the obstacles encountered when participants navigate streets, sidewalks and bike paths. I show that disabled Montrealers, in addition to the dangers that non-disabled pedestrians and cyclists face, have to move through a much less safe and hospitable urban environment. In Chapter 5, I explore one of the most mediatized disability issues in Montréal—the accessibility of public transit. Since there are three types of public transportation offering various levels of accessibility to disabled Montrealers, I have divided the chapter into three sections accordingly—the métro, the buses and Transport adapté. The métro, my personal favourite, is the least used by participants due to the low number of wheelchair-accessible stations. The bus network is more popular, but participants report several accessibility issues

limiting their capacity to ride it in confidence. Transport adapté, meanwhile, is the mode of transportation used almost daily by many of them, and it has its own rules, which largely differ from the métro and bus network.

My last chapter addresses the complicated issues of belonging in Montréal disability communities and in the city. It stems from my own personal reflections as a disabled Montrealer. Since I was curious to know whether or not the participants feel like they belong in Montréal, I chose to start by exploring whether or not they identify as disabled and as members of Montréal's disability communities. I note several obstacles that hinder this type of belonging. I then turn to the question of belonging in the city. Even though issues of belonging are central to Québec's politics, disability has historically been ignored in those conversations. The same can be said about belonging in Montréal. If walking is a means to build belonging in spaces, as argued by Michel De Certeau (1984), does it mean that disabled Montrealers who face countless obstacles when moving through the ableist city are likely to feel like they do not belong? Finally, I close the thesis by proposing actions and ideas, inspired by participants' stories, critical disability studies and mobilities research literature, to build an anti-ableist city that would facilitate wheeling and strengthen disabled Montrealers' sense of belonging.

## Chapter 1

### The Making of the Wheeling Interview

*“Being above ground in my wheelchair, just strolling around. I really love how aggressive I am able to be as a driver often. And that really allows me to exercise part of who I am that I don’t often exercise socially or verbally or affectively. That really satisfies something deep down inside of me. And this is one of the reasons I like New York a lot because I feel like I can really make glaring eye contact and insistent undeniable taking up space that in a lot of other parts of my life I feel like I don’t do that, or I feel bad about doing that. And here I just do not feel bad about doing that. Often. Sometimes I do.”*

—Park McArthur, disabled artist and activist, New York City, November 13, 2014

In fall 2014 and summer 2015, I interviewed 31 disabled people living in New York and Montréal. I was interested in the sense of belonging they had with their city. I conducted wheeling interviews with 23 of them. They guided me through their daily commutes, their neighbourhoods and the places they go for a wide variety of reasons. Video cameras were mounted on my wheelchair and on the participant’s wheelchair (if they had one). As soon as I began interviewing people and reflecting on it, it became obvious that the question of methods would be central to my research. My conversation with Park McArthur pushed me to think more deeply about my own relationship with wheeling. On the streets, I don’t *really* walk. I wheel. That does not mean that I do not identify as a pedestrian. It is complicated. And it matters. What does it mean to conduct walking interviews when you do not walk the way society expects you to? Despite the growing literature on walking practices, mobile methods, differential mobilities and mobility justice, little is known about what it means to move through cities using a wheelchair. While other mobilities researchers engage with wheeling—for example, those studying cycling, (Spinney, 2011; Aldred, 2013)—I offer a new perspective on a type of wheeling that has been historically ignored and devalued.

Building on mobile methodologist and critical disability studies scholar Arseli Dokumaci’s (2013; 2014a; 2014b; 2018) research on disability as a method and the affordances of the everyday, as well as on my own activist research on ableism at the Mobile Media Lab at Concordia University, I am forging an emerging methodology rooted in the mobile practice of wheeling. In this chapter, I reflect on the challenges, barriers and evolution in my experiences conducting wheeling interviews. My analysis is based on more than 38 hours of video recordings—30 hours of this footage were shot in Montréal. I argue that wheeling interviews are

negotiated between the researcher, the participants and the politics of the space through which they are moving. I demonstrate that the method I am developing opens up new possibilities and horizons for both mobilities and critical disability studies research. But before that, I explore the predominance of the able-bodied perspectives in mobilities research, as well as the question of methods and mobility within critical disability studies.

### *Misconnections*

The new mobilities paradigm developed by Mimi Sheller and John Urry (2006) has sparked interest in mobilities research across the social sciences in the last decade. This paradigm emphasizes both the centrality and the complexity of mobility to any understanding of the contemporary world. Different modes of mobility are currently being examined, with a fair amount of research devoted to the politics of everyday life. Critical perspectives on mobility call for the recognition of mobility as a “resource distributed unequally among social groups.” (Frith, 2012, p. 134) In other words, the mobility of some groups of people is privileged over that of others. Research conducted while on the move, which use mobile technologies, has raised numerous methodological questions and has led to the development of mobile methods for capturing macro—and micro-movements. While discussions of the politics of embodiment and power relations are central to mobilities research, this interdisciplinary field has only recently started to engage seriously with critical disability studies. Mobility, on the other hand, is a frequent and recurrent concept within critical disability studies.

Using the keyword “disability,” a search of the journal *Mobilities* from its first issue in 2006 to the present yielded 63 results. A closer look at these results, however, shows that most of these articles do not engage directly and critically with disability. Seventeen articles are not related to disability in any way. Ten of these 17 articles use the verb “disable” to describe an individual or a group of people being prevented from doing something. Twenty papers simply list disability among other categories, such as sex and gender, or use disability in a way that is not central to the paper’s argument. This left 26 articles that seriously explore issues related to disability. Of these articles, 15 had been published in 2016 or thereafter, clearly indicating that the interest in critical disability studies is a fairly recent development in mobilities research. The special 2016 issue of *Mobilities*, which celebrates the journal’s tenth anniversary, contains five articles that specifically address mobility from a critical disability studies perspective. Michelle Pyer and Faith Tucker (2017) write about transport, mobility and the leisure experience of

teenage wheelchair users in Britain. Chris Philo's article (2014) aims to contribute to mobilities research by exploring Foucauldian perspectives on mobilities and immobilities. Disability plays a central role in the development of the argument in all five articles. For example, Anna Goodman, Alasdair Jones, Helen Roberts, Rebecca Steinbach and Judith Green (2014) cite previous research that documents how the poor accessibility of London buses causes frustration in disabled youth who use wheelchairs. The authors also suggest that mobilities research has neglected young people with disabilities. Critical disability studies scholarship is mentioned in four articles, and one paper acknowledges that one of the limitations of a study on the relational mobilities of children and families in Copenhagen (Jensen, Sheller & Wind, 2015) is that the experiences of disabled people are missing. These acknowledgments of disability scholarship and experiences reveal the growing intersection of mobilities studies and critical disability studies, an encouraging development mentioned in *The Routledge Handbook of Mobilities*, edited by Peter Adey, David Bissell, Kevin Hannam, Peter Merriman and Mimi Sheller (2013). This important book for mobilities research includes an article by Kim Sawchuk that explores the concepts of differential mobilities and impairment building on critical disability studies and mobility studies literature: "The study of disability and impairment from the perspective of differential mobilities asks researchers to be attentive to able-ist presumptions of systems of design and architecture that assume a singular bodily norm and the "movement-flows" that reveal disabling environments." (p. 414) Sawchuk's article evidences how the conversations between the two fields are necessary and promising.

### *Reconnections*

Critical disability studies, on the other hand, have historically addressed the issues of methods and mobility. From the early days of this interdisciplinary field, a lot of attention has been given to mobility-related issues faced by people with physical disabilities. A search using the keyword 'mobility' in the journal *Disability & Society* produced 532 results, although only two of these papers refer to the mobilities paradigm developed by Mimi Sheller and John Urry. In fact, only nine articles make reference to the mobilities paradigm. Literature on mobile methods is also largely absent from critical disability studies literature, even though the question of methods is of indisputable importance within the field. Disabled people themselves have critiqued traditional research on disability and have argued that the methods used should enable their active participation in the research process. This generally requires thinking outside the box and developing innovative methods. Several articles explore creative methods developed to take

more control of the progress of research and to increase the participation of disabled people. For people who find spoken language alienating, methods that involve non-verbal skills, such as drawing and photography, can be used (Nguyen, Michell, de Lange & Fritsch, 2015).

Participatory video as a research methodology is used to better uncover and situate disability experiences in space and time (Porcelli et al., 2014). The lived experience of disabled researchers and the impact they have had on research has been explored, as many of them disclose their disabilities. For example, Jane Andrews (2005), a researcher using a wheelchair, writes about the methodological and practical challenges she faced while conducting interviews with other disabled participants. In her postdoctoral project at Concordia University, Arseli Dokumaci (2013) investigated the intersections of mobility, disability, performance and everyday practices through short video documentaries with disabled Montrealers in public and private places. She claims that the experience of disability itself can be used as method (2014) and that “video can capture the details that are not really visible to us throughout the flow of daily routine, the parts that we do not really see.” (2013) In another visual ethnographic project with two disabled Montrealers, one who is blind and one who has mobility-related disabilities, Dokumaci (2018) takes her “collaborators' critical insights and creative workarounds as ways of tracing what otherwise disappears in everydayness, that is, an ableist habitus.” She argues that:

If the normate, or the “preferred social body,” to use Tobin Siebers's phrasing, remains “presupposed but invisible—until a nonstandard body makes an appearance” (85), then adopting disability as method entails tracing those appearances so as to mark what otherwise goes unmarked in everydayness. This allows us to expose the possibilities that a seemingly neutral world of supports affords the normate body, while putting other bodies out of place. This ignorant occupation of space is what I refer to as “the habitus of ableism.”

Again, her camera captures the things that the “habitus of ableism renders too familiar and hence unnoticeable.” (*Ibid.*) Furthermore, through the development of a new audio description technique to make her video accessible to the blind audience, she demonstrates that disability, in this instance blindness, offer “new possibilities of media-making” (*Ibid.*). In other words, disability is not something to overcome but something that can enrich filmmaking practices. Dokumaci’s work has empowered me to embrace my wheels and explore how they shape my academic work and filmmaking.

### *The (normalized) walking interview*

Walking interviews are a data collection method used by many researchers inside and outside of academia. Jon Anderson (2004) claims that this mobile method “offers the potential to bolster and add new layers of understanding to social science research.” (p.254) Over the past few years the proliferation of mobile media has made audio and video recordings much more accessible to a wide range of people. No heavy or sophisticated equipment is required; it is now possible to record interviews with most mobile phones and mobile recording equipment is affordable and widely available. There are several reasons that researchers may choose walking interviews as a method. Walking interviews potentially create the opportunity to access a local community’s knowledge about their surrounding environment (Evans and Jones, 2011, p. 857) and to facilitate both the emergence of particular memories (Carpiano, 2009) and collaborative knowledge (Anderson, 2004, p. 254). The growing interest in walking interviews is strongly connected with the recognition of walking as a social practice that actively shapes the cities we live in. Michel de Certeau (1984) sees walking as a means to “constantly alter a landscape simply by moving through it.” (p. 98) De Certeau also theorizes walking as a subversive political act based on the tactics of everyday walkers. Furthermore, he claims an individual’s sense of belonging in a space is built through walking. On the relationship between self and place, Edward Casey (2001) argues that “there is no place without self and no self without place.” (p. 684) In this way, our identities and bodies shape places just as places shape our identities and bodies.

The interest in research methods centred on walking is not unrelated to the valorisation of walking in Western societies. Walking evokes ideals of health and freedom. This physical ability is regularly assumed to be natural for all humans and is largely accepted as a signifier of well-being. Fiona Wilkie (2014) explains that walking “inspires belief, because it has a strong legacy that can be traced and celebrated, because of its power to resist dominant structures, and because it is slow.” (p.44) Rebecca Solnit (2001) connects the act of walking to other bodily functions as fundamental as breathing. She adds that “walking generates a rhythm of thinking.” (quoted in Anderson, 2004, p. 258) She argues that the mind and the feet operate at the same speed. Solnit quotes French philosopher Jean-Jacques Rousseau who claimed “I can only meditate when I am walking. When I stop, I cease to think; my mind only works with my legs.” (quoted in Solnit, 2001).

What generally remains unacknowledged is that this conceptualization of walking cannot be universalized as it is based on the ideal of able-bodiedness, which creates norms. A typical walker is not expected to be able to run a marathon. However, a typical walker is expected to be able to cross a street within a specific amount of time and to do so on two legs that operate in a particular way. The same thing can be said about the mind: minds must function in certain ways in order to fall within the boundaries of what is considered neurotypical abilities. These norms, however, are not neutral. They are manifestations of ableism. What is considered ‘normal’ is determined by technological and cultural standards within a specific historical context. Gregor Wolbring (2003) suggests that when artificial limb technologies create super-legs that are more efficient than normal legs, the normality of what are now considered normal legs can be challenged. People who now have normal legs could become disabled because of their lack of super-legs (Wolbring, 2003, p. 156). This important critique of walking as a ‘natural ability’ is rarely discussed in the field of mobilities. Considering that ableism as a system of oppression that remains poorly understood in academia and that academia itself is still largely a space for the production of ableism (Dolmage, 2015), it is not surprising that only a few mobility scholars explicitly acknowledge the existence of differential experiences of walking, even when the use of walking interview as a data collection method should bring the issue to the fore (Cresswell and Merriman, 2012, p. 24; Wilkie, 2014, p. 44). For instance, none of the articles published in *Mobilities* features walking interviews that have been explicitly conducted by disabled researchers or with disabled participants.

#### *What I talk about when I talk about wheeling*

Unlike walking, wheeling with a wheelchair is neither valued in social science research nor in Western cultures. In the media, moving using a wheelchair is either considered a tragedy or a heroic act. Unless they receive social praise for their superior sporting skills, as Paralympic athletes do, wheelchair users are constantly described as being confined in, or bound to, their wheelchairs. The discourse of wheelchair-tragedy is regularly used as a deterrent in campaigns promoting safety when driving or diving or making healthy lifestyle choices. For example, in the spring of 2015, a public service announcement about osteoporosis prevention was released in the United States. The campaign sparked outrage in the U.S. disability activist community. The ad, which was removed from the air due to the mobilization of that community, featured an empty manual wheelchair chasing down walkers in a shopping mall. Creepy horror movie music played in the background. The message was: “Stand up to osteoporosis. Before you can’t.” (Ladau,

2014a) This type of media representation contributes to the construction of wheeling as nothing but negative and occurring in opposition to walking. Wheeling simulations, the activity of spending a day in a wheelchair, are also popular and generally considered as means of raising awareness about accessibility. Stella Young (2014) argues that “disability simulation fails to capture the nuance and complexity of living in a disabled body. And it certainly fails to give a deep understanding of systemic discrimination and abuse faced by disabled people.” These representations of wheeling are the result of power relations that devalue the disabled experience as a way of knowing the world. Jacynthe Ouellette, one of my participants, was once approached by a journalist who wanted to spend an hour in a wheelchair and then talk about the experience. Jacynthe declined the invitation because she is not comfortable with this kind of disability simulation. She talks about her discomfort:

Une heure, c’est trop court. Je trouve que c’est juste sensationnaliste pis qu’au final il ne se passe rien. Il n’y a pas de changement. Il n’y a pas plus de mobilisation venant des gens qui ne vivent pas cette situation là. [...] Ça vient les conforter dans l’idée “ils sont pas chanceux, imagine si j’étais pris dans ce context-là”. J’ai un malaise avec ça. Tu reste très en surface dans l’explication du problème.

Finally, wheeling does not come in only one form. Who has access to wheelchairs varies from one jurisdiction to another and is located within a specific historical context.<sup>5</sup> There are different types of wheelchairs and scooters. Some people have to pay for their wheelchairs, while others have them covered by private or public health insurance. Some people have access to wheelchairs specifically customized for their needs. Other people are denied the use of wheelchairs, because they are not disabled enough according to insurance requirements. Some people are full-time wheelchair users, while others do not use regularly use them.

It is also important to recognize that wheelchair users in many cases use the term walking to describe how they move in the world (Taylor, 2008). I suggest that walking and wheeling should not be seen in binary opposition. Wheeling can be thought of as a mobile practice falling under the umbrella that covers a variety of walking practices. This perspective challenges the ableist conceptions of walking that have prevailed in walking studies so far. To think about wheeling is to think about a way of moving in the world that is marginalized. To consider wheelchair users as pedestrians is to reject the idea that walkers represent the only self-sufficient individual body. Tim Cresswell (2009) coins the term “prosthetic citizen” to reveal the co-

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<sup>5</sup> In Chapter 3, I explore the politics of acquiring a mobility aid in Québec.

ingredience of the body and the world. This concept is well illustrated in the documentary *Examined Life*, wherein philosopher Judith Butler takes a walk with disability artist and scholar Sunaura Taylor in the streets of San Francisco. Butler walks with her legs and shoes while Taylor walks with her wheelchair. Together, they discuss Gilles Deleuze's Spinozistic question "What can a body do?" and talk about how walking practices that do not conform to bodily norms in terms of ability and gender are potentially subversive, and in the most dramatic cases, dangerous for those who perform them. Taylor explains how the mundane action of going out to get a coffee used to be difficult for her. Unable to use her hands in the way hands are expected to be used, she needed help to get her cup of coffee, which she holds with her mouth. She confides:

I would sit for hours beforehand in the park just trying to get up the nerve to do that. In a way, it's a political protest for me to go in and order a coffee and demand help simply because, in my opinion, help is something that we all need. And it's something that is, you know, looked down upon and not really taken care of in this society when we all need help and we're all interdependent in all sorts of ways. (Taylor, 2008)

Their fascinating discussion about the politics of different embodiments has motivated me to use a similar style for my interviews, a technique that seemed like the ideal interviewing method to elicit the conversations I hoped to have. I was not wrong. However, I had underestimated something quite important: unlike Judith Butler and Sunaura Taylor, I would not have a filming crew with me. That changed everything.

### *Creating a mobile method through challenges and barriers*

Conducting wheeling interviews with disabled people in New York City and Montréal has been a fantastic adventure on many levels. I have been forging a new methodology at the intersection of critical disability studies, mobility studies and oral history. My practice evolved greatly between the writing of my thesis proposal and the last wheeling interview I completed in Montréal 15 months later. It is through the challenges and the barriers I have faced that this method was developed. As such, it seems important to write about these challenges and barriers.

I did not know many people when I arrived in New York City. To recruit participants, I attended as many disability-related events as I could and distributed a call for participants through my various networks, many of them disability-related. The first person who replied to my call for participants was Jeanne L'Hermite, a blind woman who lives in Queens. She told me that she has no difficulty going to the places with which she is familiar. I offered to meet her in her neighbourhood. Jeanne agreed and sent me a detailed email message with the directions to

her favourite bakery. As I read her email, I realized that she did not know that I use a wheelchair. I had not disclosed it in my call for participants. I had chosen not to focus on the fact that, as a disabled woman using a wheelchair, I often face the same obstacles as many of my interviewees. After all, these interviews were not about me; they were about them. That, in any case, is what I thought. However, it turned out that Jeanne's favourite bakery was not wheelchair-accessible. We exchanged a few emails and decided to try to find an accessible place in her neighbourhood. She knew a place with an elevator, but the elevator buttons are not accessible to her because there is no braille. To be mobile, we would have to share our knowledge of access and obstacles. It was the materialities of doing a kind of *intradisability* mobilities research such as this that were at the core of my method.

Prior to conducting wheeling interviews in New York City, I had been making short videos using only one camera or one microphone. My recording equipment became more complicated in New York, as it included two GoPro cameras, two camera mounts, two microphones and two audio recorders. More sophisticated equipment was necessary to capture my perspective as well as my interviewees', and record discussions on the move in a congested urban space. I naturally opted for portable cameras and microphones. Carrying heavy equipment would not have been possible for me, and I wanted to be able to set up the equipment by myself and be free of the need for assistance. However, finding the appropriate equipment was a challenge. I did not anticipate being unable to find a camera mount that would be easy to attach to the participants' wheelchairs and that would be able to endure the continuous contact with sidewalks and streets bumps and cracks.<sup>6</sup> When shopping at B&H Photo Video, one of the largest video equipment stores in New York City, I was reminded that the video technology I was using had not been made with people with limited muscular strength in mind. The GoPro was initially developed for extreme-action videography. GoPro's brand image is often represented through seemingly able-bodied people engaging in extreme sports such as surfing and mountain biking. Using a technology to do something different from its intended purpose requires adaptation and creativity. After testing a couple of mounts, I chose a mount that required too much strength for me to use but offered stability. I had to accept that I would need assistance from either the participant or a stranger.

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<sup>6</sup> I did not have to worry about the camera on my wheelchair, as I was able leave the mount on my wheelchair, and, with my mother's help, I could set up the camera at home before leaving my apartment. I also clipped my microphone to my shirt and coat before leaving for an interview.

Given the diversity of the participants' abilities and wheelchairs, the act of setting up the cameras and the microphones turned out to be an important—and challenging—part of the interview, as well as a valuable component of my research process. Together we tried to figure out where on the wheelchair the camera mount would fit best. We did not pay that much attention to finding the best camera angles to show the images we wanted to capture on film, e.g., the ground, the faces of passers-by, traffic lights. The location where we would meet and set up the equipment also had an influence. For example, it was easier to ask a passer-by for assistance in busy public spaces. Having access to a table or a flat surface on which I could lay my equipment was also very helpful. The set-up of the camera was a negotiation between me, the participant, and the environment. This opened up a space for valuable discussions about what it means to ask for assistance in a large city, such as New York. Asking strangers for assistance is something many disabled people have to do daily. We all have different ways of negotiating it.

My technique for setting up the equipment was different in Montréal, after I got two new mounts used to attach the participant's camera as well as one audio recorder. In New York City, I had to carry the audio recorder in my hand or put it in a bag; it was either cumbersome or out of my sight. When I wheel, my left hand controls my wheelchair joystick and cannot do anything else. I could not hold two audio recording devices in my right hand. On a few occasions, one of the two audio recording devices stopped without any apparent reason. Engrossed in the conversation and not having easy access to the devices as I was wheeling, I did not notice these types of problems as they arose. The new mount allowed me to attach the audio recorder to my wheelchair. Having the audio recording device in my visual field enabled me to monitor the recording throughout the wheeling interview. The new camera mount had the great advantage of being much easier to attach and offering greater flexibility with a friction arm.

More aware of the importance of that crucial step of my method, I tried to remember to turn on my camera before setting up the participant's equipment. The camera would then capture some of the movements of our bodies and the audio recording gave a good sense of what was happening. How we adjusted the angle of the camera and attached the participant's microphone varied from one interview to another. The recording of these micro-movements offered a visual perspective on the techniques the interviewee and I developed to accomplish what is generally considered as a mundane task. The performance of these gestures was based on an assessment of the participant's abilities and mine. There were things that were taken for granted. *He is surely*

*stronger than me. My fine dexterity is less impaired than hers.* Most of the time, a series of questions were asked—out loud or otherwise. *Do you need help to clip the microphone? Can you help me to mount the camera? Can you move your wheelchair closer to mine?* Navigating those questions meant creating ways to make things work for both of us. The recording also made me remember that I regularly used my mouth as a third hand to hold the microphone or the audio recorder while my hands were busy setting up another piece of the equipment. The participants also used different techniques to assist me. Dokumaci (2013) borrows the term “affordances” from environmental psychologist James Gibson to explore how disabled people “create different choreographies to manage their daily life and to overcome obstacles.” She argues that the “affordances are the way disabled people recreate the established body techniques of the everyday.” These affordances were at the heart of what made this research a co-creative endeavour. By bringing us out of the framework of the interview room, I sent an invitation to the participants to crip the traditional walking interview. Carrie Sandahl (2003) defines crippling as “[spinning] mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects.” I use the term “crip” to indicate my position as a disabled filmmaker and researcher engaged in the exposure of compulsory able-bodiedness in media representations and discourses about accessibility and disability.

The challenges the participant and I faced while setting up the equipment did not end as we started the interview and got moving. In Montréal, camera stability proved to be a problem in 13 of the 15 interviews I conducted. Sidewalks in poor conditions certainly had an impact on the stability of the camera. The multiple shocks that travelled up from the pavement to the wheelchair and the camera were indicative of the shocks absorbed by the participants and me as we wheeled. Monitoring the video equipment while wheeling was a priority and a responsibility that I shared with the participants. Participants sometimes asked me if their camera had moved. Other senses like hearing and touching were used to monitor the stability of the camera when it was out of the participant’s sight. Participants helped to replace or anchor the camera with their hands or by placing their wheelchair in a position that enabled me to have access to the camera more easily. My interviews with Sandra Gualteri and Christian Généreux, two Montrealers who use wheelchairs, proved to be particularly difficult in terms of camera stability. Sandra took us on a tour of the horrible sidewalks in her Notre-Dame-de-Grâces neighbourhood. The sidewalks were in such terrible condition that the camera on her wheelchair moved constantly. I must have re-mounted it more than a dozen times (Figure 1). At a street intersection towards the end of the

wheeling interview, a woman approached us while I was trying to replace the camera and offered to help. Her efforts did not make much of a difference, as the camera started moving again a few minutes later, as we wheeled on a street paved with cracks and holes. Interruptions to replace the camera were an integral part of the interview.

A few weeks later, Christian brought me on a 21-kilometre trip, during which we wheeled on the sidewalks and the streets of different boroughs, took the bus and rode the métro. While wheeling on the uneven sidewalks of Jean-Talon street in Parc-Extension, Christian's camera started to react to the constant bumps. We stopped on a couple of occasions to try to tighten it, without much success. Our only hope was to get assistance from a passer-by. We were about to leave Park-Extension, a low-income neighbourhood with numerous pedestrians, and enter Town of Mont-Royal, a wealthy independent municipality, where people generally travel by car. Christian quickly spotted a female jogger coming towards us and interrupted her run. As she stopped, I took over and explained to her what we needed. This impromptu encounter turned out to be extremely helpful, as the jogger managed to tighten the camera so well that we did not have to worry about it for the rest of the interview.



**Figure 1:** I try to reposition Sandra's camera with my right hand. This is my sixth attempt.

Collaborative monitoring of the camera went beyond tackling technical problems. It included a deep engagement with the act of filming. The participant's wheelchair became a filming tool just as much as the camera was. Control of the camera was enacted through the control of their wheelchair. Participants had to keep in mind the presence of the camera on one

side of their wheelchair, which made them wider than usual, redefining their corporeality and their relationship with the space they were moving through. On a handful of occasions, the camera hit an object, forcing us to stop and reposition it. Negotiating the space with the video and audio equipment, as well as with mobility aids, speaks to the issue of “other materialities,” as developed by Ole Jensen (2016). He argues that “materialities are not just external to the human, but rather permeable as in a deep relationship of osmosis.” (p. 593) In Western popular culture, wheelchairs, for example, are considered as objects that confine the people who use them. Thinking about other materialities while wheeling challenges this idea. Wheelchairs and video and audio equipment are not inanimate objects; they are actors facilitating, affording, and entangling mobile practices (Jensen, 2016). In New York City and Montréal, they have been active participants in the development of the wheeling interview as a mobile method.

### *Talking on the move*

My initial objective when choosing my interviewing method was to explore other people’s mobility in their cities. I knew that my presence would have an influence on their mobility and the discussions we had. However, I had underestimated the collaborative dynamics of these wheeling interviews, as well as my own ability privileges. I did not learn so much about how participants move in their city as much as I learned about how we move together. My presence changed everything. The participants did not move like they usually do. They moved with me. We moved together. In their article, “Moving together: Mobile Formations in Interaction,” McIlvenny, Broth and Haddington (2014) write that “people traveling or moving together have to work, sometimes intensely, to maintain alignment, a sense of presence, mutual awareness, frameworks of co-participation, and to coordinate transitions between modes of mobility while maintaining togetherness, pace, and flow.” (p.105) This resonates with my experiences conducting wheeling interviews. While talking, thinking, wheeling and walking at the same time appeared to be so easy for Judith Butler and Sunaura Taylor to perform, the participants and I encountered difficulties.

Talking while moving shaped how we moved together and exposed the complexity of ableism. Different techniques of wheeling, walking and communicating definitely played an important role in making each wheeling interview an occasion to rethink what it means to move together with different embodiments and to engage with the importance of situated knowledge in a world marked by uneven and unequal mobilities (Murray, Sawchuk, Jirón, 2016). Wheeling and

talking at the same time is something I can usually perform easily. I had never put too much thought into it. I took it for granted. Wheeling interviews proved to be an effective method to face my own ableism, and then challenge it. Jeanne L’Hermite makes her way around the city with her white cane. We talked about what kind of assistance she needs when walking. For example, I asked if I should warn her about upcoming obstacles and traffic light changes. Wheeling with Jeanne, I realized that while I don’t walk with my legs, I definitely walk with my eyes. The sociologist Siegfried Saerberg (2010) explores the different styles of perception of blind and sighted pedestrians. Blind himself, he explains that sighted people believe that their way of perceiving space is the only possible way, and as a result, they are unable to give useful route instructions to blind people.

Shafeka Hashash, a blind student at New York University, used her white cane and explained to me how she has her own techniques for getting around New York City. She talked about how she regularly unsettles sighted people who feel the need to tell her what to do. For her, this is a clear manifestation of ableism. At one point in the interview, we crossed a busy street—Broadway!—and she took a path different than mine. Instead of going straight, she deviated to the right. I was surprised and felt a bit uneasy. I was unable to follow her, as the path she took was not wheelchair-accessible. The curb cut was in front of me. Crossing the street going straight was my only option. That moment disrupted our discussion, as we parted and then regrouped a few seconds later. It spoke of our different ways of crossing a street and my own discomfort as a sighted person. I was confronted with my own normalizing of space for as mundane an action as crossing a street. As Saerberg explains, as a result of their respective knowledge, skills and needs, blind and sighted people create space differently. Sighted people tend to take for granted that their perception reflects the true nature of space, when, in fact, it simply indicates how they construct space.

My experience with Luc Fortin, a blind man who lives in Montréal, was different. I have known Luc for more than two years. We worked together, and we have a friendly relationship. Nonetheless, our experience of walking and wheeling together was very limited prior to conducting the wheeling interview. We knew that it was going to be a challenge. Luc suggested meeting at his workplace in downtown Montreal and heading east towards his home. Because of the inaccessibility of the métro system, we decided to cover as much distance as he was physically up to travelling above ground. At the beginning of the interview, he said that he would

prefer to hold on to my wheelchair than to use his white cane, because then he would not have to focus on himself. He folded up his white cane and grabbed the handle on my wheelchair. Every obstacle had to be named and explained to make our walk as safe and smooth as possible. Our conversation was constantly interrupted by the need to articulate the environment we were navigating. After wheeling/walking together for about an hour on narrow and often uneven sidewalks, we found ourselves on a large and newly built sidewalk. Relieved, I said to Luc “C’est le fun ici. Il y a un super trottoir. C’est large. Il me semble que ça va bien.” He replied:

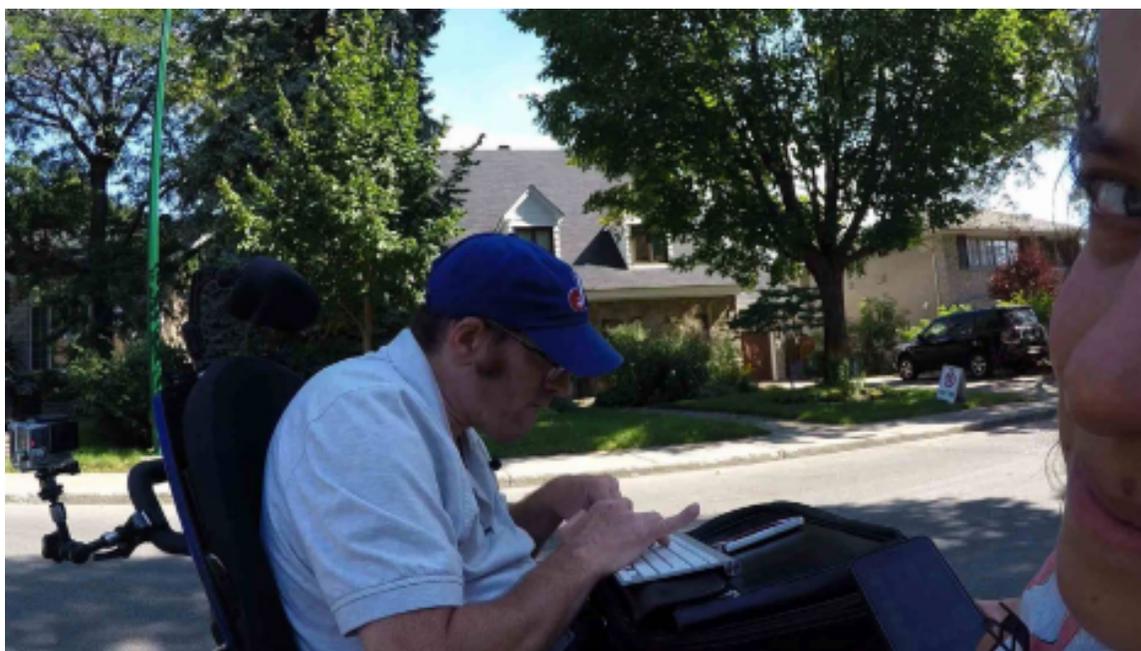
Oui, c’est vrai ça semble aller bien, mais tu vois, moi je ne peux jamais me dire ça parce que je fais toujours un pas à la fois. Ça m’est arrivé, sans dire régulièrement, mais trop souvent, de penser “ah ça va bien” pis de rentrer dans quelque chose. [...] Fait que même quand tu penses que ça va bien, tu y vas un pas à la fois. C’est comme “mon pied est là et ma face n’a rien touché. Je suis correct.” ([see video Fortin-2](#))

His reply made me aware of my privilege as a sighted person. With other sighted participants, we avoided countless obstacles without even talking about them. Luc’s comment brought me to think about our intersubjectivity. Different feelings were emerging through our experience of our differential mobilities. We were together on this walk, and yet we were navigating based on different maps and privileges.

The often taken-for-granted aspect of moving while talking was also challenged during the interviews with Christian Généreux, Marie-Josée Blais and Laurence P. Rousseau. Before Christian and I met for the wheeling interview, we exchanged a few emails to discuss how we could make the interview accessible to both of us. Even though I have known Christian for many years, we have not spent much time together. We are used to communicating via email. I have not yet developed the skills to understand Christian’s speech easily. When he talks to me, I often need to ask him to repeat. When we met for the interview, Christian gave me a short text he had written describing the route he had chosen to wheel with me. For him, that meant thinking in advance about what would unfold as we wheeled. His short text gave me a good sense of what we would talk about during the interview. His contribution guided me towards questions that could lead to interesting conversations as we wheeled. Communicating while moving was facilitated by the use of a wireless keyboard and our mobile phones. Christian typed his responses, questions and thoughts on the keyboard and sent them to me via Facebook messenger. We stopped several times to communicate. These pauses allowed me to monitor our video and audio equipment functioning and think about the interview as it was happening (Figure 2).

For Marie-Josée and Laurence, talking was easier when we were stationary and facing each other. Marie-Josée is hearing and visually impaired. She also uses a motorized wheelchair. To facilitate communication, we stopped in different places to have longer conversations. This made me conscious of the sound landscape in which we were moving. Laurence, who walks assisted by her service dog, explained that walking and talking at the same time made it harder to keep her balance. She suggested going to a park so we could talk. On our way to the park and back, we talked about her life as a young disabled woman, and about key issues such as the meaning of accessibility. On a few occasions, she stopped to explain something in more detail.

While both Laurence and Marie-Josée associated their need for pauses with their disabilities, all the wheeling interviews I have conducted included pauses—besides the ones imposed by the environment and other mobile actors. There are many reasons to stop during a conversation—to think, to make a point, to acknowledge or to experience an emotion. Pausing can be desirable, imposed, necessary, negotiated or disruptive.



**Figure 2:** Christian and I are stopped on a quiet street in the Town of Mont-Royal. While Christian types what he wants to say on his keyboard, I take the time to turn back at my camera to check if it is still recording.

Being able to talk on the move and maintaining togetherness also had much to do with adjusting to each other's speeds and the ways in which we negotiated our environments. The assemblages

of our bodies and our mobility aids such as wheelchairs, scooters, white canes, and service dogs revealed the complexity of harmonizing our movements. I am very aware of what I can accomplish with my wheelchair. I am able to make the distinction between an obstacle that must be avoided and an obstacle that can be negotiated. This does not mean that I am able to do the same assessment for other wheelchair users. With Sandra Gualteri, a Montreal participant who uses a motorized wheelchair, I discovered obstacles I would not have noticed otherwise. The spasticity of her arm controlling her joystick combined with rough sidewalks paced the rhythm of our stroll. On other occasions, participants inquired about my capacity to follow them. As we approached a curb cut, which looked more like a small step than a curb cut, Louise asked me if my wheelchair could handle it. To get to a picnic table in the middle of a park, Laurence and I had to wheel and walk on the grass for about forty meters. The terrain seemed a bit uneven. She asked me if I could wheel on the grass just as I was wondering if walking on the grass would be a problem for her.

Additionally, wheeling side-by-side while maintaining a conversation was compromised by the narrowness of many sidewalks and the presence of several obstacles. These obstacles often forced us to single file to continue on our way. When moving in public spaces, I am often expected to be either alone or with an able-bodied person. Wheeling with another disabled person disrupts this expectation. At the beginning of the interview with Louise Blouin, a disabled Montrealer using a scooter, we had difficulty wheeling side-by-side, due to the narrowness of the sidewalk. In the middle of a story about her youth, Louise and I encountered an obstacle. Two empty garbage cans were blocking half of the sidewalk, forcing us to proceed in single file. Louise exclaimed, “Oh!”, as we stopped our conversation to negotiate the obstacles. Then, we encountered two pedestrians, which forced us to remain in single file. (Figure 3) When we were finally able to wheel side-by-side again, Louise remarked on the difficulty of the situation and expressed some concern about our ability to conduct the interview. I asked her what she usually does when she goes for walks with her boyfriend, who also uses a wheelchair. She answered that they wheel in single file and do not have conversations. Their objective is to get from A to B. Therefore, talking while wheeling was not something Louise was used to doing. To make her feel more comfortable, I suggested that we regroup at intersections and take occasional breaks to talk. She agreed but immediately continued her story as we started wheeling again on the same narrow sidewalk. We quickly developed a technique so we could talk in spite of numerous disruptions. The issue of narrow sidewalks came up in other interviews. To overcome this obstacle, many



**Figure 3:** Wheeling side-by-side with Louise

Photo captions:

A: Louise is talking about transitioning from a special school for disabled children to a regular school. They are looking at each other, and Laurence is listening.

B: Louise and Laurence are looking at the two garbage cans blocking their path.

C: Louise passes in front of Laurence.

D: Laurence brings up the rear as they pass by the garbage cans.

E: Louise and Laurence encounter two pedestrians on their left, forcing them to remain in single file.

F: Louise is looking over her shoulder, as she makes space for Laurence to join her.

G: Laurence and Louise can finally return to wheeling side-by-side. A happy looking Louise is talking to a smiling Laurence.

participants chose to go on sidewalks that were wide enough for us to talk while we were moving. When such sidewalks were not available some participants decided to take quiet streets with which they were familiar. Despite being more vulnerable to cars many participants mentioned feeling safer on the street. They have learned to avoid narrow sidewalks in poor condition. When wheeling with participants on unfamiliar streets, I had to trust their good judgment and be more cautious of my surroundings. Wheeling on the streets is also used to save time to reach a destination. Due to the lack of accessible transportation in Montréal, wheeling remains the most efficient way to get around the city for many.

Another factor that influenced how we moved together was the politics regulating our movements. Which movements were permitted? Which were not and why? How did we navigate regulations? During the wheeling interviews we faced different levels of regulations. There are unwritten pedestrian laws that influenced how we move together, rules that were highlighted by the wheeling interviews. Wheeling side-by-side often meant blocking the sidewalks for other people. People would either have to pass by us and deviate from their path or wait for us to single file. This caused tensions on a few occasions. Jacynthe, who uses a manual wheelchair, expressed discomfort about wheeling side-by-side. “J’aime pas ça quand des gens prennent toute la largeur du trottoir et me bloquent. Ils me ralentissent. Donc, j’aime pas ça qu’on fasse ça à d’autre monde en ce moment. Je comprends que c’est pour l’entrevue, mais ça me dérange,” she admitted. On a busy boulevard, Laurence and I had no other choice but to use the sidewalk, a portion of which is shared with cyclists. With her service dog, we occupied the totality of the sidewalk and they could not easily disrupt our togetherness. Most cyclists stepped out onto the street, allowing us to continue our way; while others looked annoyed and made us feel out of place. These two situations illustrate the existence of unwritten pedestrian codes that are transgressed during wheeling interviews.

Other regulations are enacted through policies or legislations and are thus more difficult or impossible to transgress. In 2010, the Québec government (which covers the cost of and distributes wheelchairs to disabled people with a medical diagnosis requiring the use of a wheelchair) decided to limit the maximum speed of all new motorized wheelchairs to 10 kilometers per hour. I got my wheelchair in 2012, which means that my speed is restricted to 10 km/h. The materiality of this state limitation on my mobility became manifest during my interview with France Geoffroy. As soon as we started wheeling, I noticed that I could not keep

up with her. France got her wheelchair before the new regulation passed. Even though she is qualified to get a new wheelchair, she does not want to lose an important component of her mobility—her speed. During the interview, France wheeled more slowly so we could wheel side-by-side, which led to a discussion about these speed regulations, its discriminatory nature and its effects on our daily lives and mobility practices.

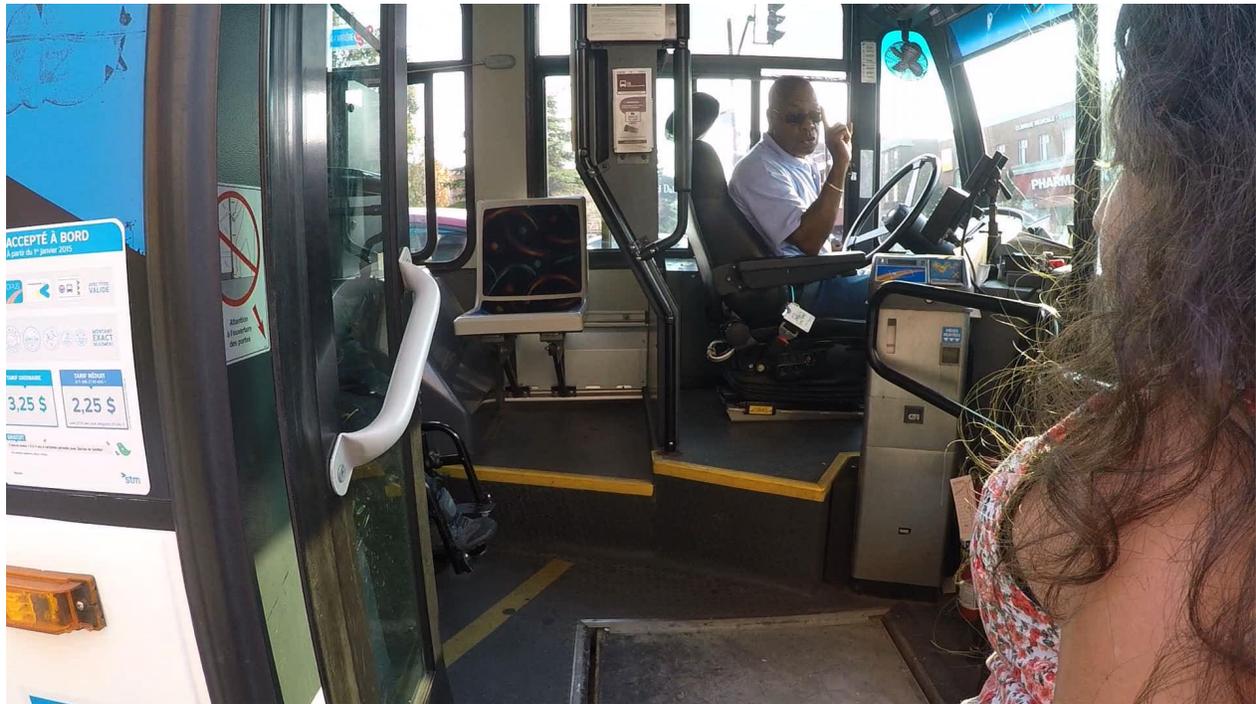
Kéven Breton and I faced another restriction compromising our ability to move together. Kéven chose to bring me on his route between his downtown workplace and his Villeray home. This consisted in wheeling, riding the subway and taking a bus. Kéven has to get off at Jean-Talon métro station and then board a bus because Jarry méro station, the nearest station to his home, is not wheelchair-accessible. As regular public transit users, we were aware that the Société de transport de Montréal does not allow two wheelchair users to share the reserved space and ride the same bus.<sup>7</sup> We also were aware that the enforcement of this rule depends on the driver. Some of them do not care or are not aware of it, while others are quick to enforce it. Riding the métro together is *just* a matter of coordinating our movements with other the movements of other subway users, and creating and taking the space we needed. Riding the bus means facing uncertainties and potentially having to argue with a bus driver.

Unsure about how things would unfold as the bus approached, Kéven and I agreed to meet at his destination if I was blocked from riding the bus with him. I would wheel to catch up. The bus driver activated the mechanism to deploy the ramp. Kéven got on and I followed him, both trying to make our entrance as normally as we could. Just when I was about to get on the bus, the driver stopped me and started lecturing (Figure 4). As a long-time activist for accessible public transit, I have encountered this situation before. This time felt differently. I was in the middle of an interview. I was working. I was in a researcher's state of mind. I suddenly had to embrace my two identities as a researcher/activist to keep the interview going. However, when trying to convince the driver to let me on, I was strangely at a loss for words. Kéven joined in the conversation and proposed a compromise that he had used before. He suggested transferring from his manual wheelchair to a regular seat. Technically, only one wheelchair user would then be riding the bus. The driver, visibly annoyed, did not have much choice but to let us on. He accused Kéven of being a troublemaker and told us to never do that again. This situation illustrates not

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<sup>7</sup> This is a rule established by the Société de l'assurance automobile du Québec (SAAQ). At the time of the interviews, 100% of the buses had only one reserved space.

only the effect of rules on our capacity to travel together but also how ableist regulations and infrastructures can limit a disabled researcher's ability to conduct fieldwork.



**Figure 4:** Laurence tries to get on the bus after Kéven. She is on the ramp at the door while the driver talks to her and raises a finger indicating that only one wheelchair user is allowed on the bus.

### *Conclusion*

In this chapter, I have offered a brief overview of the misconnections and reconnections between mobilities studies and critical disability studies. I have tried to reflect on the methodological journey that I took while conducting 23 wheeling interviews with disabled participants in Montréal and New York City. I have navigated multiple intersections, including street intersections, narrative intersections, identity intersections, and body and technology intersections. I have also argued that wheeling with a wheelchair—a way of moving that continues to be devalued in the twenty-first century—is a mobile practice that falls under the umbrella of walking practices. This claim destabilizes the apparent neutrality of walking.

While on our wheels and on our feet, the participants and I co-created a method in

response to the multiple barriers and difficulties that were—often literally—in our way. This method highlights our relational identities (Kafer, 2013), as well as the differences between different disabilities. It points to the ableist regulations affecting the everyday mobilities of disabled people in the city. Assembling the equipment and talking on the move were two critical performances of the wheeling interviews that pushed me to engage with the notion of affordances and reflect on the reproduction of ableism not only in mobilities research but also in data collection. Conducting and filming a mobile interview required us to think about a series of mundane gestures that are generally not problematized within mobilities research and filmmaking. The participants and I figured out which devices and arrangements would best suit our needs and abilities. The filming became a shared responsibility with the participants. Together, we crippled methods and filmmaking. By making my wheelchair an integral part of my creative practice, including my disabled body in the camera frame and exposing its interactions with the ableist landscape, I engaged with “crip aesthetics.” (Reid, 2016) Embracing disability and its “affordances of everyday life,” to borrow Dokumaci’s words, shed light on both what I had been taught to overcome and what I had learned to hide.

## Chapter 2

### Mutual Sightings: Situating Participants and the Oral History Interview

*August 19, 2015. While wheeling with Sandra Gualteri:*

*Sandra: Are you from here?*

*Laurence: I am from a small town, between Montréal and Québec City. Not very far from Victoriaville but I moved here 13 years ago. Just after finishing high school.*

*Sandra: Wow.*

*Laurence: So, I kind of feel I am from here now somehow.*

*Sandra: Was it accessible?*

*Laurence: Was it accessible there?*

*Sandra: Yeah.*

*Laurence: Well it was different 'cause it was the country.*

*Sandra: Yeah.*

*Laurence: I was living with my parents. The school bus was accessible.*

*Sandra: Yeah.*

*Laurence: The school was accessible. To shop, it's mostly in big shopping malls in the city. You have to drive. I was too young to drive at the time. So, it's really in Montréal that I have discovered obstacles because there, access was not really an issue.*

*After the wheeling interview with Sandra, I reflected on my life before being introduced to disability studies and disability rights about a decade ago. This interview, this PhD, this thesis, could have never happened.*

*I have been so busy and engrossed with my research and activism that I tend to forget that disability has not always been one of the main elements of my universe. At the time I was finishing high school, I was all set for a life in which I would be overcoming obstacles without really thinking about it. I had just been through elementary and high school only surrounded by able-bodied students and teachers. I was pretty good at fitting into the able-bodied world. I believed I could achieve anything I wanted.*

*I wanted to be a journalist in international politics and travel the world.*

*For years, none of my friends or acquaintances were disabled.*

*And I didn't care.*

*In fact, deep inside me, I probably thought I didn't need or even want disabled people in my life. I would have never imagined that disability would become my predominant field of interest and that my professional life would revolve around it. I didn't know that disability could be about something other than medicine and rehabilitation. I was ready for a life where disability would be the thing I would have nothing to do with except for annual medical check-ups. But things did not go that way. My life took a different turn. Somehow living in Montréal as a young disabled woman steered me away from my dream of one day saying on national television "C'était Laurence Parent pour Radio-Canada à Kaboul." Disability became a political issue and Montréal my battlefield. And living in the city, without being connected to other disabled people, is now unimaginable. Embracing disability both makes my life better and harder.*

—August 20, 2015

In the field of oral history, it is a common and necessary practice to pay particularly close

attention to the process surrounding the production and collection of stories and testimonies and to be reflective about this process. Mary Jo Maynes, Jennifer L. Pierce, and Barbara Laslett (2008) claim that “in conducting personal narrative research and in presenting its results, it is necessary to be transparent about both how the narratives were constructed or collected and how they were interpreted.” (pp. 124-125) “The interview context is essential to understanding what was recorded,” argues Steven High (2014, p. 126). Ben Rogaly and Kaveri Qureshi explain (2017) that oral history narratives “are told in relation to contemporary cultural norms and the specific location and atmosphere of the interview.” (p. 192) In this chapter, I aim to situate the wheeling interviews I conducted with 15 disabled Montrealers between August and November 2015 because their stories are at the very heart of my thesis. Personal narratives have been used and continue to be used to advance the rights of marginalized people around the world. Maynes, Pierce and Laslett (2008) explain that these “have provided counternarratives that dispute misleading generalizations or refute universal claims.” (p. 1) However, the complexities of the lives of people behind these stories are seldom explored. Kay Schaffer and Sidonie Smith claim that personal narratives are “rarely allowed to have space to reveal [their] own internal dynamics, especially in relation to the rest of the person’s life story.” (as quoted in High, 2014, p. 193)

In my thesis, I have chosen to embrace the subjectivities of my participants’ stories. Even though the Montréal disability rights movement regularly bases its demands on disabled people’s stories around particular issues (i.e., the need for better homecare support or accessible public transit), there is a scarcity of literature and stories that put disabled people’s lives at the forefront and embrace the subjectivities of their life experiences. In 2014, while I was in a meeting with the director of a disability rights organization and wearing the hat of the co-founder of the Facebook group *Transport mésadapté*, which serves as a space for disabled people to share their experiences in public transit, I was told that the stories shared on the Facebook group were not credible because they were “remplies de faussetés.” The director claimed that people were sharing incorrect information about public transit accessibility and *Transport adapté* services. This comment shook me and forced me to take a moment to reflect on the content of the stories that were published on a social media page for which I was co-responsible. While I was quickly reassured that these stories were not based on false claims but on people’s personal experiences and truths, the situation got me thinking about which stories get told and which are ignored because they are dismissed as “untrue.” Since then, my interest for disabled people’s own truths is even stronger. It largely explains why oral history is at the core of my thesis and why I decided

to build my research around disabled people's stories.

The participant profiles presented in this chapter aim to give a sense of the lives behind the stories, the uniqueness of each participant as well as how they are connected to each other. They comprise five key components: a short biography, information about the weather, the itinerary and the distance we wheeled/walked together, an excerpt of our discussions as well as a description of my relationship with the interviewee. These components explore individual (biography), environmental (itinerary, weather) and relational (quote from the interview, my relationship with the participant) dimensions that shaped the wheeling interviews and the stories told. It is the articulation of those dimensions that brings alive and recognizes the voices of the participants on which my thesis is based. One of the things that became very clear throughout the wheeling interviews was how my method and the questions I asked the participants changed from one interview to the next. The questions asked and the paths taken during our conversations were influenced by previous interviews. As a result of the importance of the moment in the research process that the interviews took place, I arranged the profiles chronologically. During the interviews, I would often remember something someone had said in a prior interview and explore that path or issue with the participant I was talking with. It allowed me to more deeply explore some issues deeper with the participants I met near the end and to think about similarities and differences between their experiences. On pages 59 and 60, I explain how a discussion on the "dimension politique du handicap" with Louise Blouin allowed me to address the same issue with following participants and to put their perspectives in conversation. The profiles also include a short description of the weather on the day of each interview since the meteorological conditions had an impact on the interviews themselves. For example, in August, I conducted interviews on four days in a row during a heat wave. I remember being physically exhausted and emotionally drained. The wheeling interview with Sandra, notably, was shortened significantly because I could not handle the scorching heat. We found refuge in an air-conditioned McDonald's where most of the interview ended up taking place. In short, the order of the interviews as well as the weather conditions the interviewees and I faced are highlighted in these profiles because they contribute to the shaping of the interviews.

At the time of the interviews, the median age of the participants was 36.5 years old. The youngest participant was 35 years old and the oldest was 55. Six participants were in their thirties, four in their forties, two in their twenties and two in their fifties. I wheeled with ten

women and four men. All of them have physical disabilities affecting their ability to walk except for one participant who is blind. Nine of them were born and raised in Montréal and its suburbs and four of them are from other Québec regions (including Abitibi, Beauce, Centre-du-Québec and Saguenay–Lac-Saint-Jean) and moved to Montréal as young adults. Nabila Nouara was born in Algeria. In addition to being the only participant born outside Canada, she was also the only racialized participant.

Thirteen speak French at home and one speaks English. They all live outside of institutional contexts and seven of them have home support services to enable them to live independently. However, at least three of them expressed not having all of their needs met by those services. Of the 31 participants, eight participants share their lives with their respective partners; they are all in heterosexual relationships. Caroline Goyette and Nabila Nouara are mothers of minors. The group of participants is particularly well educated since 12 of them have at least one post-secondary diploma. In terms of occupation, eight of them have a full-time or part-time job, five are unemployed and one participant is a full-time graduate student. This employment rate is much higher than the rate of employment within the disability community in general,<sup>8</sup> which suggests that many of the participants were in a better financial situation than most disabled people.

All participants are or have been active in at least one disability organization located in Montréal. Some participants have occupied administrative or leadership roles while others have limited their participation to being members or supporters.<sup>9</sup> Even though most participants do not identify themselves as disability activists, all of them are interested in disability issues. Many of them are or have been members of the same organizations and groups, which is likely the reason why they know each other. It is interesting to note that Sandra Gualteri, the only English-

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<sup>8</sup> In 2006, 40% of disabled people between the ages of 15 to 64 were out of the labour force (versus 73% of non-disabled people of the same age bracket) (Institut de la Statistique du Québec, 2010, p. 206). Furthermore, 45.9% of disabled people earned less than \$15,000 a year compared to 34% of people without disabilities; 41% of non-disabled people earned at least \$30,000, while only 21% of disabled people earned a similar annual income (*Ibid.*, p. 100).

<sup>9</sup> In Chapter 3, I provide a short overview of the Québec disability rights movements to give a larger historical and political context to the many issues explored throughout my thesis and to introduce the many disability organizations to which I refer. This brief look at the movement also helps to explain the activist context in which participants found themselves at the time of the interviews. A glossary with short descriptions of disability rights organizations and groups that the participants and I are or have been involved with is available in Appendix C.

speaking participant, is the person who has the fewest connections with other participants, which seems to indicate the presence of a language divide within the Montréal disability community.<sup>10</sup> This situation resonates with Elspeth Probyn's description of the Montréal lesbian community: "Linguistic nationalist politics habitually enter into all corners of the city, and class geography now overlaps with a gay one. [...] Anglo and Franco lesbians seem to rarely meet." (1996, p. 69) All participants live on the island of Montréal in eight high-density neighbourhoods. With the exception of Caroline, who lives in Pointe-aux-Trembles, participants live in what are considered to be central boroughs, which are more likely to be well-served by public transit and have better infrastructure for pedestrians. The participants and I ended up wheeling through ten different boroughs as well as the Town of Mount Royal. The average distance of each wheeling interview was 8.42 kilometres, for a total of 126.32 kilometres. The distances varied greatly. For example, Laurence and I walked and wheeled 2.59 kilometres while Christian and I wheeled 21.21 kilometres.<sup>11</sup> In addition to the weather conditions, various factors influenced the length of our route such as the ability to walk/wheel long distances, the type of mobility aids used and the areas the participants wanted to go.

### *The subjectivities of everyday life*

In his essay "What makes oral history different?", Alessandro Portelli (1991) argues that subjectivity is not the weakness of oral history but its strength, that subjectivity is the oxygen of oral history. "Oral sources tell us not just what people did, but what they wanted to do, what they believed they were doing, and what they now think they did," (*Ibid.*) explains Portelli. By embracing the subjectivities of participants' stories, I am, at the same time, recognizing that the knowledge we produced during the wheeling interview is situated. Maynes, Pierce and Laslett remind us that "knowledge is always produced from a specific social location and always aimed toward a specific audience and audiences." (p. 98) In other words, the people I have interviewed are not abstract people but embodied social beings living in a specific historical and cultural context. The value of their stories is located in their subjectivities and multiple positionalities. Furthermore, their stories do not just tell us about their personal lives but also about the society

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<sup>10</sup> Most organizations listed in my thesis (see Appendix C) conduct their activities exclusively or mainly in French.

<sup>11</sup> In addition to wheeling, we also took a bus and the métro between Henri-Bourassa and Jean-Talon stations.

they live in, and in this case more specifically about the city they move through. Maynes, Pierce and Laslett state that:

the value of personal narrative analysis lies in their potential to see people and their actions as both individual and social, and to understand human lives as governed simultaneously according to the dynamics and temporalities of the individual life course and of collective histories.” (p. 69)

In the wheeling interviews, the participants and I have navigated between present, more or less recent past and childhood memories. Maynes, Pierce and Laslett argue that “personal narrative analysis does allow for the possibility of understanding agency and its motivations as it operates and changes through time.” (p. 35) The exploration of various periods of participants’ lives varied from one participant to another and generally was linked to their first memories of moving in the world while disabled. Pierre, for example, has vivid memories of playing in the forest while using his motorized wheelchair as a young child and explained how his wheelchair had always been part of his everyday life. France, on the hand, talks about how she learned to get around Montréal using a wheelchair after her accident when she was 17. The participants’ relationship with disability identity as well as their interest in disability activism have been discussed to see how these changed over time.

One of the main topics in the field of oral history is the relationship between the interviewees and the interviewers. Maynes, Pierce and Laslett write that “careful attention to this relationship is important because it inevitably shapes the form and content of personal narratives and their analysis.” (p. 99) For Portelli, “an interview is an exchange between two subjects: literally a mutual sighting. One party cannot really see the other unless the other can see him or her in turn. The two interacting subjects cannot act together unless some kind of mutuality is established.” (quoted in Maynes, Pierce and Laslett, p.120) In his book, *The Battle of Valle Giulia: Oral History and the Art of Dialogue* (1997), Portelli uses the term “dialogical encounter.” In other words, as an interviewer, I participate in the creation of stories shared by the participants. Those stories are, as argued by Maynes, Pierce and Laslett, “joint productions.” (p. 100) The subjectivities of the interviewees and my own subjectivity meet and form new narratives. Considering the importance of these “mutual sightings” to the production of oral history sources, it is of foremost importance to be transparent about my relationships with each participant. This is why every participant’s bio is followed by a short description of my relationship with them.

In the past decade, I have met many disabled Montrealers through my activism in the disability movement. Since I already knew many disabled people in the city, I decided not to put out a call for participants and to reach out to people I knew that could contribute to my research by email or Facebook messenger. This decision, which happened long before conducting the first interviews, had a tremendous impact on my research. I made a choice to meet people that were already part of my activist and friendship worlds and who spoke either French or English.<sup>12</sup> I first hesitated as to whether or not I should only conduct interviews with people using mobility aids, such as manual and electric wheelchairs and scooters. I decided to also interview Laurence and Luc who, respectively, use a service dog and a white cane in order to get a broader view of the complexity of mobility experiences in the disability community. I was interested in meeting people who wheel or walk a lot in the city or wish they could do so more easily and who have different experiences and perspectives on mobility. It was also one of my priorities to meet with people living in different neighbourhoods. I wanted to avoid wheeling only in the neighbourhoods I am very familiar with such as Rosemont–Petite-Patrie and Plateau Mont-Royal.

Among the 15 persons who agreed to be interviewed, most are members of the Montréal disability community. However, while I have known them through this community for a number of years only a few of them are close friends. This means that my knowledge about their life stories and their personal lives varied greatly from one participant to another. My pre-existing friendships with some participants definitely had an impact on the discussions and how comfortable I felt asking some questions since I knew what issues could be sensitive and what would lead to interesting conversations. Since I already knew all of the participants and my position as a disabled person and disabled activist was clear to all of them, it helped to establish trust from the outset (Tillmann-Healy, 2003). However, my position posed some challenges. Steven High (2014) explains that “the dynamics of an interview are much more complicated than simply community insiders versus community outsiders. Age, gender, ethnicity, language, and generation all played a part in the interview space.” (p. 49) In the case of this project, Montréal

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<sup>12</sup> I know a few amazing Deaf activists and scholars who communicate in either *langue des signes québécoise* (LSQ) and American sign language (ASL). However, I did not interview anyone that communicates in these languages because they identify as Deaf, not disabled. Secondly, I must acknowledge that I am unable to communicate in *langue des signes québécoise* (LSQ) and American sign language (ASL) and, as a hearing person, my knowledge about deaf culture is quite limited.

disability politics as well as my position as a critical disability studies researcher, complicated the category of “community insiders,” which I shared with the participants.

Prior to the interview, all participants were quite familiar with my activism. Most of them had read open letters I wrote, attended disability activism events I co-organized and seen the volume disability-related content I put on social media. They were aware that I had been one of the leading figures of the Regroupement des activistes pour l’inclusion au Québec (RAPLIQ), an organization that is very active and controversial within the Montréal disability rights movement. I knew that some of them might have reservations about RAPLIQ and, by the same token, my own politics. Likewise, I personally had some reservations about some of the organizations to which some participants belong. Furthermore, since I had quit RAPLIQ in difficult circumstances, talking about RAPLIQ can sometimes be tricky for me. In the eyes of many, I am still seen as one of the greatest supporters of RAPLIQ, and sometimes an active leader, even if I have been in disagreement with some of RAPLIQ’s actions and approaches since I quit. I generally chose not to share my disagreements publicly or with people I am not close to, because I believed it would do more harm than good. “Community insiders may not wish to pose difficult questions or to hear discomfoting “truths,” writes Steven High (2004, p. 29). This was something I navigated throughout the interviews. Even though I tried to set my own politics and ideas about certain disability organizations aside, it is clear that these are some sensitive topics and debates I chose to avoid.

As an activist and a researcher, I was obviously very interested in talking about what I would call in Anglophone academic language “the various manifestations of ableism in the everyday.” However, as a Francophone who is very much aware of the language used within the Montréal Francophone community and the ideas that circulate about disability in that context, I knew that I had to use different words. At the time of the interview, the term “capacitisme,” a French equivalent of “ableism,” was not used in the Montréal community. I was still in the process of finding the best term to talk about ableism in French in Québec (Parent, 2017). Moreover, as much as I can feel like an insider of the Montréal disability rights movement, I can also feel like an outsider. As I explained in the thesis introduction, most of my critical disability studies knowledge and disability activism and culture references are rooted outside of Montréal and the French-speaking community.

For most of the interviews, I had to find ways to approach “the various manifestations of ableism in the everyday” by using words that would be significant for the participants. As Carolyn Zaikowski (2006) argues, “just because someone doesn’t completely understand your words, doesn’t mean they aren’t as oppressed or revolutionary as you.” For example, at one point during my interview with Louise Blouin, who was involved in various disability organizations for many years, I asked her “Quand as-tu découvert la dimension politique [du handicap]?”. To my great surprise, she replied that she still had not discovered it:

Moi, je n’ai pas découvert la dimension politique encore. Puis, je te dirais que je suis beaucoup moins impliquée si je me compare à toi et à de personnes comme Deborah. Moi c’est un accident si je suis impliquée. [...] Tu es une militante beaucoup plus que moi je dirais Laurence. [...] Je sais pas si tu vas te rendre compte. Je te dirais que je suis plus une bénévole qu’une militante.

This moment was striking. It points to the fact that even though we speak the same language, the words that we used do not have the same meaning and we have different understandings of disability and activism. Furthermore, Louise insisted on a difference between us: she saw me as being more “militante” than her. Her statement destabilized me and I said, as I was trying to find the best way to explore what she had just claimed, “c’est comme ça que tu te sens?”. Her response was fascinating because this is when she made the most politically charged statement in our interview. After confiding that she did not like to be in a position of leadership<sup>13</sup> in the movement, she explained that she felt that the younger generation, my generation, seemed to think that some battles were over but that they will never be over. “Il y a des batailles qu’on perçoit comme gagnées, mais c’est juste une perception,” she asserted. “À quoi tu penses?”, I asked her. “Comme on pense que l’accès à l’université ça va de soi, mais je pense que c’est fragile pis si on baisse les bras, on peut perdre,” she replied. I then tried to come back to my initial question by explaining that by “dimension politique du handicap,” I meant that disability issues are not individual issues but societal issues. She immediately agreed with that point. Reflecting back on what happened, Louise’s initial response were elicited by the words that I had used and the difference she perceived regarding our involvement in the movement. She saw me as a leader, which I have indeed been, while she did not feel comfortable being put in that position.

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<sup>13</sup> She was Action des femmes handicapées de Montréal (AFHM) president at the time of the interview. It sounded like she was not there by choice but because the organization needed her in a difficult time.

In the interview three days later with Laurence P. Rousseau, I tried a different approach to explore the “dimension politique du handicap.” I explained to Laurence the misunderstanding I had with Louise and I asked her when she started to be aware of different disability issues. She explained that it was when she got a job at the Association québécoise des étudiants ayant des incapacités au post-secondaire (AQEIPS) and that she learned that many disabled students did not get the accommodations they should be able to access. She said:

J’ai réalisé qu’il y a des enjeux, mais je te dirais, que moi le mot politique me dérange parce que moi j’ai l’impression que je fais cette job-là pour les étudiants. C’est pour eux que je fais ça. C’est pas pour la classe politique. Donc, pour moi, il y a une dimension qui est politique, mais pas tant que ça. Je ne le vois pas comme ça.

Once again, the participant and I belong to the same disability rights movement yet we did not share the same understanding of the concept of “politique.” Maynes, Pierce and Laslett raise questions relevant to the situation that I faced. They ask “To what extent do analysts share with life story narrators an understanding of concepts and categories? Or, are analysts imposing categories that don’t make sense to narrators? When and how does this matter?”. (p. 115) One solution proposed by these scholars is for the researcher to be open to revision. They explain:

[It does not] mean that analysts must always agree with narrator’ interpretations of their own lives. Where there is disagreement, we are suggesting, analysts are responsible for acknowledging it, for explaining why they chose one interpretation over another, and, to whatever extent is possible, for querying their own analytic categories vis-à-vis the terms in which narrators relate their own histories. (p.116)

Since I am writing my thesis in English and 14 of the 15 wheeling interviews have been conducted in French, the issue of interpretation that Maynes, Pierce and Laslett mention is even more complicated. Working in two languages involves an additional layer of interpretation since translation is an interpretative act. Meaning risks getting lost in the translation process. I have decided to keep Francophone participants quotes in French in the hope of not losing anything in the translation process. However, I have done some translation because my analysis is written in English. Words used to talk about disability, in particular, are challenging to translate. As a Francophone working in both French and English, I am well aware of the great differences between these languages and linguistic communities. While the terms “handicap,” “personne handicapée” and “personne en situation de handicap” are generally used by most Francophones, myself included, most Anglophones cringe at the use of “handicap” and “handicapped person.” Anglophones unfamiliar with the Francophone disability community in Québec may be puzzled

when reading participants' quotes in which they use the word "handicap." Furthermore, the words used in English to talk about disability are subject to debate.<sup>14</sup> In my work, I generally use the terms "disability" and "disabled people" following the practices of many disability activists in Canada, United States and United Kingdom. The lack of consensus around this terminology became manifest in an exchange with one participant many months after the interviews. I wrote a journal article in English about the wheeling interview as a mobile method and I emailed it to the participants. After reading the article, Sandra Gualteri emailed me to congratulate me and to suggest that I include at least one sentence about the word "disability" in my upcoming publications. She noted that I use the term "disabled people" while this term is disliked by people who prefer people-first language. "Just by having the 'dis' in front of 'ability' has negative connotation," she wrote. She added:

There's no correct word that the disabled population can agree on. I can't say I do have a preferred word. The word disability never really bothered me. The word that I really dislike and cringe when I hear is "crippled" and "handicap."

I welcome her suggestion and I carry it with me as I write this thesis.<sup>15</sup> This exchange reminds me of something Louise told me during our interview: "C'est un autre problème le vocabulaire. Qu'est-ce qu'on dit? Limitation fonctionnelle? En situation de handicap? Tu vois, d'emblée, j'ai dit handicapée. Ça doit être ça ma réalité." I asked her if she had a preference for a term in particular, and she replied, "J'aime beaucoup en situation de handicap. Ça ramène aussi à l'environnement, mais j'ai un peu de la misère avec tout ça. Cette évolution qui change tout le temps. Je trouve qu'on finit par mélanger la population." Unlike Louise, I am not a big fan of the term "en situation de handicap." To me, it sounds like another attempt to separate the person from disability. I consider disability as a part of my identity. Here, I must acknowledge that as the researcher and the writer of this thesis, I have a lot of power over the analysis of the wheeling interviews, on the language I use, on the translation process and the "final product."

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<sup>14</sup> "What we call ourselves can also be controversial. Different constituencies have vibrant debates about the politics of self-naming. 'People first' language asserts that if we call ourselves 'people with disabilities,' we put our humanity first and consider our impairment a modification. Others claim disability pride by getting our identity right up front, making us 'disabled people.' Others, like many sign language users, reject the term 'disability'," writes Rosemarie Garland-Thomson (2016).

<sup>15</sup> Many disability activists and scholars, myself included, prefer to use the term "disabled people," and argue that disability does not mean inability (Brown, 2016; Carter-Long, 2015; Egan, 2012).

The participants and I share different positionalities and motivations in these “mutual sightings.” Maynes, Pierce and Laslett argue that “inequalities in status and power between the analyst and the storyteller complicate the research situation even further.” (p. 121) While I obviously care very much about the fight for disabled people’s rights, my main objectives with this research are to write a thesis and get a PhD. For their part, participants all have expressed support for my academic endeavour and interest in sharing their stories to contribute to the elimination of obstacles and disability discrimination in the city. However, their participation in this project will not have the same benefits in their lives as it will have in mine. Furthermore, since my group of participants does not reflect the diversity of the Montréal disability communities, including in terms of class, race and sexual orientation, the stories and the interview content reflect this situation. I, myself, move in the world with multiple privileges. I have ability privileges in terms of speech, hearing, sight and cognitive capacities. I am a white, middle-class, cisgender woman. In the interviews with the 14 white participants, for example, we did not talk about racism. The white participants and I had the privilege to navigate the city without the fear of discrimination based on our race or national origins. We had never experienced racism. The only person I talked to about racism was Nabila, the only racialized participant. This highlights how I found myself adjusting my approach and questions through the negotiations of our different positionalities and intersectional identities.

At the same time, I tried to leave as much space as possible to the participants to allow them to show me the paths that they wanted to take and the issues that they wanted to talk about. Steven High (2014) writes that “interviews should be a space of dialogue, a shared journey upon which, whenever possible, the conversation is interviewee-led.” (p. 42) This does not come without challenges. Maynes, Pierce and Laslett highlight the importance of acknowledging “the limits of what can be known through any particular research relationship—and indeed becomes part of the knowledge produced through intersubjective research.” (p. 102) High (n.d.) shares his thoughts about the “ideal location for the historical researcher”: “Each location leads to a different kind of conversation—not better, not worse: just different. There is methodological strength in this kind of diversity.” Keeping that in mind, I believe that, despite the limits of the diversity of my group of participants from an intersectional perspective,<sup>16</sup> the following profiles show that the stories presented in my thesis come from a variety of locations and offer the

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<sup>16</sup> The concept of intersectionality developed by Kimberlé Crenshaw (1991) helps to comprehend how different systems of oppression intersect.

opportunity to look at Montréal from multiple vantage points—multiple sightings. As mentioned at the beginning of this chapter, these profiles contextualize the stories shared in my thesis and introduce the 15 people without whom this research project would not exist.

## *Participants' profiles*

### **Geneviève Vanier**

34 years old

Has been living in Montréal since: 2002



Date of the interview: August 9, 2015

Weather: Cloudy. 25 °C

Distance travelled during the interview: 9.13 km

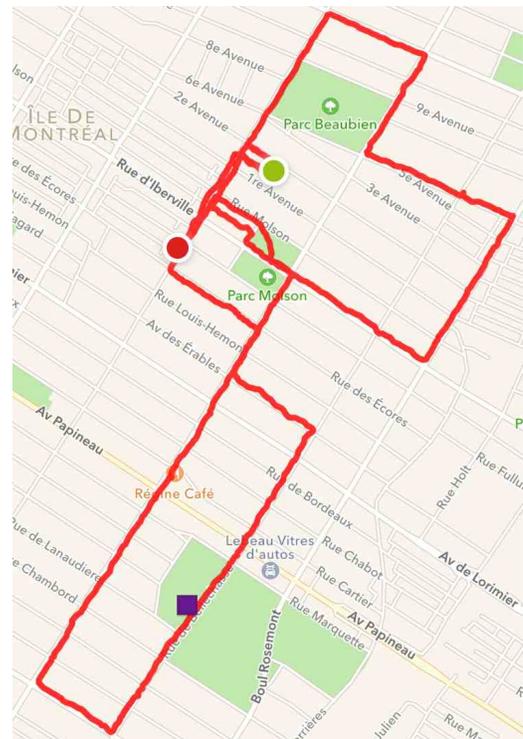
Total distance I travelled: 12.13 km

We wheeled around: Rosemont–Petite-Patrie (enlarged map in Appendix A)

While wheeling with Geneviève...

on Bellechasse street in Rosemont–Petite-Patrie (purple rectangle)

Geneviève : Quand on est à l'étranger, on disait toujours qu'on vient de Montréal. "D'où tu viens?" "De Montréal!" T'es contente de venir d'une ville francophone en Amérique sauf que d'un autre côté, je pensais à ça avec David l'autre fois... Il y a plein de bouts de Montréal que je ne connais pas parce que je me déplace pas tant que ça. On se déplace en auto. Ce n'est vraiment pas la même chose. Tu traverses vite pis tu crées pas de liens quand tu rentres pas dans les places. Tu t'en vas à une place pis c'est ça. Il y a plein de places que je suis jamais allée, que je suis jamais rentrée, que je sais pas c'est où. Quand les gens, les étudiants étrangers à l'université te demandent "c'est où le métro?". Tsé, je ne suis même pas sûre de savoir il est où. Je sais qu'il y en a un, mais tu es mieux de regarder sur Google. Je ne peux pas bien t'orienter. [rires] Je ne sais pas où il est. ([see video Vanier-3](#))



Geneviève Vanier grew up in Montréal's South Shore. She has a brother with the same medical diagnosis. At one time in her life Geneviève used a mobility scooter to go to school however, she started using a manual wheelchair when she was twelve years old. In 2002, Geneviève moved to Montréal to study mechanical engineering at Polytechnique. She completed a master's in environmental engineering in 2011 at École de technologie supérieure de Montréal. Geneviève's studies brought her to travel overseas. She discovered that physical accessibility to public places and public transit varies from one city to another, as do perceptions towards disabled people. For example, getting around Valencia (Spain) turned out to be quite easy because the public transportation infrastructure was wheelchair-accessible. When she was a student in Montréal, Geneviève relied mostly on Transport adapté to get around the city. She realized that her mobility was severely restricted. Shortly after graduating from Polytechnique, Geneviève bought a car to be more independent. Since then, her car is her principal mode of transportation. Geneviève has been actively involved in the Association québécoise des étudiants ayant des incapacités au post-secondaire (AQEIPS) for five years and served as the president for three of those years. She advocated for inclusive education in post-secondary institutions across Québec. Geneviève now works full-time as an engineer for the Ville de Montréal. She lives in Rosemont–Petite-Patrie in a home she bought with her boyfriend David three years ago. They are expecting their first child in 2017.

Geneviève and I:

I met Geneviève at a job fair for disabled students organized by Comité d'adaptation de la main d'oeuvre (CAMO) pour personnes handicapées, a non-profit organization that had the mandate to connect disabled job-seekers with employers in various sectors.<sup>17</sup> At the time, we were both in our early 20s and were just starting to get involved in disability issues. I can't remember why we were there since we were not looking for jobs. We may have been there to represent disability organizations. We exchanged our email addresses and kept contact, mostly via MSN Messenger. At the time we met, she was one of the only disabled people of my age I knew. In 2009, Geneviève visited me in Toronto and attended the Critical Disability Studies' Association conference. When I moved back to Montréal a few months later, I joined the AQEIPS board as vice-president of external affairs while Geneviève was the president. During the student strike in 2012, we worked together to mobilize disabled students. We organized one contingent of

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<sup>17</sup> CAMO was forced to close its doors in June 2016 after its funding was cut (Allard, 2016).

disabled students and took part in at least one of the large demonstrations on the streets of Montréal. In 2014, I interviewed her about her voting experience in the provincial election. Her polling station was not wheelchair-accessible. With my colleagues at Concordia we made a short video featuring Geneviève's story. Geneviève and I mostly keep touch via Facebook. She is a member of the group Transport mésadapté.

Connections to other participants:

Facebook friends: All participants for the exception of Nabila  
Involved in AQEIPS at the same time as Marie-Eve Veilleux

**Pierre Lemay**

32 years old

Has been living in Montréal since: 2006



Date of the interview: August 13, 2015

Weather: Cloudy. 22.4 °C

Distance travelled during the interview: 6.52 km

Total distance I travelled: 13.32 km

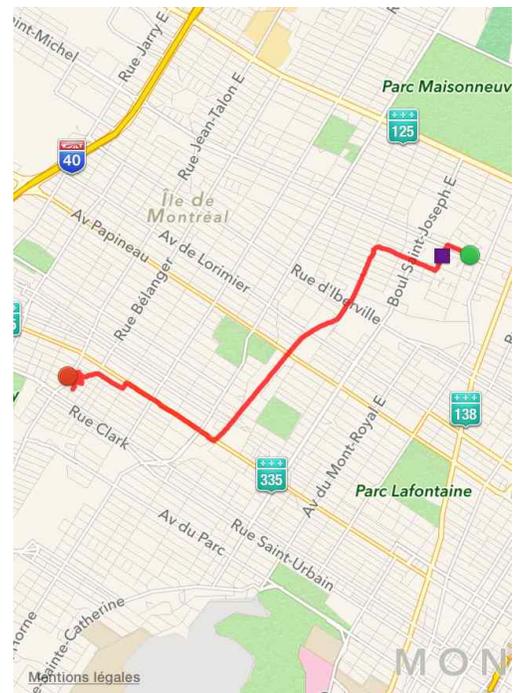
We wheeled around: Rosemont–Petite-Patrie (enlarged map in Appendix A)

While wheeling with Pierre...

on boulevard Saint-Michel in Rosemont–Petite-Patrie (purple rectangle)

Pierre : On restait proche de cousins et cousines dont on était très proches. Tsé ils avaient le même âge que nous pis tout ça. Même avec les quelques autres amis dans le quartier, on a tout fait. Tsé on jouait au hockey comme on le pouvait avec notre bâton. On tirait un bâton. On jouait avec des fusils à pétard. Ça c'était probablement ce qu'on préférait. On était vraiment des petits gars de fusils à pétard donc. [rires] On a joué amplement. Se promener, faire des camps dans les bois. Nous autres on prenait un râteau pis on raclait les chemins tsé en tirant le râteau avec notre chaise. Pis les autres, ils faisaient les murs, des petites cabanes.

Pierre was born and raised in the 1980s in a rural area near Drummondville, a city located about 100 kilometres north-east of Montréal. He shares the same medical



diagnosis as his brother Michel who is two years younger. They both began using motorized mobility devices as preschoolers. Pierre got his first power wheelchair when he started kindergarten. In Drummondville, they were mostly driven around by their parents who have an adapted car, since public transit is not very developed in the rural areas of Québec. Pierre moved away from Drummondville after CÉGEP to study economics at Université de Sherbrooke. From 2003 to 2009, Pierre was involved in the disability organization Association des personnes handicapées de Drummond. In Sherbrooke, he lived in a house where he had the support to live independently. In 2006, he moved to Montréal, which was where he had always wanted to live. While a graduate student at École des sciences de la gestion of UQÀM and then at École nationale d'administration publique, Pierre lived in student housing located downtown. Through a homecare support program, he hired attendants to enable him to live independently. In addition to being a student, Pierre got involved in Comité pour les droits humains en Amérique latine and the Forum social québécois. He remembers that he and his colleagues did not know much about disability rights, but they did what they thought was best for the community. In 2009, he moved with his brother into an apartment located in Rosemont. Pierre is now working full-time as an executive in a Centre intégré universitaire de santé et de services sociaux. In the past few years, he became more interested in disability issues. He is one of the co-founders of Québec accessible. As one of the organizers of the Montréal edition of the World Social Forum, which took place in Montréal in August 2016, he worked, along with his girlfriend Marie-Eve, on bringing accessibility issues to the attention of the World Social Forum organizing committee. At the time of the interview, Pierre was looking forward to moving into a new condo he bought with his brother in the same neighbourhood. In June 2016, he moved in with Michel and Marie-Eve.

Pierre and I:

I met Pierre when he became a member of RAPLIQ, a disability rights organization I co-founded in 2009. We became friends through our great online conversations. We enjoy talking about disability rights and politics. We have many things in common that have influenced our life courses as disabled people: we are only one year apart in age, come from the same region, have great support from our parents, have never been in a difficult financial situation, have used power wheelchairs for many years, have completed post-secondary studies without facing many difficulties and need homecare support to live independently. We are both co-founders of Québec accessible, which advocates for stronger accessibility legislation in Québec. During my stay in

New York, Pierre visited me with his girlfriend Marie-Eve (I introduced them!). Pierre has shown great interest in my doctoral project from its beginning. We both share a love for public transit, especially underground networks.

Connections to other participants:

In a relationship with Marie-Eve Veilleux

Facebook friends: Caroline, France, Geneviève, Isabelle, Kéven, Laurence, Marie-Eve and Marie-Josée

## Isabelle Boisvert

33 years old

Has been living in Montréal since: birth

Date of the interview: August 17, 2015

Weather: Sunny and hot. 31 °C (felt like 38 °C). We met at the end of the afternoon and it was a bit windy.

Distance travelled during the interview: 18.86 km

Total distance I travelled: 37.6 km

In addition to wheeling we also took: the bus

We wheeled around: Ville-Marie and Ile des Soeurs (enlarged map in Appendix A)



While wheeling with Isabelle...

in a park nearby her apartment on Ile des Sœurs (purple rectangle)

Laurence : Est-ce que tu te souviens c'est à quel moment que tu as commencé à être plus consciente, plus conscientisée par rapport à l'accessibilité?

Isabelle: Par rapport à l'accessibilité, je l'ai tout le temps été, je pense. Toujours, mais un peu plus dans le sens de « faut faire avec ». C'est quand je suis vraiment devenue une militante là j'ai comme fait « woah là! On a le droit de revendiquer une place » pis ça a été un changement de mentalité.

Laurence: Qui s'est fait comment ? Avec certaines personnes?

Isabelle: C'est vraiment avec AFHM que j'ai découvert plein d'affaires comme le féminisme. Oui, c'est vraiment par le féminisme que je me suis dit « bon ça me correspond ». Je l'étais avant. J'étais féministe sans connaître c'est quoi le féminisme



d'aujourd'hui, des jeunes d'aujourd'hui. Puis à partir de là, j'étais plus militante. J'étais dans l'idéologie de revendiquer. C'est sûr que je suis très douce. Je suis moins du genre à me pitcher contre les murs et aller bloquer toutes les portes. Je suis moins de ce genre là. Comme là mon doctorat est purement féministe sur les violences particulières aux femmes handicapées. Mon doctorat me permet de revendiquer, mais c'est une autre sorte de revendication. C'est plus ça que je suis.

Isabelle has always been a Montrealer. She lived the first years of her life in Villeray. Her family moved to Rosemont when she was a teenager. She remembers living only a couple of blocks from Masson Street where she would go for strolls and ice cream with her family. Isabelle was born with cerebral palsy and is the only disabled child in her family. She used both a manual wheelchair and a walker through her childhood. She attended a specialized elementary school. She later transitioned to a regular high school. Even though Isabelle faced many obstacles from a young age, she thought she simply had to deal with them. She became an advocate when she discovered feminism through Action des femmes handicapées de Montréal (AFHM). She recognized herself in those ideas and values and felt like she had the right to advocate for disabled women's rights without necessarily taking part in direct action. Isabelle contributes to the disabled women's rights movement through her involvement with AFHM, the Fédération québécoise des planifications des naissances and the Fédération des femmes du Québec. She is currently working on her PhD in community psychology at Université du Québec à Montréal (UQÀM). Her research investigates different forms of violence against disabled women. She has been living on Île des Sœurs with her mother for a decade now. When we met, she was also living part-time in her boyfriend's apartment, which is in the same building.

Isabelle and I:

Isabelle and I are about the same age. We were undergraduate students at UQÀM at the same time prior to our involvement in the disability rights movement. I remember seeing Isabelle regularly at the Office for Students with Disabilities where I would go because they provided access to a computer and a locker. We never spoke to each other and barely acknowledged each other's existence except for making some eye contact and offering each other timid smiles. We met a few years later at AFHM and finally talked to each other. I interviewed Isabelle for a documentary I made for the 25<sup>th</sup> anniversary of AFHM. Isabelle is one of the few disabled women of my generation I know who proudly identifies as feminist. This is why I wanted to wheel with her.

Connections to other participants:

Facebook friends: All participants except Nabila and Marie-Josée



Jacynthe : Ta propre carte de Montréal, ouais! Dans un cours à un moment donné en créativité dans ma première session, la prof disait « essayez juste pour le fun de changer vos habitudes et de prendre des chemins différents pour venir au cours ». J'ai essayé puis à un moment donné j'ai fait « non, j'ai définitivement le meilleur chemin et c'est ça que je vais faire ». Les autres chemins que j'ai essayé d'emprunter... Il y a des raisons. Le trottoir est scrap, le coin est plus difficile, il y a des vidanges tout le temps. Il y a des raisons qui font que tu adoptes un chemin tsé. C'est l'efficacité d'abord.

**Sandra Gualteri**

47 years old

Has been living in Montréal since: birth



Date of the interview: August 19, 2015

Weather: Sunny and very, very hot. 31 °C (felt like 39 °C). We were forced to stop at McDonald's, the only wheelchair-accessible place nearby, to cool down. I found this interview particularly difficult because of the extreme heat.

Distance travelled during the interview: 3.09 km

Total distance I travelled: 21.71 km

We wheeled in: Notre-Dame-de-Grâce (enlarged map in Appendix A)

While wheeling with Sandra...

on a quiet street nearby her apartment in Notre-Dame-de-Grâce (purple rectangle)

Laurence: Do you go sometimes for walks just for fun?

Sandra: Oh yeah! But I wish the sidewalks were better.

Laurence: So, you don't have to think about the sidewalks all the time.

Sandra: Yeah.

Laurence: And what do you like about going for walks and strolls?

Sandra: Being out and doing what I need to do. Like everyone else.

[...]



people. However, there are many places Sandra cannot enter because they are not wheelchair-accessible. She admits that she would consider moving to a more accessible city such as Ottawa, which she likes and visits every year, but that she stays in Montréal because her family and friends are here. She now lives with her boyfriend Adam, who is also a power wheelchair user.

Sandra and I:

I met Sandra through one of her best friends while I was the vice-president of RAPLIQ. They wanted to file a complaint against VIA Rail. Sandra and I met at Jean-Talon market to talk about it. She wanted to challenge VIA Rail because it can accommodate only one power wheelchair user per train. For Sandra it means that she couldn't travel with her boyfriend between Montréal and Ottawa. Sandra ended up sending a letter to the Canadian Agency of Transport only to receive a disappointing letter. Unfortunately, I have not followed up on this issue. Even though I left RAPLIQ, Sandra and I stayed in touch through Facebook. She is an active member of the Facebook group Transport mésadapté. She is one of its only English-speaking members.

Connections to other participants:

Facebook friend: Marie-Eve

**France Geoffroy**

42 years old

Has been living in Montréal since: she was 17 years old

Date of the interview: August 20, 2015

Weather: Sunny and hot. 30 °C (felt like 38 °C). Even though the weather was similar to the previous day, when I wheeled with Sandra, the heat felt less difficult to endure. I see two main explanations for this: we wheeled in areas where there were many trees, which made finding shade easy, and we wheeled faster, which produced a cool breeze.

Distance travelled during the interview: 4.5 km



Total distance I travelled: 10.7 km

We wheeled around: Plateau Mont-Royal (enlarged map in Appendix A)

While wheeling with France...

on a quiet street nearby her home in Plateau Mont-Royal (purple rectangle)

France : Il y a quelque chose de différent aussi qui a changé en moi. Au début de mon accident, je ne voulais pas me promener avec quelqu'un en fauteuil roulant. J'avais honte. Aujourd'hui là, je regarde ça puis je me dis « mon dieu que j'étais superficielle. J'étais handicapée et je jugeais les handicapés ».

Laurence : Ah oui, mais...

France : C'était terrible.

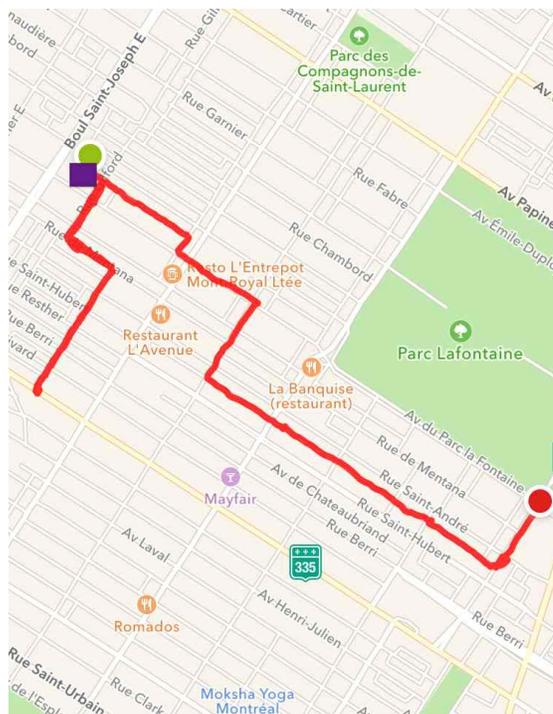
Laurence : Si ça peut te rassurer moi-même qui est née handicapée, mais j'étais dans un milieu non handicapé. J'étais la seule. J'avais pas...

France : On va tourner ici.

Laurence : J'avais pas de modèle pis moi aussi j'avais ces idées là. Moi je n'étais pas handicapée pis les handicapées... Tsé je n'avais pas d'amis handicapés. À l'université, il y avait le centre des étudiants handicapés où je devais aller des fois pis je parlais pas à personne.

[...]

France : J'ai commencé à avoir besoin de mon milieu pour exercer mon métier. Après ça, j'ai commencé à vouloir avoir d'autres handicapés sur scène. Il a fallu que je rencontre d'autres personnes. On dirait qu'au départ tu as honte de ton milieu, mais après ça tu te rends compte que d'être en contact avec des personnes handicapées c'est super enrichissant parce qu'elles te donnent des trucs. Elles te partagent leur vécu. Souvent, tu vis les mêmes angoisses, les mêmes interrogations donc je trouve ça super important. Aujourd'hui, je me fais un devoir. Mes cours sont super inclusifs. Fait que c'est ça, je me fais un devoir d'accepter le plus de monde possible.



France spent her childhood and teenage years in Laval. In 1991, at age 17, she hit her head at the bottom of a pool and became tetraplegic. With the help of rehabilitation professionals, family and friends, she moved to her first wheelchair-accessible apartment two years after her accident. The apartment was located on Plateau Mont-Royal in front the École de danse of UQÀM. At the time, France dreamed of performing there one day. France continued her studies and slowly learned to live an active life as a wheelchair user. She discovered the world of integrated dance and became a dancer herself. In 2000, after three internships with CandoCo, a famous integrated dance company based in London, France founded Corpuscule Danse, the first integrated dance company in Québec. Corpuscule Danse is now well-known in the contemporary dance scene in Québec. France's dream also became a reality—she teaches at École de Danse of UQÀM. She is a proud Plateau Mont-Royal resident who loves to wheel in her neighbourhood. She also owns a wheelchair-accessible van, which is driven by her attendants. She is in a heterosexual relationship but lives alone by choice.

France and I:

I met France through my good friend Marysol in 2006. Marysol was one of France's attendants. At that time, I did not know many disabled people using wheelchairs. I remember going to see one of France's shows with Marysol. France lent me her wheelchair-accessible van when my wheelchair broke in the middle of Plateau Mont-Royal once. When I co-founded RAPLIQ,

France became one of our first supporters. She gave a powerful speech at the first Journée de l'accessibilité organized on Mont-Royal Avenue in 2010, convincingly claiming that she wanted and needed to see real change in her neighbourhood. She explained that some of the only wheelchair-accessible stores had been renovated and became inaccessible. During the wheeling interview, we discovered that we shared the same love for one alley in particular. The alley is well paved and smooth. It allows us to wheel between Mont-Royal Avenue to Cherrier much faster than if we had to use the sidewalks. We wheeled there regularly but never ran into each other. We each had the feeling that it was “our” alley.

Connections to other participants:

Facebook friends: Geneviève, Isabelle, Louise and Laurence

**Marie-Josée Blais**

35 years old

Has been living in Montréal since: 2004

Date of the interview: August 27, 2015

Weather: Cloudy. 22 °C

Distance travelled during the interview: 6.19 km

Total distance I travelled: 19.99 km

We wheeled around: Côte-des-Neiges (enlarged map in Appendix A)



While wheeling with Marie-Josée...

on Côte-des-Neiges street, a few blocks from Université de Montréal (purple rectangle)

Laurence : Pour quelles raisons est-ce que tu as déménagé à Montréal?

Marie-Josée : Parce qu'il y a plus de liberté. En premier lieu, bon c'est sûr au début c'était pour les études. Mais quand j'ai vu que j'aimais vraiment ça de vivre à Montréal, qu'on pouvait aller à des endroits différents. Il y avait beaucoup d'activités. Il y avait beaucoup de services. Je voyais beaucoup de possibilités pour les personnes handicapées de vivre à Montréal. Tout ça pis des opportunités parce que vivre à la campagne, tu es dépendante à 100% de tes parents. Moi je ne peux pas conduire à cause de ma vision pis à la campagne, il n'y a rien à faire à part de rester dans la maison et écouter la télévision, internet. C'est pas vraiment un style de vie que je voulais avoir. Pis éventuellement peut-être me trouver un emploi à Montréal. J'avais travaillé aussi dans un emploi d'été. J'avais travaillé pour la Ville de Montréal, un emploi étudiant pis j'avais adoré l'expérience. Je me suis dit « bon des organismes communautaires il y en a beaucoup plus à Montréal ». Je voyais beaucoup plus de possibilités. C'est sûr qu'avec TA il y a des hauts et des bas et tout ça. Pis là éventuellement, je vais commencer à prendre l'autobus de la ville un peu par moi-même parce que j'ai souvent des rendez-vous à Lucie-Bruneau. C'est de choisir un trajet plus facile avec mes intervenantes et conjointement avec l'institut Nazareth-Louis-Braille. En fin de compte, c'est de travailler la confiance en soi parce que je n'avais pas beaucoup de confiance.

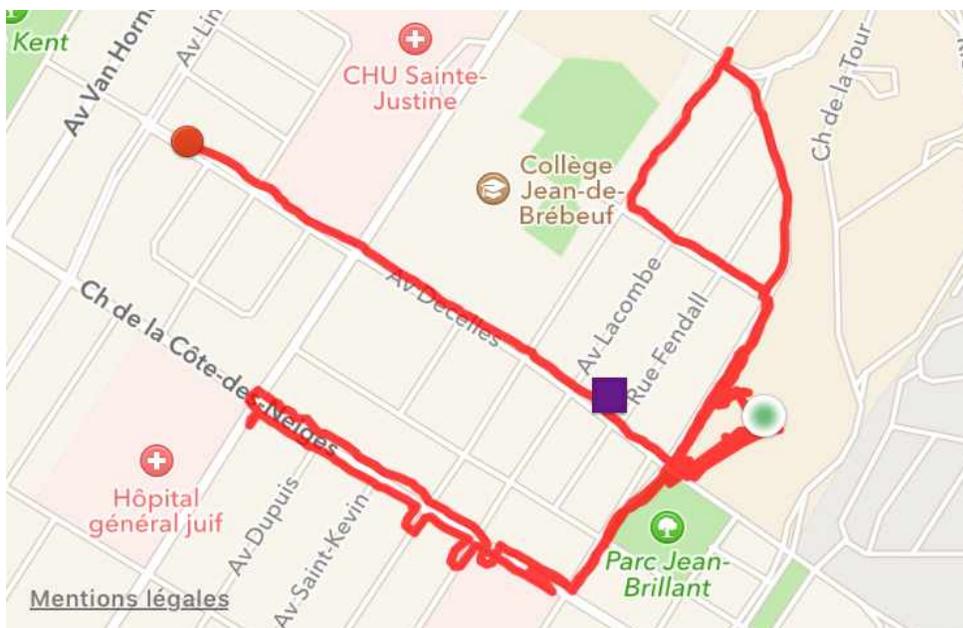
J'étais habituée à ma petite affaire. Ma bulle aux résidences. J'avais ma chambre. Je sortais pour prendre l'autobus [adapté] pis pour manger des fois à l'université. Mais non, c'était pas plus que ça là.

Laurence : Tu ne sortais pas vraiment à l'extérieur du campus?

Marie-Josée : Pas vraiment. Peut-être un petit peu, mais pas plus que ça.

Laurence : Est-ce que c'était quelque chose que tu aurais aimé faire?

Marie-Josée : Peut-être pas à l'université de Montréal. Ce serait ailleurs. Probablement ici. C'était difficile. C'est sûr je pense qu'en fin de compte si je sortais pas vraiment, c'était parce que c'était pas accessible. Il y avait beaucoup de côtes. L'hiver, oublie ça! Je ne sortais pas. Quasiment pas là. Ce n'était pas toujours bien déblayé. C'était du sport. ([see video Blais-3](#))



Marie-Josée stayed with her parents in their family home in St-Jean-sur-Richelieu for the first twenty-three years of her life. She is an only child. Marie-Josée was diagnosed with a rare type of dwarfism along with visual and hearing impairments. Her doctor's prognosis was not good for her future and her parents were advised to place her in an institution, which they refused to do. She went to regular elementary and high schools but experienced many frustrations and social isolation. She remembers spending most of teenaged years alone in her parents' basement. She got her first manual wheelchair customized to her needs at age 17. Unable to drive a car due to her visual impairment, Marie-Josée felt stuck in St-Jean-sur-Richelieu, a small city without proper adapted transit. She decided to leave her family home to study at Université de Montréal.

Despite facing many obstacles and dealing with chronic health issues, she found in Montréal a city with more opportunities than her hometown. During her undergraduate studies, she lived on campus. In 2012, she moved in her first apartment at La Maison des Sourds, a new residential building in Villeray for people who are deaf or hard of hearing. At the time of the interview, she was involved with the tenants committee and participates in different activities. Marie-Josée, is now unemployed and is not looking for a job due to her health problems. She is trying to get more involved in the deaf community but is facing many obstacles such as difficulties learning LSQ and ableism from people in the deaf community.

Marie-Josée and I:

We met online in 2004 through her boyfriend at the time. We met in real life at social activities organized by the Association québécoise des personnes de petite taille (AQPPT). I visited her a couple of times when she was living on campus. Her small studio was in the same student housing building as my cousin Andrée-Anne. Over the years, Marie-Josée and I have hung out a few times and built a friendship. We have spent hours chatting online about a variety of subjects often related to our experiences of disability. When we met, neither of us had much knowledge about disability from a critical perspective. When I was active with RAPLIQ, Marie-Josée became interested in disability activism but was reluctant to get involved directly. Protests, for example, scared her. As time has passed, she became used to going out more often than in the past, and doing different things with a handful of friends that she trusts. I am lucky to be one of those friends. On October 14, 2016, she chose to participate in her first protest for the accessibility of the métro because she knew I would be there. More recently, we had many discussions about how she experiences ableism in the deaf community and audism in the disability community.

Connections to other participants:

Facebook friends: Geneviève, Kéven, Louise and Pierre  
Took a dance class given by France

**Kéven Breton**

26 years old

Has been living in Montréal since: 2013

Date of the interview: September 1, 2015

Weather: Sunny. 27 °C

Distance travelled during the interview: 8.05 km

Total distance I travelled: 17.38 km

In addition to wheeling we also took: the bus and the métro

We wheeled around: Ville-Marie, Rosemont–Petite-Patrie and Villeray (enlarged map in Appendix A)



While wheeling with Kéven...

in a métro car between Beaubien and Jean-Talon stations (purple rectangle)

Laurence : Qu'est-ce qui a fait en sorte que tu as décidé, que tu as commencé à t'impliquer spécifiquement pour l'enjeu du métro?

Kéven : C'est vraiment romantique. J'ai une vision de Montréal très romantique. Ça inclut nécessairement le métro. [...] C'est un symbole super fort. Il ne faut oublier de sortir à la prochaine [station]. C'est un symbole. Je pense qu'on doit y avoir accès comme les Montréalais, à part entière.

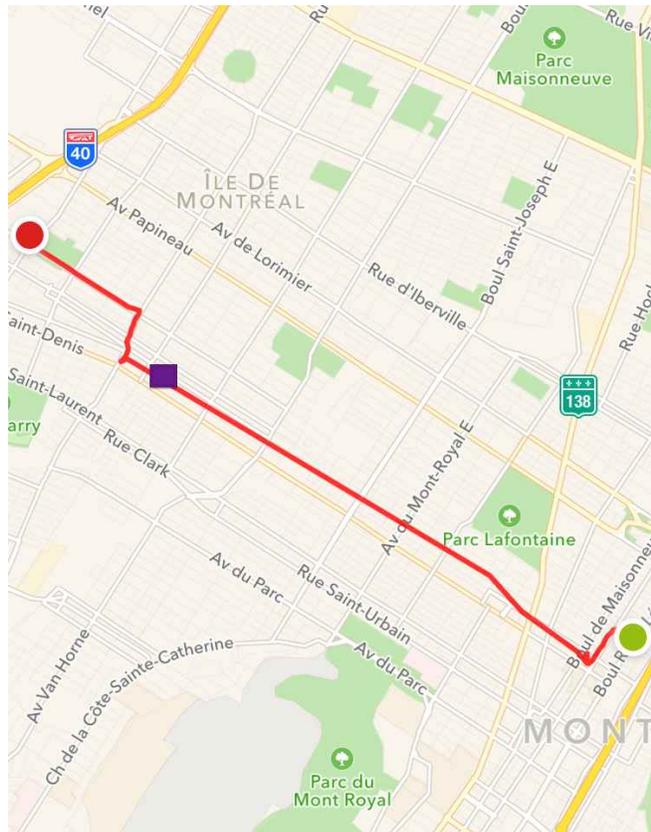
Laurence : Le gros bon sens...

Kéven : Pardon?

Laurence : Le gros bon sens.

Kéven : Ouais, pis je l'aime le métro. C'est un peu romantique comme vision aussi là.

Kéven grew up in the Beauce region about 300 kilometres from Montréal. He was born with a type of dwarfism and has had several surgeries during his childhood. He went to a regular elementary and high school. At age 9, Kéven started using a manual wheelchair. When Kéven turned 16, he got his drivers license and a car, like many teens of his age living in rural areas. After CÉGEP, Kéven moved to Sherbrooke to do an undergraduate degree in communications. He worked as a journalist for *La Tribune* and *EnBeauce.com* and was a managing editor of *Le Collectif*, the student newspaper. On a few occasions, Kéven critiqued the poor accessibility of Université de



Sherbrooke's campus. After graduating from a short program in applied politics, Kéven travelled to Europe for a communications internship at the Parlement Wallon in Namur, Belgium. In 2014, Kéven moved to Montréal for work. He was hired as communications officer at Ex Aequo, a disability rights organization. Once his contract expired, Kéven continued to work in the field of disability media in Montréal. He also worked with two photographers to put together *À la porte*, a photo project denouncing the lack of accessibility in the Montréal métro. He has a blog on *Urbania* and regularly writes on disability issues from a witty and critical perspective. Passionate for sports, Kéven is a blogger for the sport website *Balle Courbe*. In February 2016, Kéven became the host of the television show *Ça me regarde* on AMI channel. In June 2016, Kéven moved from his partially wheelchair-accessible in Villeray to his first fully wheelchair-accessible apartment in Griffintown.

Kéven and I:

Kéven contacted me through Facebook before moving to Montréal to ask me questions about the accessibility of the city, especially about public transit. I remember reading an article he wrote about the accessibility problems in Sherbrooke and looked forward to meeting him in real life. We met a few times for work and in activist contexts. We collaborated for the photo project *À la porte*, were invited together on a radical show at Radio-Canada to talk about disability issues and we wrote an open letter together which was published in *Le Devoir*. Kéven and I had countless great conversations online on different topics—mostly ableism, the STM and hockey. We are now good friends.

Connections to other participants:

Has worked with Luc

Facebook friends: All participants except Nabila and France

## Christian Généreux

46 years old



Has been living in Montréal since: birth

Date of the interview: September 11, 2015

Weather: Sunny and hot. 25 °C

Distance travelled during the interview: 21.21 km (longest wheeling interview)

Total distance I travelled: 23.61 km

In addition to wheeling we also took: the bus and the métro

We wheeled around: Rosemont–Petite-Patrie, Parc-Extension, Town of Mount Royal, Ahuntsic-Cartierville, Plateau Mont-Royal and Saint-Laurent (enlarged map in Appendix A)

Excerpt from the text Christian handed me at the beginning of the wheeling interview. I read it before leaving at Jean-Talon métro station. He described why he enjoys wheeling in the Town of Mount Royal (purple rectangle)

Après, nous arriverons à Mont-Royal! J'ai un aveu à te faire. C'est un territoire où je m'y sens bien. Politiquement, je suis plus au centre (même si de fois l'idée de gauche et droite politique j'y crois plus ou moins) donc, la richesse, je vis bien avec cela. Ai-je de l'envie? Oui, je m'en confesse. Donc, j'aime bien Mont-Royal, ses maisons, ses rues ombrées, ses parcs, etc. J'y viens souvent. ([see video Généreux-1](#))

Mont-Royal s'est essentiellement roulé dans la rue! Je roule là essentiellement parce qu'il y a plus d'espace. Je suis peut-être un peu délinquant, mais j'aime bien rouler dans la rue sur des petites rues tranquilles comme un en retrouve ici. Ça donne un sentiment de liberté. Cependant, il m'arrive quelquefois de passer de la rue au trottoir et vice-versa en fonction des situations qui se présentent.



## Christian and I:

I remember our first actual encounter, which took place at a bus stop of the line 30 at the corner of Berri and Ontario while I was in CÉGEP. It was late afternoon and the sky was cloudy. I don't remember if it was cold, but I was looking forward to being home. A guy in a power wheelchair was already waiting for the bus at *my* bus stop. It was the first time that this had happened to me. As soon as I saw him, I knew that it meant that I could not take the bus because of the one wheelchair user limit *per* bus. I decided to approach Christian, and we exchanged a few sentences. He used a communication keyboard to communicate because I was unable to understand his speech. It was the first time in my life that I communicated with someone using this kind of device. After a few minutes, I left and wheeled all the way home. Christian and I eventually met again at disability events. Since we have known each other, we have had great conversations, mostly through emails or chats. Christian is very critical of the Québec disability rights movement, just like I am, but we often have very different perspective and political views. We occasionally run into each other because we live in the same neighbourhood. Christian is the participant who expressed most vividly his pleasure in wheeling Montréal.

## Connections to other participants:

In a relationship with Louise

Facebook friends: Geneviève, Isabelle, Kéven, France, Louise, Laurence and Marie-Eve

**Caroline Goyette**

40 years old

Has been living in Montréal since: she was 17

Date of the interview: September 17, 2015

Weather: Sunny. 27 °C

Distance travelled during the interview: 5.12 km

Total distance I travelled: 41.72 km

We wheeled around: Pointe-aux-Trembles (enlarged map in Appendix A)



While wheeling with Caroline...

in a small forest nearby her apartment (purple rectangle)

Caroline : Ça c'est notre sentier en arrière. J'adore mon saule pleureur.

Laurence : Oh wow!

Caroline : C'est sûr que c'est un petit peu cabossé.

Laurence : Off-road.

Caroline : Mais c'est quand même pas si pire. Tu sens la chaleur là. Tu sens le bois là. Tu sens tout ça. Moi j'adore ça ces affaires là. Ça me rappelle ma jeunesse.

Laurence : Ça te rappelle l'Abitibi un peu?

Caroline : Ça me rappelle l'Abitibi. Je m'ennuie beaucoup, beaucoup de ça. C'est sûr que mes meilleurs trips, je les ai vécus là-bas.

Caroline is from Abitibi, a region in northwest Québec. When she was young, she spent a lot of time playing sports and enjoying nature. Injuries, such as joint dislocations, became a part of her life. At this time of her life, Caroline did not have a medical diagnosis to help her to make sense of these injuries. When her parents divorced in her teenage years, she felt stigmatized and found refuge in delinquency. At age 17, she left her native region and moved to Montréal to be closer to the healthcare services that she needed to treat the Hepatitis C that she had



contracted. While in Montréal, she did various jobs in construction, however, she remembers missing Abitibi and nature. When Caroline got pregnant at 33, she was shocked since she thought she was infertile. Her health condition deteriorated throughout her pregnancy and finally led to the medical diagnosis that explained the numerous injuries she had sustained throughout her life. Caroline was diagnosed with Ehlers-Danlos syndrome, which affects connective tissues. Unable to work full-time or even part-time, Caroline found herself in a precarious financial situation as a single mother. A year ago, she moved into a fully wheelchair-accessible apartment with her daughter. Located near a small forest in Pointe-aux-Trembles, Caroline has felt at home for the time since living in Montréal. ([see video Goyette-2](#)) This coincided with her first use of an electric wheelchair, a mobility tool that greatly improved her ability to get around the city. Even though her new physical limitations frustrate her, Caroline has developed a passion for justice and disability rights. She became involved in different disability rights organizations and attended numerous disability events. When she sought assistance through the public healthcare system to have the support she needed to take care of her daughter, she repeatedly was told that the system could only cover her individual needs: the support she required to raise her daughter was never acknowledged. Aware that her health issues were worsening and her physical mobility was declining, Caroline made a desperate and heartbreaking decision for the good of her daughter—she found a good foster family and then alerted the DPJ. When I met Caroline for the wheeling

interview, her six-year-old daughter had just moved out. She was obviously very emotional about it.

Caroline and I:

In March 2015, I saw a news story about a mother using a wheelchair who was denied access to a STM bus on a freezing winter day. She clearly explained her indignation to the television reporter. Her anger was raw and profoundly honest. She clearly was not afraid to speak her mind. I loved it. I found her on Facebook and sent her a friend request. We had a few conversations about inaccessibility of STM buses and strategies on how to bring the issue forward. We met in person at a disability arts event a few weeks later. Since then, we occasionally see each other at events organized by the disability community. Every time I see her, Caroline encourages me to continue my academic and activist work.

Connections to other participants:

Facebook friends: Geneviève, Isabelle, Kéven, Laurence and Pierre

**Louise Blouin**

54 years old

Has been living in Montréal since: 1985

Date of the interview: September 18, 2015

Weather: Sunny. 28 °C

Distance travelled during the interview: 11.7 km

Total distance I travelled: 13.1 km

We wheeled around: Rosemont–Petite-Patrie and Plateau-Mont-Royal (enlarged map in Appendix A)



While wheeling with Louise...  
on a sidewalk in the Mile-End (purple rectangle)

Louise : Le premier logement que j'ai visité je l'ai pris parce que quand j'ai visité des logements... Connais-tu Linda Blais à Québec?

Laurence : Je la connais juste de nom.

Louise : Ok. J'étais avec Linda en auto. Elle avait une auto à l'époque pis je ne voulais pas qu'elle vienne tout le temps. Fait que j'ai pris le premier logement que j'ai visité sur le Plateau, mais c'était assez cher même pour l'époque en 85. C'est drôle c'est l'année que tu es née ça. Je payais 300\$ pour un 2 et demi.

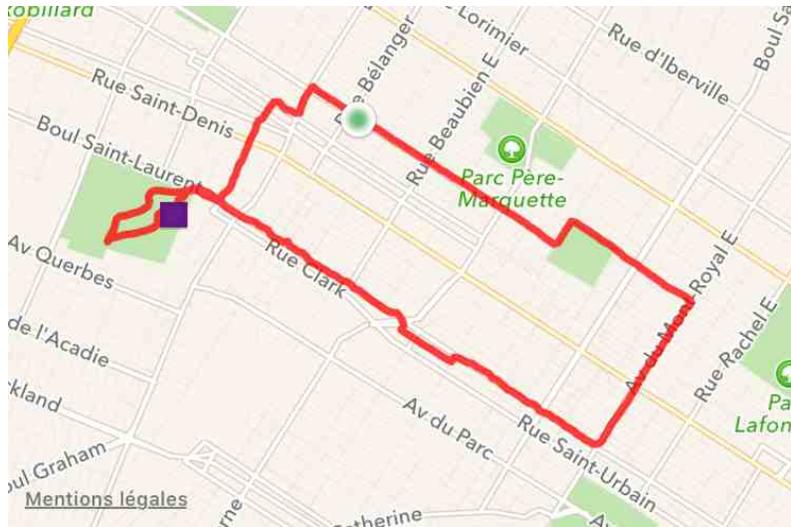
Laurence : C'est quand même cher.

Louise : C'était très cher. C'était très petit. J'ai fait beaucoup d'apprentissage en plus d'être à l'université pour la première fois. En plus de partir de chez mes parents. J'avais mis la barre haute, mais j'ai passé au travers.

Laurence : Est-ce que tu avais de l'aide?

Louise : Non. Je ne savais même pas que ça existait [des services de soutien à domicile]. Ça a pris du temps. J'ai eu de l'aide seulement en 99.

Louise was born in the 1960s in Chicoutimi in the Saguenay region. She had a happy childhood. She was diagnosed with cerebral palsy, which affected her mobility and speech. Louise went to a specialized school for disabled children. Even though Louise did not go to the same school as most children in her



neighbourhood, she played with them. She remembers feeling included in their games. When her father got a job for the Québec government, her family moved to the Quebec City region. Louise was 16 years. She was transferred to a regular high school. Louise was integrated into a 9<sup>th</sup> grade classroom, because they did not know where she was at in her schooling. When her able-bodied friends started dating in their teen years, Louise felt excluded from this rite of passage. She realized that being disabled made her different. In 1985, Louise left Québec and moved to Montréal. Her first apartment was located on Plateau Mont-Royal. It was tiny and expensive. While Louise was learning to live independently, without any assistance, she studied writing at the Université de Montréal. Alone in Montréal without a support network, she struggled. Louise completed a master's in historical geography at the Université Laval, in Quebec City. She went back and forth between Québec and Montréal before finally settling in Montréal after getting a job at the Association Québécoise des étudiants ayant des incapacités au secondaire (AQEIPS). This is where she met Christian who has been her partner for 16 years. In 2003, she bought her first mobility scooter to be able to keep up with Christian who uses a motorized wheelchair. Involved with Action des femmes handicapées de Montréal (AFHM) for many years, Louise

explained that it is after meeting the late disabled feminist Maria Barile and joining the board of AFHM for a second time in 2011 that she started to identify as a disabled woman instead of a disabled person. Louise now works part-time as a freelance writer, editor and researcher. She mostly works for disability organizations. She lives in Hochelaga in an apartment that is up a flight of stairs.

Louise and I:

We met through our involvement in the disability movement many years ago. I can't remember exactly where and when, but I remember that Louise was doing freelance work as a researcher and editor for a disability rights organization for which I was a board member. At the time, I was more on the sidelines and had not found my activist voice. Even though we have been attending the same disability events and meetings numerous times, we never had the opportunity to get to know each other personally. In the past few years, I have run into Louise occasionally since her partner Christian lives only a few blocks from me in Rosemont-Petite-Patrie. Every time I see Louise, we have brief, but always friendly, conversations. She is open-minded and interested in many issues. As a researcher and writer herself, she has shown an interest in my academic and activist work for as long as I can remember.

Connections to other participants:

In a relationship with Christian Généreux

Facebook friends: All participants except Pierre, Sandra, Caroline, Nabila Luc

**Laurence P. Rousseau**

29 years old

Has been living in Montréal since: birth



Date of the interview: September 21, 2015

Weather: Sunny but a chilly in the morning. 20 °C

Distance travelled during the interview: 2.59 km

Total distance I travelled: 17.99 km

We wheeled around: Ahuntsic-Cartierville (enlarged map in Appendix A)

While wheeling with Laurence...

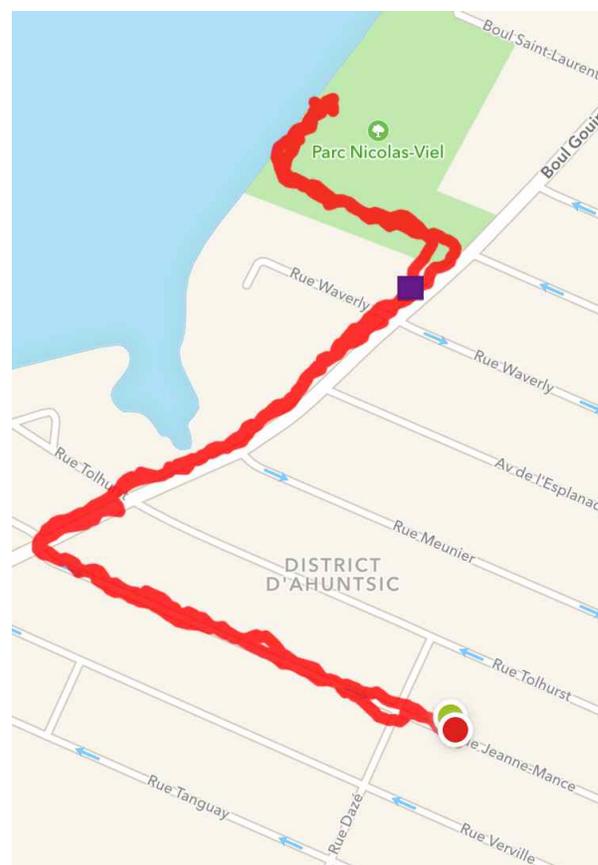
on Gouin, a few blocks from her apartment (purple rectangle)

Laurence Parent : Est-ce que tu te verrais habiter dans un autre quartier?

Laurence P. Rousseau : Oui et non. Oui, j'aimerais ça quitter un jour le cocon familial, mais non, dans le sens où comme je te l'ai dit, je n'ai pas le sens de l'orientation. Pour moi vivre dans ce quartier-ci, c'est rassurant parce que je sais tout. Dans un autre quartier, il faudrait que je me réhabitues. Les distances, des choses comme ça. Pis, j'ai besoin de vivre dans un quartier comme ça. De vivre dans un quartier que oui tu as des services proches, mais qui fait très résidentiel quand même. Je ne pourrais pas vivre dans le centre-ville dans le fond. Tu n'as jamais tout à la même place. Ça, je n'aimerais pas ça. J'ai besoin de me sentir un peu à la campagne.

Laurence was born in Montréal in 1987. She has lived in Ahuntsic for the past twenty years of her life. A year ago, she moved into an apartment that is located above her mother's apartment. During her childhood she underwent several surgeries. She wore braces and occasionally used a

manual wheelchair. Laurence remembers a generally happy childhood even though other children judged her because of her disability in her second elementary school. From ages 12 to 16, her health was stable, and she did not use any mobility devices. She did not identify as a disabled person. At 18, she went on a backpack trip in France for three months by herself. When she came back, she had health issues that forced her to acknowledge her physical limitations. Laurence completed an undergraduate degree in theatre at UQÀM. At 21 years old, she started to consider herself as a person with disabilities. Five years ago, she got her first service dog to help her to keep her balance when she walks. In January 2014, Laurence started a part-time job at the Association québécoise des étudiants ayant des incapacités au post-secondaire (AQEIPS) as a communications and social media officer. Six months later, she became the director general of the organization. Through her work, she discovered several important disability issues and got to know a few disabled people who became her friends. She now advocates for a more inclusive education system in Québec.



Laurence and I:

Laurence and I became friends on Facebook in May 2014. We got in touch because of our work in the disability movement. Prior to the wheeling interview, we did not know each other very well. I had the feeling that she was not a big supporter of direct actions and I remembered wondering what she thought about my activism. I also had the feeling that Laurence might be one of those disabled people who prefer not to hang out with other disabled people. The wheeling interview finally gave us the opportunity to have a conversation and that was great. I remember that I recognized myself in one of the stories Laurence shared with me. She told me that she grew up surrounded by able-bodied family members and friends and never felt the need to have friends with disabilities. It is finally when she started working at AQEIPS that she made disabled friends.

“Comment je pourrais dire ça? Je me sens plus comprise. Les gens autour de moi ont toujours fait un effort puis ils ont toujours été très compréhensifs, mais avec des amis en situation de handicap comme toi ça fait en sorte qu’ils comprennent naturellement,” she explains. Laurence was not one of those disabled people who did not want to hang out with other disabled people. I was wrong!

Connections to other participants:

Facebook friends: All participants except Nabila, Sandra and Marie-Josée

**Marie-Eve Veilleux**

34 years old

Has been living in Montréal since: 2002

Date of the interview: September 23, 2015

Weather: Sunny but chilly in the morning. 23 °C

Distance travelled during the interview: 7.95 km

Total distance I travelled: 18.95 km

We wheeled around: Plateau Mont-Royal and Ville-Marie (enlarged map in Appendix A)



While wheeling with Marie-Eve...

on St-Denis street in Plateau Mont-Royal (purple rectangle)

Marie-Eve : Le bureau des étudiants handicapés m'a invitée à aller à une conférence de NEADS, le pendant canadien de l'AQEIPS. [...] Je me suis mise à être très, très, très active.

Laurence : Est-ce que c'est à cette époque là que justement tu as commencé à avoir autre perspective sur la question du handicap?

Marie-Eve : Oui, oui, oui, oui.

Laurence : À quel moment?

Marie-Eve : [...] C'est sûr que ça a eu une influence, mais tsé d'être impliquée dans le milieu étudiant handicapé, je ne suis pas sûre que c'est ça. Je ne suis pas sûre que... Tsé j'organisais des trucs pour l'AQEIPS. En fait, j'aidais les gens, les employés à organiser des trucs à l'AQEIPS, mais je sais pas à quel point j'y croyais tsé. C'est comme ce qu'on disait. Je ne pense pas que j'avais les notions et les outils pour mettre des mots là-dessus. Pour moi, je défendais une cause pis des acquis, mais sans vraiment avoir les convictions qui viennent avec tsé. [...] C'était

vraiment juste : on veut des services pis c'est ça qui est ça. On a le droit d'avoir des services ça s'arrêtait là. Ok, ici on peut descendre et passer devant ma résidence.

Laurence : Ok, super.

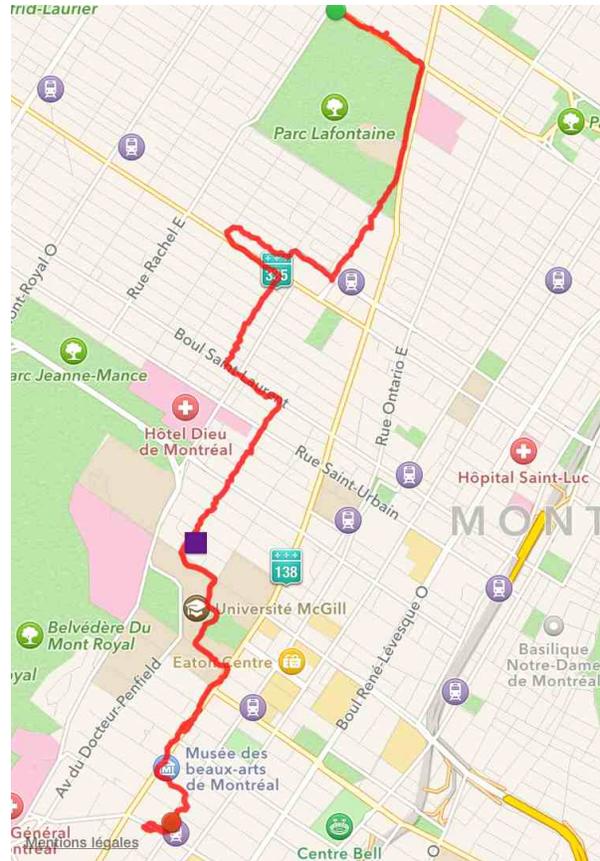
Marie-Eve : Je vais te laisser passer.

Laurence : On pourra traverser?

Marie-Eve : Non, mais derrière l'autre coin de rue on peut. Genre, ici on peut, mais là, on va traverser sur Milton.

Laurence : C'est à quel moment que ça a changé?

Marie-Eve : Quand je t'ai connue. [rires] Ok, ok plus impersonnel... Quand j'ai connu le RAPLIQ. [...] C'est ça en 2010. Fait que je pense que ça été ça. Et d'assister, d'être en contact avec ce genre de discours là, le modèle social. [...] J'ai besoin d'avoir une raison. Une raison logique pour croire à des trucs. J'ai besoin que ça soit logique sinon je doute tout le temps. Tsé, j'ai besoin de preuves. Je ne sais pas si je suis trop scientifique, mais j'ai besoin de preuves. Pour moi ça m'a donné comme cette espèce d'assise théorique pour vraiment arrêter de penser que c'est moi qui a un problème pis qui faut qui combatte ça pis qui surmonte. Tsé, très réadaptation.



Marie-Eve was born and raised in a Montréal suburb. At 18 months old, she was diagnosed with juvenile arthritis. She went through many surgeries and became accustomed to hospital stays. Her walking capacity and her need for a wheelchair fluctuated over the years. Marie-Eve went through the mainstream school system although she missed many weeks of school due to surgeries. In 2002, she moved to Montréal into her best friend's condo. She got a summer internship at the Fédération des travailleurs et travailleuses du Québec and was confronted with the inaccessibility of the public transit system which caused her a lot of anxiety. Marie-Eve remembers that she did not have much leisure and spent much of her time at home. In the fall 2003, she started an undergraduate degree in microbiology and immunology with a minor in translation at McGill University. Throughout her studies, Marie-Eve volunteered for the Arthritis Society of Canada and became a spokesperson. She also joined the board of the Association québécoise des incapacités au post-secondaire (AQEIPS) and acted as a president between 2008

and 2010. In 2009, she moved into her fourth apartment which was her first step-free apartment in Montréal. Marie-Eve got a mobility scooter and started to go out more often. After completing a graduate degree in translation, Marie-Eve became the translation coordinator of the Canadian Longitudinal Study on Aging. In addition to her part-time job as translation coordinator, Marie-Eve is involved in various disability rights projects. She explains that she felt stronger as a disability activist when she discovered the social model of disability. In 2016, she co-organized the Disability, deaf culture of barrier-free society at the World Social Forum with her boyfriend Pierre. She now lives in Rosemont in a new condo with her Pierre and her brother-in-law Michel.

Marie-Eve and I:

We met through RAPLIQ and we have collaborated on numerous projects, wrote reports and open letters, organized events and created the Facebook group Transport mésadapté. We are both co-founders of Québec accessible. Marie-Eve and I have traveled together. We are now very close friends. We share a common passion for disability issues, in particular representations of disability in the media. I regularly consult Marie-Eve for her thoughts and opinions on my work as a researcher and an activist. She has helped me out countless times. Because I know her so well, I already knew many of her stories and was able to ask her about some memories in particular.

Connections to other participants:

In a relationship with Pierre Lemay

Facebook friends: All participants except Caroline and France

**Nabila Nouara**

50 years old

Has been living in Montréal since: 2009

Date of the interview: October 6, 2015

Weather: Cloudy and chilly. 14 °C

Distance travelled during the interview: 5.65 km

Total distance I travelled: 19.05 km

We wheeled around: Côte-des-Neiges–Notre-Dame-de-Grâce (enlarged map in Appendix A)



While wheeling with Nabila...

At the top of the stairs of De la Savane métro station, an elderly man stopped to ask us if we needed help. He was very sweet. We talked with him for a few minutes. He said that the métro should be accessible to all. One of the questions he asked Nabila was “where are you from?” (purple rectangle)

Laurence : Des petites rencontres comme ça est ce que ça t’arrive régulièrement ? Des gens qui viennent te parler?

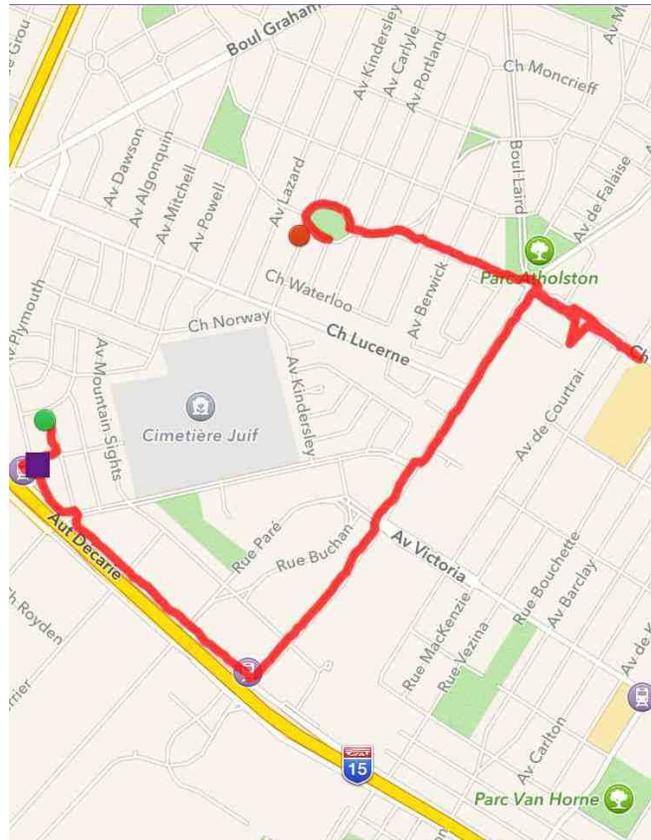
Nabila : Ah oui. Il y a des gens, mais des fois je dirais que la plupart du temps c’est quand même des discussions assez sympathiques. Mais il y en a d’autres... Une fois j’ai été agressée verbalement. Il a failli même aller plus loin. Ma religion l’avait révolté. Ce jour-là, c’était clair c’est pas parce que je suis handicapée. C’est parce que je portais le foulard, mais il n’a pas respecté mon handicap. J’ai eu tellement peur ce jour-là.

Laurence : C’était à quel endroit que ça s’est produit ?

Nabila : Ce jour-là, je me rendais au CLSC Côte-des-Neiges. Je suis sortie de chez moi en roulant jusque là-bas donc. Et tout de suite en arrivant au coin de Côtes-des-Neiges et Côte-Sainte-Catherine, il est venu vers moi en m’insultant de loin. Ensuite, il s’est rapproché en continuant à

m'insulter. Il s'est rapproché très, très près de moi. D'ailleurs, je pensais qu'il allait me frapper, puis il est parti.

Nabila comes from Algeria. Her parents raised her in Algiers, the country's capital. As a child with disabilities, Nabila quickly discovered what it felt like to be excluded when she was denied entrance to a regular school because she used crutches to get around. Despite this exclusion, Nabila managed to study and became an electronics engineer. After her studies, Nabila married an able-bodied man and they had two daughters. In Algiers, they had a car and were quite mobile as a family. Nabila's husband could easily store her crutches or manual wheelchair in their vehicle. However, getting around was challenging for Nabila due to poor accessibility. They decided to move to



Montréal to have more opportunities for their two young daughters. This turned out to be a bittersweet decision. Even though getting a power wheelchair increased her mobility, she was shocked to be confronted by countless obstacles in the city. Furthermore, finding work has proven to be impossible for Nabila and her family is in a precarious financial situation. As a Muslim woman wearing the hijab, Nabila encounters prejudices towards her religion regularly. She is now a stay-at-home mom and is busy taking care of her family. At the time of the interview, Nabila was also involved with RAPLIQ and sat on the board.

Nabila and I:

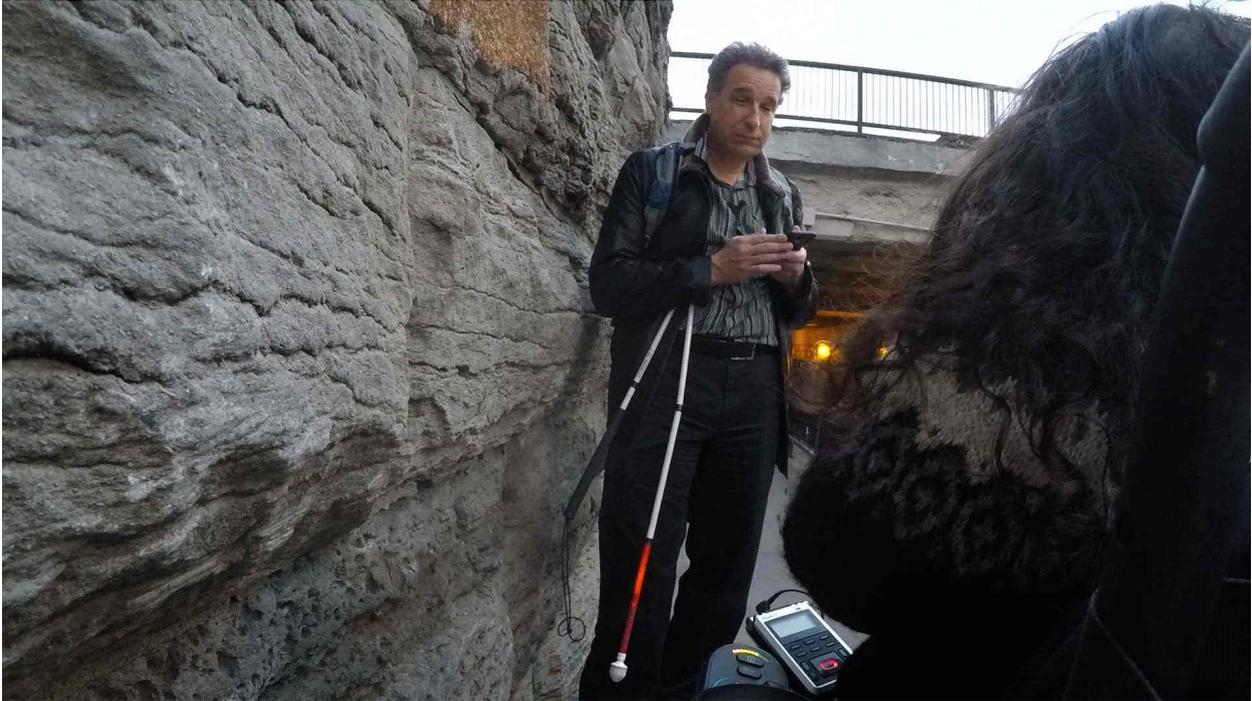
I met Nabila while I was vice-president of RAPLIQ. I always have enjoyed our short conversations. In particular, I was interested in her acute analysis of different disability issues. The wheeling interview was a great occasion to get to know her better. It brought us closer. I was especially touched by the stories she shared on her experiences as a disabled mother. After the

interview, we worked together on two different accessibility issues that were raised during our stroll in her neighbourhood: the Transport adapté policy limiting the number of people over 14 years old who can travel with her to one and a sidewalk in disrepair that broke her wheelchair a few months ago. After many months, the sidewalk was finally fixed by the City. The Transport adapté policy has not changed yet, but Nabila's story was featured in the television show *La Fracture* on Radio-Canada in February 2016. Nabila and I are still communicating by email and we chat on Facebook Messenger occasionally.

Connections to other participants:

Facebook friends: Laurence and Marie-Eve

**Luc Fortin**  
53 years old



Has been living in Montréal since: birth

Date of the interview: October 22, 2015

Weather: Sunny but not too cold for that time of the year. We met at the end of the afternoon and by the end of the interview, around 6 p.m., it was dark outside. 17 °C (max)

Distance travelled during the interview: 6.51 km

Total distance I travelled: 17.43 km

We wheeled around: Ville-Marie and Hochelaga-Maisonneuve (enlarged map in Appendix A)

While wheeling with Luc...

on Ontario street in Hochelaga-Maisonneuve (purple rectangle)

Laurence : Ici on passe sous un viaduc.

Luc : Un train qui s'en vient? Ah non, un autobus. Et là on se trouve où?

Laurence : Sur Ontario.

Luc : Oui sur Ontario, mais ce qu'il y a au-dessus de nous, le sais-tu?

Laurence : Ça doit être...

Luc : On va sortir de l'autre côté. Je vais faire comme si tu n'étais pas là. Je vais demander à Siri parce que je suis curieux.

Laurence : Je sais pas si c'est St-Michel?

Luc : Mais Pie-IX se rend jusqu'à... Ah, c'est peut-être Davidson?

Laurence : Le mur est en pierres et irrégulier.

Luc : Merci.

Laurence : Ça, c'est le mur est très irrégulier.

Luc : Attends un petit peu. Je vais juste sortir mon téléphone. Tu vois, ça je trouve ça excitant moi.

Laurence : De pouvoir faire

Luc : De pouvoir savoir quelque chose que je n'aurais pas pu savoir avant. Je ne le fais pas tout le temps pis tout ça là. [...] Mais de dire «eille, prends le temps». Pis tranquillement, je connais ma ville comme ça maintenant. Je me laisse aller en autobus ou en taxi «ah, tel restaurant! ». Quand les gens parlent de ce restaurant-là, il est ici. Avant, je ne le voyais jamais fait que...

Laurence : Sur la carte, ça dit tel restaurant est à telle place.

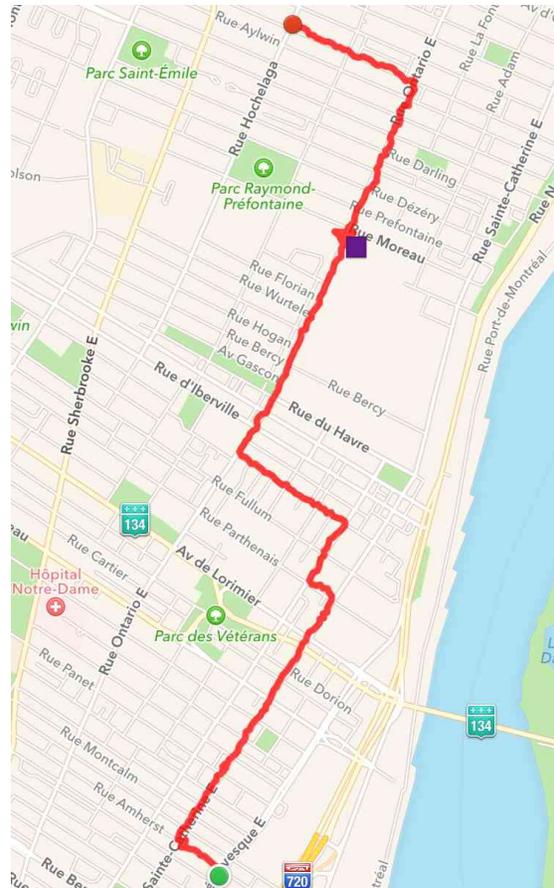
Luc : C'est ça. Exactement!

[...]

Laurence : Mais avant, tu avais déjà ton image, mais là c'est une autre image qui se superpose.

Luc : C'est ça. C'est que les trous tranquillement se remplissent entre tel lieu que je connaissais et tel lieu que je connaissais. En même temps, il faut faire attention comme il me parle encore du club Vidéotron en face de chez moi pis ça doit faire huit mois qu'il est fermé. Pis on m'avait dit que ces cartes là c'était beaucoup plus rapides au niveau de la mise à jour.

Luc was born in St-Léonard<sup>19</sup> in the 1960s. He was partially sighted during his childhood. He would come to Montréal occasionally with his parents. He started going to the city by himself after he turned 18. At 20 years old, Luc's vision loss was significant and required him to start using a white cane. For many years, he alternated between guide dogs and white cane. In 2010, Luc decided that a white cane was better for him. After living on Montréal's South Shore from 2007 to 2012, Luc came back in Montréal. He has worked as a radio host for nearly a decade. He was the host of the first season of the television show *Ça me regarde* on AMI channel. Over the



<sup>19</sup> St-Léonard was amalgamated into the Ville de Montréal in 2002.

past few years, Luc has developed an expertise in disability issues. He advocates for video description to make television and other visual media accessible to blind and visually impaired people. Luc is currently a member of RAPLIQ. Luc is the father of a young adult. He lives alone in Hochelaga.

Luc and I:

I met Luc because he interviewed me on his radio show on Canal M when I was RAPLIQ's Vice-president. In 2013 and 2014, I worked as a researcher on his show called *Accès Libre*. I also had a monthly column on *Midi 14h*, which Luc hosted daily. Through my work as a researcher, I came to work closely with Luc and had frequent phone conversations with him. Our common interest in disability issues brought us closer. Prior to the interview, we had walked and wheeled together a few times and it had proven to be informative. When we move together, the obstacles we encounter seem to double. This wheeling interview was not an exception. We faced a particularly high number of obstacles related to the construction work going on in the city. Luc even injured himself with a construction sign put in the middle of a sidewalk, when he hit the sign with his leg. I clearly still have learning to do to be an efficient guide.

Connections to other participants:

Has worked with Kéven

Facebook friends: Geneviève, Isabelle, Kéven, Laurence and Marie-Eve

### ***Conclusion***

This chapter has provided a space for me to introduce each participant and to highlight both the diversity within the group and the limits of this diversity, notably in terms of gender, social class, language, race and sexual orientation. The participant profiles emphasize the subjectivities of their stories, provided some information on the context in which the participants share their stories. They outline my relationships with each participant. In introducing them, I offer readers the possibility to acquaint themselves, briefly, with the participants before reading their stories throughout the thesis. I also reflect on the process that shapes the interviews and the stories. According to Maynes, Pierce and Laslett (2008), “transparency and clarity about the processes that shape the production and analysis of the personal narratives, we argue, goes a long way toward making arguments persuasive.” (p. 10) Thinking about my relationships with the

participants and my influence on how they told their stories helps one appreciate the uniqueness of their narratives.

The maps of the routes that we have wheeled are a testimony of the diversity of the areas explored as well as the limits. There are parts of the city that we did not explore at all. It is hard to identify any particular route patterns since our routes were influenced by our abilities, mobility aids, our objectives and the weather. With eight participants, the interviews ended in the exact location where they started. In the other cases, we did not come back to our meeting point, either because it was too far away or because of other plans that one of us had for the rest of the day. Our speed had an impact on the lines produced by the mapping application<sup>20</sup> that I used. The faster we moved (i.e., when we were on a bus or wheeling at our top speed) the straighter the lines. Slower movements created uneven lines. The rhythms of our movements were influenced by our conversations and the pauses we took to go deeper into an issue, to think or communicate through the use of mobile media in the case Christian Généreux.

Overall, the profiles give an idea of how the participant's experiences in the city differ and connect according to multiple sightings. Instead of trying to draw a universalized portrayal of the participants, the profiles insist on their complexities to convey their richness. Here, it is vital to acknowledge that the narratives on which this thesis is based are partial and are works in progress. Maynes, Pierce and Laslett (2008) comment on this partiality in their discussion of Portelli's work: "The narrative themselves, according to Portelli, need to be considered as work in progress: They change over the life cycle and they involve not just placing events in a narrative sequence but also figuring out which narrative sequences an event belongs in." (p. 40) I have insisted on the importance of the context in which the participants produced their narratives, in alignment with the claims of numerous oral historians. I will now turn to the historical and political context behind the stories. Considering that stories "are told in relation to contemporary cultural norms," (Rogaly&Qureshi, 2017, p. 192) I will explore two issues that directly affect participants lives and stories and are still poorly researched in the academia: the history of the Montréal disability rights movement and the politics of acquiring a mobility aid in Québec. The following chapter will build on participant profiles and fill some gaps in the literature. By exploring some of the history and politics in which participant lives take place, the meeting with these participants continue in another way.

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<sup>20</sup> I used the application MapMyWalk.

## Chapter 3

### The Historical and Political Context Behind Participants' Stories

*Je me souviens assez clairement du moment où devant mon écran d'ordinateur, j'ai découvert l'existence des critical disability studies. Cette soirée-là, j'ai lu un article sur une tranche de l'histoire des États-Unis qui m'était complètement inconnue: celle des droits des personnes handicapées. Et de recherches en recherches, je suis tombée sur un programme d'études en critical disability studies à l'Université York. J'étais alors loin de me douter que ma vie allait changer. Je me suis mise à me poser des questions que je ne m'étais jamais posées sur l'histoire des personnes handicapées et les enjeux socio-politiques du handicap dans un contexte québécois. Et j'ai rapidement découvert que les réponses n'étaient généralement pas disponibles.*

—June 10, 2018

The stories of the participants that appear in my thesis cannot be separated from their historical and political contexts. However, literature on these contexts is still scarce. Having access to disabled people's stories also remains difficult. Media productions, such as podcasts, videos and blogs, on disability issues in Québec, either in French or English, are limited. As mentioned in the introduction of my thesis, there are major gaps to fill. This is particularly evident when we look at the variety of resources available in English that address the context of the United States. A quick Google search on the history of the U.S. disability rights movement will provides numerous sources. The same can be said about disability issues in the United Kingdom. This is far from the case in Québec. A not-so-quick Google search yields few results. Since disability issues cannot be understood without a deep understanding of the context in which they take place, the lack of literature and other resources is disconcerting. Through my work as a researcher and an activist, I have often been approached by people who assumed that disabled Quebeckers never fought for their rights, unlike disabled people south of the border. This assumption is because the history of these movements is largely untold. I argue that this lack of knowledge on the history of Québec's and Montréal's disability rights movements hinders people from recognizing disability issues as political issues. To make up for this lack of literature and to situate participants' stories in a context, I will explore some of the history of the Québec disability rights movement. I will examine one notable disability issue: the politics of getting a mobility aid, such as a wheelchair or a scooter. Most participants use one. Moreover, as I mentioned in the thesis introduction, wheelchairs are political. Even though there is a substantial

amount of writing about the cultural meanings of mobility aids in some English-speaking contexts, the politics of who can get a mobility aid, and the history and the regulatory conditions that determine how they acquire their device, is poorly documented. As a wheelchair user, I am often surprised when people assume that I paid for my wheelchair by myself. It is worth nearly \$7,000. This assumption speaks to a general lack of knowledge on disabled people's rights, as well as a lack of awareness of the responsibilities of Québec government towards its disabled population.

### *The history of the Québec disability rights movement*

In this short and partial overview of the Québec disability rights movement, I do not claim to tell the definitive story of this movement. I also must acknowledge that my position as a Montréal-based activist has influenced the disability history that I write about and the way I write about it. The objective of this exercise, however, is to provide insight into the historical and political context for actions of the individuals, organizations and groups that are mentioned in my thesis. As mentioned in the introduction, the literature on Québec disability history is scarce. The literature available is focused primarily on Francophone organizations. It does not pay much attention to the dynamics between the federal and provincial governments and how these relationships affect the movement. I will try to fill in some of these gaps.

### *The infancy of the disability rights movement in Québec*

In 1947, Montréal Mayor Camillien Houde launched a charity campaign for the Société des enfants infirmes. In an interview on Radio-Canada radio, he claimed that disabled children “appartiennent à une classe de malheureux.” (Radio-Canada, 1947) This short statement is a powerful example of how disabled people were perceived during this period of Québec history. Many were forced to stay in institutions or kept at home. In the film *La Grande Sortie*, Murielle Larivière, a disabled woman involved in the disability rights movement in the 1970s, explains what it was like to live in an institution during her childhood. “L’institution c’est ça. C’est vide de sens je crois,” she emotionally remembers (OPHQ, 1983). The ecclesiastic power and some philanthropic groups ran the various institutions in the province. Normand Boucher, Patrick Fougeyrollas and Pierre Majeau (2003) write that the main mission of these institutions was to “educate or re-educate ‘crippled, blind, deaf/mute children, etc.’” (p.170) Boucher et al. explain that it was common to see disabled bodies in places of pilgrimage waiting for a miracle—a

miracle that would “save” them from their impairment. At the same time, medicine and rehabilitation were making enormous progress and the number of disabled people increased (Boucher, 2005, p. 148).

The election of Jean Lesage in 1960 marked the beginning of a series of changes in Québec society known as the Révolution tranquille. Profound changes in the healthcare and education systems were under way. While the state aimed to provide a variety of public services, many disabled people were still isolated in institutions or at home and faced countless obstacles. For example, elevators were not considered as necessary infrastructure for disabled people. Tremblay, Campbell and Hudson (2005) explain that during the post-war period (1945–1970), elevators were seen primarily as serving to transport pianos, rather than transporting humans. They explain that “disability was considered a biomedical or rehabilitation issue, with solutions based on the adaptation of the individual to society.” (p.113) In 1971, the Commission d’enquête sur la santé et le bien-être social published the Castonguay-Nepveu report. The authors claim that “the handicapped like any other citizens, should have access to goods and services necessary to his blossoming. He should be able to share the same hope and enjoy the principle of equality of opportunities in all areas of development.” (Québec, 1971) According to Patrick Fougeyrollas, Normand Boucher and Yan Grenier (2018), the Commission “fait littéralement la découverte des ‘handicapés’ comme groupe social défini principalement par son exclusion du marché du travail.” (p. 145) The Commission also made recommendations to break down the control of the Church over this population (*Ibid.*). Increasingly, religious institutions were overburdened and unable to meet the needs of the growing disabled population. The stars were aligned for the newly formed Québec welfare state to act. Many disabled people, like Murielle Larivière, experienced a movement of deinstitutionalization that occurred mostly during the 1960s and the 1970s. This transition did not go smoothly. There were very few services available and obstacles were numerous. Access to public transportation, unsurprisingly, became one of the first struggles faced by an important portion of the disabled population (Boucher, Fougeyrollas & Gaucher, 2003, p.140). Negative attitudes towards disabled people were also common. Murielle Larivière, who experienced deinstitutionalization, talked about how she felt when she started going out in public. “Quand j’ai commencé à sortir ce que je trouvais le plus pénible au début c’était la pitié que je voyais dans les yeux des gens,” she says (OPHQ, 1983). Louise Blouin, one of the participants, went to a specialized school for disabled children even though her disability had no affect on her

capacity to follow a regular educational program. Born in the early 1960s in Chicoutimi, Louise explains:

Moi, j'ai été intégrée à l'école ordinaire quand on a déménagé à Québec. J'avais 16 ans. Tu vois, je suis pas de cette génération de l'intégration scolaire. [...] L'école, j'ai longtemps aimé ça, mais ma dernière année à l'école spéciale n'a pas été très heureuse. [...] Il y avait des profs qui disaient qu'on n'iraient pas plus loin. Ils nous faisaient faire des cours de cuisine, des cours de bricolage.

Thousands of children like Louise did not have access to the same quality of education as their non-disabled peers. Because of the numerous problems faced by disabled people and their families, non-profit organizations were created to advocate for disabled people's rights. Such organizations were founded largely by veterans and parents of children with disabilities. However, as disabled people started to live in their communities, initiatives led by disabled people themselves started to emerge (Fougeyrollas, Boucher & Grenier, 2018, p. 149). Many initiatives and projects were developed by young disabled people with physical and visual impairments who were part of the baby boomer generation and the counter-culture of the time. One of these includes the journal *Feux verts*, which featured articles on disability issues from a critical perspective (*Ibid.*, p. 147). The journal also tried to connect with other marginalized groups but it was not a success. Fougeyrollas, Boucher and Grenier (2018) write:

Adoptant une posture de droits de la personne et de contestation des pouvoirs normatifs autoritaires et producteurs d'exclusion sociale, le journal s'intéresse aux handicapés, mais aussi aux autres groupes marginalisés, minorisés et discriminés. Pendant une première période, *Feux verts* tente de créer des ponts avec ces mouvements: féministe, pauvreté, immigration, syndicats; mais cette initiative se heurte rapidement à un manque de reconnaissance des luttes des handicapés dans ces mouvements parallèles. (pp. 146–147)

However, they argue that *Feux verts*' orientations were not shared by all disability groups, in particular groups of parents of disabled children and health professionals, who were much more conservatives (*Ibid.*, p. 147). In 1973, the *Feux verts* editorial board supported the creation of the Comité de Liaison des handicapés physiques du Québec, a disability rights organization led by disabled people. Three years later, Robert Bourassa's Liberal government submitted Bill 55 on the "protection des handicapés." The presentation of the bill was followed by an unprecedented wave of protests (OPHQ, 1983) because it did not meet the Comité de Liaison des handicapés physiques du Québec's demands. Thirty-three briefs were sent to the government. Only five of them were written by disability rights organizations. Most of the briefs forwarded a medical understanding of disability. Unfortunately, the critical perspective developed by disabled activists involved in *Feux verts* and the Comité de liaison des handicapés physiques du Québec was not

shared by many other organizations. Bill 55 ended up disappearing following the election of the René Lévesque and the Parti Québécois government in November 1976.

In 1977, the new government presented Bill 9. Some of the objections made against Bill 55 were taken into consideration (Parent, 2012a; Fougeyrollas, Boucher & Grenier, 2018). The word “protection” disappeared from the bill and a ‘people first’ approach was used to describe disabled people (“personnes handicapées” used “handicapés” instead). During the summer of 1977, 26 briefs written by disability organizations were sent to the government. However, only the Comité de liaison des handicapés physiques du Québec and the Mouvement sur les chiens-guides rejected Bill 9 because, in their estimation, it did not secure disabled people’s rights as it should be. Between August 5 and 30 1977, the Comité travelled the province of Québec and met with disabled people. In a short amount of time, the Comité managed to unite 125 provincial, regional and local organizations. “On formait une force absolument extraordinaire,” remembers Murielle Larivière (OPHQ, 1983). Their brief was well documented. One of their critiques was that the Bill planned for the concentration of special services for disabled people in the hands of a special office. The Comité argued that “handicap” should be added as a prohibited ground for discrimination in the *Charter of human rights and freedoms* adopted in 1975. This unprecedented, well-organized coalition created a turning point in the history of disability rights in Québec. Boucher (2005) argues that it gave birth to the emergence of a new political actor: the Québec disability rights movement (p. 146).

On June 23, 1978, the *Act to secure handicapped persons in the exercise of their rights with a view to achieving social, school and workplace integration* was unanimously adopted by the Assemblée Nationale du Québec. One important demand of the Comité was heard: the *Charter of human rights and freedoms* would, from now on, protect people from discrimination based on “un handicap ou un moyen de pallier à un handicap.” (Québec, 1978) However, many of the demands put forth by the Comité were not taken into consideration. Murielle Larivière recalls:

On était très conscients que l’Office ferait en sorte que les gens dans la société se donneraient bonne conscience en disant “bon écoutez vous avez un Office, ben allez vous référer à votre Office. Nous on s’en lave les mains maintenant.” Alors les gens s’en sont effectivement lavés les mains. (OPHQ, 1983)

The adoption of the law, in other words, was a bittersweet victory for the Comité. Despite this discontent, disability rights activists did not contest the new law but got together, again, to make the best of the situation.

In the years that have followed the adoption of this law, numerous new organizations have been created by disabled people. In 1980, *Nous nous intégrons en commun* (which was eventually renamed *Ex Aequo*) and the *Regroupement des usagers du transport adapté de Montréal (RUTA)* were founded. In 1981, the *Association multiethnique pour l'intégration des personnes handicapées (AMEIPH)* was created by four immigrant parents of children with disabilities. These three organizations, along with many others, were invited to participate in a socio-economical summit, called the *Conférence socioéconomique (CES)*, on disability issues organized by the *Office des personnes handicapées du Québec (OPHQ)*. The summit was another occasion for disability rights organizations to learn to work together. Luciana Suave, one of the founders of *Association multiethnique pour l'intégration des personnes handicapées (AMEIPH)*, explains:

C'est que, pendant la CES, c'était un déclencheur du mouvement associatif qu'on connaît maintenant, parce qu'il n'y avait pas de mouvement associatif avant. Il y avait des organismes qui ne communiquaient même pas entre eux, la majorité, et chacun cherchait à faire avancer son propre dossier de son côté. [...] Déjà, pendant la CES, la deuxième journée, on s'était rencontrés, un tout petit groupe. [...] Nous avons décidé de créer un comité de coordination [...] une fois le Sommet terminé, nous avons continué à nous rencontrer, jusqu'au point où on a décidé de s'incorporer et c'est devenu ce qu'on appelle maintenant la *COPHAN*. (Fougeyrollas, Boucher & Grenier, 2018, p. 156)

At the international level, the United Nations declared 1981 the year of people with disabilities. Disability rights organizations took advantage of this event to bring attention to their demands. In 1984, the government adopted the policy “*À part égale*,” which guided the implementation of various policies and measures. In 1982, the *Table de concertation des organismes provinciaux de promotion* (which was eventually named *Confédération des organismes de personnes handicapées (COPHAN)*) was created. The founding assembly of the *COPHAN* took place in 1985. The *Regroupement des organismes de promotion du Montréal métropolitain (ROPMM)*, consisting of 19 disability rights organizations in the Island of Montréal, was founded the same year. In 1986, five disabled women founded *Action des femmes handicapées de Montréal (AFHM)*. They claimed that disabled women's issues were not taken seriously within feminist and disability rights organizations. The following year, disabled feminist Maria Barile, one of the founders of *AFHM*, published a feminist critique of the policy “*À part égale*,” entitled “*À moins qu'à part égale: les femmes handicapées au Québec*” (Barile, 1987). She remembers:

Les groupes de personnes handicapées étaient encore pires parce qu'ils n'iaient. Je me rappelle le directeur de la *COPHAN* à l'époque, quand je suis allée le voir pour lui

demander de l'aide, il m'a demandé pour quelles sortes de sujets. J'ai parlé de violence. J'ai parlé de la statistique qu'on venait d'avoir à Action. Il m'a dit « ben non. Il n'y a personne qui veut agresser une femme handicapée! C'est pas possible. » (Parent & Rouleau, 2011)

In 1989, the Club du Petit Monde du Québec, which was initially founded by three short-statured persons, changed its name for Association québécoise des personnes de petite taille (AQPPT) and officially became a disability rights organization working for the recognition of people with dwarfism as disabled people who should have access to accommodations and services.

### *Disability politics and the rise of neoliberalism in Québec*

Boucher (2005) explains that the creation of OPHQ and the adoption of the policy “À part égale” in 1985 had a major impact on the configuration of social and political dynamics of the Québec disability rights movement (p. 149). The new law conferred the responsibility of financing disability rights organizations on the OPHQ. Furthermore, OPHQ hired several activists from the disability rights movement. Fougeyrollas, Boucher and Grenier (2018) explains that putting people with a profound understanding of disability issues in leadership positions in the public administration has created a climate of trust between the OPHQ and the movement. However, it also has had the effect of weakening the movement since many disability leaders ended up leaving their disability organizations to work for the government (*Ibid.*). For example, Murielle Larivière, a leader in the Comité de liaison des handicapés physiques du Québec and the Mouvement sur les chiens-guides, was hired by the OPHQ. Even though Larivière was employed by the OPHQ, she remains involved in RUTA (Parent, 2010, p. 40). However, as Boucher et al. (2003) note there was an “emergence of a confusion surrounding the objectives pursued by both government organization and the Disability Rights Movement.” (p.153) Disability organizations worked closely with the OPHQ to develop disability policies, however as Boucher et al. (2003) contend “in a more general sense, the disability movement has been affected in such a way that its advocacy role became more oriented to achievement of global policy objectives.” (p.154) Larivière, for one, remembers that after the adoption of “À Part Égale,” disability rights organizations tempered their demands. She says:

J'ai l'impression que cette Politique d'ensemble a eu un effet de somnifères puisque plusieurs représentants de personnes handicapées sont devenus silencieux. Avant 1984, nous sortions dans la rue, nous nous faisons entendre du grand public en utilisant les médias d'information, etc. Et puis, après 1984, nous étions passablement effacés. [...] Les personnes avaient plus facilement de subventions et c'est sûr que quand qu'on commence, on veut pas mordre la main qui nous nourrit, n'est-ce pas? [...] Les représentants d'organismes ont commencé à travailler de plus en plus avec le gouvernement qui

demandait constamment d'attendre car les services allaient s'améliorer." (Parent, 2010, pp. 41–42)

Fougeyrollas, Boucher and Grenier (2018) echo Larivière's testimony: "Graduellement, le recours aux manifestations s'est raréfié pour faire place aux mécanismes de concertation entre l'État et les associations." (p. 161) This period of massive transformations in Québec disability rights politics also coincides with the rise of conservatism and neoliberalism in the province. Even though the Québec government recognized that disabled people should not have to pay costs related to their disability, public expenditures were cut in the second half of the 1980s (Boucher et al, 2003a, p. 159). Nevertheless, various programs, policies and services were developed which opened new possibilities for disabled people. For example, higher education slowly became more accessible. However, many obstacles persisted, and students faced problems accessing the services they needed. Again, as a need was identified, organizations were formed. In 1991, the Association québécoise des étudiants ayant des incapacités au post-secondaire (AQEIPS) was founded by disabled students with the support of COPHAN to promote the rights of these students in Québec post-secondary institutions.

By the second half of the 1990s, there existed tensions between some disability organizations over differing strategies and objectives. In 1995, the Alliance québécoise des regroupements régionaux pour l'intégration des personnes handicapées (AQRIPH) was created. Fougeyrollas, Boucher and Grenier (2018) explain that this led to divisions between the national and regional disability rights organizations (p. 165) and that disagreements between AQRIPH and COPHAN were common in this period. Some disability rights organizations signed agreements with the state to provide services (*Ibid.*, p. 164). This, as Fougeyrollas et al. (2008) argue, had the effect of weakening the movement because the objectives and financing methods were different (*Ibid.*). As result, many disability rights organizations that had been formed in the wake of Bill 9, now found themselves in precarious financial situation. Fougeyrollas et al. (2008) argue that the failure of the state to cover all disability-related costs created inequalities between disabled people themselves which hampered the ability for a broad-based coalition to form. Some disabled people were able to stay at home and participate in Québec society with the support of the services that were offered by the state while other disabled people continued to face obstacles accessing the services and programs that they needed (p. 100).

These inequalities have persisted and in some instances have worsened at the beginning of this century. In *Entre la colère... et la rupture du lien social*, Patrick Fougeyrollas, Line

Beauregard, Charles Gaucher et Normand Boucher (2008) explore the social and health consequences of the inaccessibility of services and financial compensations for disabled people and their relatives. They interviewed 47 disabled individuals and five parents of children with intellectual disabilities living in the regions of Montréal, Québec and Trois-Rivières. They found that disabled people's lack of trust towards public services is particularly acute when they think about the future (p. 109). Parents of children with intellectual disabilities share a similar worry regarding the future of their children when the moment comes that they will not be able to care for them. The wind of optimism and the great mobilization that characterized the Québec disability rights movement in the seventies and eighties no longer blows.

*The Montréal disability rights movement aka "le milieu associatif"*

In the context of Montréal, the past 15 years have been marked by a rapprochement between the local disability rights movement, known as the "milieu associatif" de la défense des droits des personnes handicapées," or simply "milieu associatif,"<sup>21</sup> and different municipal institutions. For example, Ex Aequo, one of the most influent disability rights organizations in Montréal, claims to work in close partnership with the Ville de Montréal, the Agence de la santé et de services sociaux de Montréal (ASSSM), the Société de transport de Montréal (STM), the Agence métropolitaine de transport (AMT), the Centre de réadaptation Lucie-Bruneau (CRLB), the Centres de santé et de services sociaux (CSSS), the Société d'habitation du Québec (SHQ) and the Office des personnes handicapées du Québec (OPHQ). (Ex Aequo, n.d.) Marie Turcotte, the executive director of Ex aequo, has been one of the few spokespersons for the Montréal disability rights movement who was in dialogue with the Ville de Montréal. Turcotte has sat on the board of the STM as a representative for individuals who use Transport adapté.<sup>22</sup>

Regarding accessibility issues, the distinctions between the discourse of the Montréal disability rights movement and various municipal institutions are often difficult to discern. Even though potential conflicts of interest are obvious, there is, to my knowledge, no discussion about them in the movement. Marie Turcotte has regularly claimed that she might wear different hats but she always has the same discourse. The proximity between the movement and the municipal institutions has led to the adoption of policies on universal access. For example, the STM adopted

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<sup>21</sup> It is important to note that all organizations that are a part of the "milieu associatif" conduct their activities exclusively or mainly in French.

<sup>22</sup> She sat on the board of the STM from 2001 to 2017. In December 2017, much to my own surprise, I replaced Marie Turcotte.

one in 2009 and the Ville de Montréal did the same in 2011. The movement has invested much energy in the implementation of policies that stipulate that institutions must eliminate obstacles that prevent disabled people from enjoying equal services in the city. However, there is a caveat in the policy that has allowed institutions to avoid making changes towards the implementation of universal accessibility: the policies state that they will be implemented *according to the financial resources available*. Remember that these policies were adopted at a time when austerity measures struck various spheres of Québec society. This neoliberal political context, which prioritizes budget cuts over social services to mitigate social inequities, has proven problematic. Politicians constantly refer to a lack of funds to justify their inaction, which upholds the presence of obstacles and barriers throughout the city. Furthermore, these policies contain no enforcement mechanisms and do not engage with the private sector. Despite these limitations, the Montréal disability rights movement, led by a small group of leaders (both disabled and non-disabled) from the “milieu associatif,” has been confident and optimistic about the benefits and efficiency of such policies. This group of leaders has succeeded in being recognized as the official representatives of all disabled Montrealers. Close collaborations and partnerships with the city have become institutionalized as the only valid advocacy methods to advance accessibility. To be invited at the table and be part of the conversations and consultations, one had to adopt these methods and be affiliated with the “milieu associatif.”

In 2009, four disabled Montrealers, myself included, founded the Regroupement des activistes pour l’inclusion au Québec (RAPLIQ). The founders of RAPLIQ believed that the movement needed different advocacy methods and tactics, such as direct action and protests, to fight discrimination based on disability. Similar to the organizations that emerged in the 1970s and 1980s, the organization had no funding and no office. What makes the beginning of RAPLIQ different is that the Internet enabled the founders to interact with other disabled people, allies, politicians, business owners, journalists, etc. from their homes. One of the first projects of the organization was to create a website and a Facebook page to make its existence known and to connect with disabled people. The first protest that received media attention took place at Montréal City Hall in December 2010. The protesters denounced the failure of the Ville de Montréal to respect its own transit plan regarding the retrofitting of métro stations with elevators (RAPLIQ, 2010b). This action was not well received within the disability rights movement that favoured close collaboration with the City, and did not use the media. RAPLIQ’s protest was seen as a threat to the partnership between the movement and municipal institutions. RUTA, for

example, reacted by sending a letter to the City reasserting its desire to work in close collaboration. The organization also criticized one of their board members who had joined RAPLIQ's protest. In its first year of existence, RAPLIQ filed numerous complaints with the Commission des droits et libertés de la personne et de la jeunesse, which was another tactic that was generally not used by other disability organizations. On several occasions, the critiques articulated by RAPLIQ towards the Ville de Montréal and the STM indirectly questioned and challenged the advocacy model developed by the movement. Fougeyrollas, Boucher and Grenier (2018) suggest that this new generation of activists, at the periphery of the disability rights movement that developed and established itself as the representative of disabled people, was badly perceived by the organizations that had been around for more than 25 years. About this new generation of activists, they write:

De nouvelles modalités de revendications plus radicales—manifestations événementielles, art engagé, fierté des différences, intersectionnalité, lutte contre le capacitisme et l'audisme, tendance à la juridicisation—marquent cette époque. (*Ibid.*, p. 168)

Social media has been a powerful tool for disability rights activists. In 2013, Richard Guilmette, a disabled man living in Saint-Jean-sur-Richelieu, founded the Mouvement Citoyen Handicap-Québec (MCHQ) with the objective to denounce the numerous injustices faced by disabled people, in particular those requiring home care support to live independently. Like RAPLIQ, MCHQ did not have any office and it made itself known on social media. In 2013 and 2014, MCHQ organized the Marche des 10%, a peaceful protest in the streets of Montréal to demand better living conditions for disabled people. Only a handful of representatives of “traditional” disability rights organizations joined the protests, which again indicates that the tensions between the more traditional disability rights movement and emergent activist organizations. As a founding member of RAPLIQ, I have witnessed and been involved in these tensions. Neither RAPLIQ or the movement trusted each other, which has made the possibility of building genuine alliances nearly impossible. These mobilizations, at the margins of the traditional disability rights movement, have taken place in a context in which the membership of these organizations is aging. The movement struggles to attract the younger generation in its ranks. Fougeyrollas, Boucher and Grenier (2018) attribute that to successful policies that had for effect to integrate young disabled people in mainstream settings (p. 165). They write:

Ce succès d'intégration contribue à leur désintérêt et à leur méconnaissance du mouvement de défense des droits des personnes handicapées, de son rôle d'acteur dans le dialogue avec

l'État et de sa fonction essentielle de vigie pour le suivi et l'évaluation des résultats des politiques dites inclusives. (*Ibid.*)

Even though I recognize that many people from my generation have had access to more opportunities and services than disabled people from previous generations and that this may have pushed them away from getting involved in the disability rights movement, I argue that this is not the main reason why they are not well represented within traditional disability rights organizations and do not know the movement. The battles fought by older activists are generally unknown to younger activists because this history is not yet easily available. It is difficult to be inspired by a movement you have never been told about. I also suggest that the strategy employed by the movement (collaboration with the institutions) may be less appealing than strategies favouring direct action and the use of the media.

In 2014, Didier Gysler and Benoit Racette conducted a study with young disabled people about their engagement in disability rights in Montréal. They found out that disabled youth are represented in small numbers in disability rights organizations, but that a majority of young people would like to be more involved (p. 14). In fact, as the study indicates, some are active on social media and in the traditional media such as the press, radio and television, acting as disability advocates without necessarily being affiliated formally with a disability rights organizations (Breton & Parent, 2015; Parent & Veilleux; 2014; Pomerleau, 2015; Veilleux, 2014). Here there is not only a generational schism, but a schism based on the use of new media. In the traditional disability rights movement, the arrival of new technologies, such as social media, has had very little impact on the working methods (Parent & Veilleux, 2017, p. 8). For example, COPHAN has a website but is still absent from Facebook.<sup>23</sup>

The power of these tools to create a sense of belonging to a movement, at this moment, is worth noting and provides new organizational opportunities. In 2013, Marie-Eve Veilleux and I created the Facebook group *Transport mésadapté* to offer a virtual and public space for disabled people to share their stories about the inaccessibility of public transit in Québec. Twenty months after the creation of *Transport mésadapté*, the group had over 500 members. The rapid growth of *Transport mésadapté* shows that there is a real interest for disabled people to connect online with other disabled people. During its first year of existence, this group succeeded in creating a sense of community among many of its most active members. For example, between December 1 and

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<sup>23</sup> COPHAN joined Facebook on May 29, 2018.

14, 2014, 41 posts were published. Given changes in the mainstream media, which also relies on new media platforms, the group became a source of information for journalists writing stories about transit accessibility issues. As a result, Transport mésadapté has been invited to comment on issues in the media. A few months after its creation, a member suggested creating a disability rights group to fight for the right of disabled people to use public transportation in Montréal. Members of Transport mésadapté replied that such an organization already exists but that it is not participating to the discussions and debates online. This provoked other members of Transport mésadapté to demand that RUTA should be active online and attentive to their stories. RUTA finally commented on the group discussion, but only to exert its own existence as an official organization. RUTA refused to participate in the Facebook group and to pay attention to the stories shared, arguing that Transport mésadapté is not a legitimate group and that many stories are false (Parent & Veilleux, 2017, p. 9). This points again to tensions between more established movements and new activist initiatives, which operate differently from traditional organizations (i.e., no board members, different power dynamics and working methods). For example, many organizations hold their meetings on weekdays. This is an obstacle to participation for disabled people who work or go to school.

Despite these difficulties, the reality of online disability activism is here to stay for the moment, and that the movement is moving forward towards some kind of recognition. In the past few years, some activists have argued that the universal access policies have had a limited impact on disabled people's everyday lives and that coercive measures are necessary to ensure disabled people's rights (Fougeyrollas, Boucher & Grenier, 2018). In 2014, Accessibilize Montreal, an activist group mainly composed of students and allies from Concordia and McGill universities organized a protest in the métro, which and called on the government to adopt legislation to guarantee disabled people's rights (Bachelder, 2014). The group has tried to build bridges with other marginalized populations and regularly claimed that disability politics should be intersectional. The latest initiative I have been involved with is the foundation of Québec accessible. In 2015, five disabled persons, myself included, launched this project to advocate for a new law to ensure disabled people's rights in Québec. The same year, Kéven Breton along with two photographers, launched the project À la porte, an online photo exhibition featuring photographs of disabled people and allies in front of inaccessible métro stations. The website of the exhibition hosted a petition demanding the government to adopt a law enforcing accessibility. This petition has been supported by Ex Aequo, Kéroul, RAPLIQ, Mémo-Québec, Québec

accessible and Société des enfants handicapés du Québec. Research conducted by disability rights lawyer Melanie Benard (2017) and Lucie Lamarche, Andrey Leshyner and Linda Gauthier (2015) also have argued for legislative changes.

All these actions have forced COPHAN to address the issue of accessibility legislation. In January 2016, Québec accessible was invited to give a presentation to the COPHAN members. Following this presentation, COPHAN set up an internal committee to investigate the issue and eventually determine whether or not advocating for legislative changes was a necessity.<sup>24</sup> Moreover, another sign that things might be changing: in October 2016, at the 15<sup>th</sup> anniversary of the métro, RUTA called for a protest to denounce the underground public transit system's lack of accessibility. The protest ended up gathering together different disability organizations and groups such as RAPLIQ and Transport mésadapté. At the moment, it is difficult to assess the impact of such interactions between traditional organizations and new disability activism initiatives on the overall disability movement in Québec, but they must, at least, be acknowledged. The influence of online disability activism on Québec's and Montreal's disability politics can be expected to grow in the coming years.

In the next section of this chapter, I explore the politics of procuring a mobility aid in Québec. This is a process that I took for granted until I realized that not everyone who needs a mobility aid can access one with ease. This provides an example of a disability issue that cannot be universalized, since the politics of acquiring mobility aids vary from one province to another. Although mobility aids are considered medical devices—and health care services must, in theory, be free across Canada—not all provinces cover their costs. In Québec, one must meet specific criteria to get a mobility aid, which, theoretically is fully covered through the public health system. This opens the door for inequalities between disabled people depending on their medical diagnoses.

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<sup>24</sup> However, this initiative has been put on hold on September 2016 due to the lack of interest of committee members to make it a priority. Some leaders in the movement, who have been involved for many years and are disappointed by the mixed results of the *Act to secure handicapped persons in the exercise of their rights with a view to achieving social, school and workplace integration*, which was modified in 2004, claimed that a new law would not change anything because it would not be enforced.

## ***The politics of acquiring a mobility aid in Québec***

*When I told my mom that my friend Pierre got his first power wheelchair when he was only five years old, she, just like I had, reacted with surprise. A few days later, she told me she had thought about it and wondered why I only got one at twelve years old. She wondered if she would have advocated for one and if I would have liked to have one at such a young age. She confided that she and my father did not know anything about what to expect in terms of my mobility when I was young. They trusted the doctors. I told her that they were right, not only to reassure her but also because that is really what I think. What I feel. I don't feel like I have missed anything. On the contrary, I have vivid memories of the fun I have had using my manual wheelchair. I remember the contact of my hands on the wheels trying to wheel as fast I could and the mix of dirt and blood on my fingers. I remember the fun I had wheeling freely in the mall while my mom was shopping. I remember feeling that I was the fastest wheelchair user around (I don't think I ever met another one at this shopping mall). I felt great. When I was wheeling fast, no one could stop me to ask intrusive questions in an infantilizing tone. When I was wheeling fast, I was too focused on my speed to notice if people were staring at me.*

*I rarely think about my experiences with the medical world and their implications for my life story. However, thinking about disability from a critical perspective should not mean rejecting my experiences with the medical world. These experiences matter. Even though I remember going to medical appointments from a very early age, I don't have any clear memories about any discussions about my mobility. A few years ago, I found a copy of the notes taken by Dr. Marie Laberge-Malo, whom I have been seeing since I was three. These notes allowed me to revisit parts of my past from another perspective. Dr. Laberge-Malo is the doctor who prescribed my first manual and electric wheelchairs. One note dated December 1995 revealed that my mother had asked my doctor if I could get a power wheelchair when I was 10. Contrary to my mother's memory, she did not passively wait for the doctor's decisions. She was actively involved.*

—February 4, 2017

*Dr. Marie Laberge Malo's note:*

*“Côté déplacements, la mère demande s'il n'y aurait pas possibilité d'un fauteuil roulant motorisé lorsque l'enfant ira au secondaire pour faciliter ses déplacements et son autonomie. [...] Nous prévoyons, à la prochaine visite, un moulage pour un fauteuil roulant motorisé pour que Laurence soit davantage autonome dans ses déplacements lorsqu'elle ira à l'école secondaire.”*

—December 19, 1995

Even though there is ample material in critical disability studies literature that criticize the negative connotations associated with the use of a wheelchair, there is little written from the perspective of disabled people on the process of acquiring a mobility aid—a process that varies from one jurisdiction to another in Canada. I did not find anything on the process in Québec. During the wheeling interviews, I asked wheelchair and scooter users about their first memories

with their mobility aids. Their responses pointed to the complexities of transitioning towards being a mobility aid user and the limits of public mobility aid coverage in Québec. In this section, I explore the politics of getting a mobility device in Québec, which involves an assemblage of the rehabilitation industry, government policy, healthcare professionals, family, a culture of ableism and the built environment.

### *The Québec system*

Canada's constitution distributes legislative powers between the federal and provincial/territorial governments. The Canadian provinces and territories have responsibility for healthcare and must provide medically necessary services to insured persons. Eligibility and service coverage vary between the provinces and territories. The *Health Insurance Act* states that an insured person is a resident or temporary resident of Québec who is registered with the Régie d'assurance maladie du Québec (RAMQ). This public insurance does not apply solely to medical services but includes a variety of devices used by disabled people, such as wheelchairs and scooters. In order to be eligible, an insured person must obtain a medical prescription that indicates the "nature" of the disability and go to one of the facilities authorized by the RAMQ (RAMQ, 2016).<sup>25</sup> Simply put, the state controls who gets mobility aids, which are covered by public insurance, and who do not. In doing so, the provincial government regulates the mobility of disabled people. This is a manifestation of what Michel Foucault (1975) calls "disciplinary society." Foucault argues that power is largely exercised through disciplinary institutions, such as schools, prisons and hospitals. By having the power of deciding who is disabled enough to get a mobility aid, the state directly intervenes in the shaping of how certain disabled bodies can move.

Among the 12 participants using a wheelchair or a scooter, 10 of them got their mobility devices through the Québec healthcare public system. Geneviève, Louise and Nabila each faced a different limitation within RAMQ's coverage. Geneviève's and Louise's mobility aids were not covered by the public insurance, whereas Nabila had to wait three months for her mobility aid after her arrival in Québec in 2009. According to a RAMQ rule, any person arriving in Québec

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<sup>25</sup> Fougeryollas et al. (2008) explain that the coverage of disability-related costs in Québec varies from one disabled person to another according to the cause of the disability and the type of disability. For example, a wheelchair user that has cerebral palsy from birth does not have the same coverage as a person who becomes a wheelchair user in an accident involving a vehicle. The first individual's wheelchair is covered by the RAMQ while the second individual's wheelchair is covered by the Société de l'assurance automobile du Québec (SAAQ).

from another Canadian province or another country must wait a period up to three months before being granted coverage by the RAMQ. This is a significant problem for disabled people arriving in Québec without the mobility aid they need. Nabila arrived in Québec from Algeria without the mobility aid she needed. Shortly after immigrating, she was put in touch with Wassyla Hadjabi, a disabled woman involved in helping disabled women and immigrants exercise their rights in Québec. Wassyla helped Nabila make an appointment at her local CLSC in order to get the wheelchair she needed just to leave her home. However, she was told she was not yet eligible. She remembers her first experience of discrimination in Montréal:

La première fois que j'ai été discriminée à Montréal c'était au CLSC Côte-des-Neiges. J'ai été très mal reçue. La personne à l'accueil m'a refusé tous les services. À cause du droit. J'avais droit à rien. Je voulais emprunter un fauteuil manuel. Il me fallait au moins un manuel pour sortir. Mais elle a refusé car je n'avais pas encore ma carte de la RAMQ. Ça prend trois mois. Je suis restée trois mois chez moi. Je sortais parfois avec mes cannes.

It was only after a frustrating delay that Nabila had access to a wheelchair and started to move around her new city.

Geneviève's wheelchair and the FreeWheel, a device she regularly attaches to her wheelchair to improve her ability to navigate curbs and other obstacles, are not on the list of mobility devices approved and covered by the RAMQ. The wheelchairs that are covered are not as light as Geneviève's wheelchair, which is made of titanium. Having a light wheelchair is key to Geneviève's mobility. Luckily, she was able to afford her wheelchair through private insurance. Of course, the list of devices covered is subject to change over time. Manufacturers design new wheelchairs and technologies evolve. However, the most expensive and technologically advanced devices tend not to be included on the RAMQ list. Furthermore, RAMQ can change eligibility criteria.

France talks about one change that affects people using powered mobility aids in Québec. While it used to be possible to have both a motorized and a manual wheelchair, this is now only possible for disabled people who work or go to school. "Moi j'ai eu mon fauteuil, mes deux fauteuils à une époque où on pouvait avoir deux fauteuils," she explains. The RAMQ did not cover Louise's mobility aid even though the mobility aid that she uses is on RAMQ list. Louise's occupational therapist refused to write her a recommendation for a scooter. "L'ergo m'a toujours dit que ça ne valait pas la peine," she says as we are wheeling in Jarry Park and talking about how useful her scooter is in her everyday life. As a result, Louise relies on the support of her family to

pay for her mobility scooters. Since 2003, she has had three mobility scooters, all paid for by her family. Louise explains that snow and rain create rust, which reduces the scooter's life. Patrick Fougeyrollas et al. (2008) assert that since access to free and public disability services is based on a medical diagnosis and type of disability, some disabled people have their needs met more than others. André Guillemette et al. (2001) claim that without adequate coverage, numerous disabled people must pay for disability related costs out-of-pocket (as cited in Fougeyrollas et al., 2008, p. 102). For many people, this worsens their already precarious financial conditions (Berthelot, 2006; Fougeyrollas et al., 2005). Louise's experience with her occupational therapist when trying to get a scooter covered by RAMQ shows the powerful role played by healthcare professionals in the process of getting a mobility aid in Québec.

### *Healthcare professionals and childhood*

The role of healthcare professionals is particularly critical when the person getting a mobility aid is a child. Most participants using mobility aids got their first set of wheels when they were minors. In all cases, their parents were able-bodied and had never used a mobility aid. Marie-Eve and Marie-Josée have talked about their interactions with health care professionals during their childhood and the impact of these interactions on their perceptions of walking and wheeling. Marie-Eve's ability to walk has varied over the years, depending on flare-ups of her arthritis as well as the medical interventions she has undergone. Marie-Eve explains me that she had been raised to think that she should maintain her physical capacity and that she is responsible for its maintenance:

Avec l'arthrite, j'ai juste comme toujours été élevée avec l'idée qu'il ne faut pas que tu perdes ce que tu as. Dans une pensée très réadaptation. J'avais de la physio toutes les semaines. Il fallait que tu fasses des efforts même si ça fait mal. Il faut que tu forces par-dessus tout parce que si tu arrêtes de l'utiliser, tu vas le perdre.

Marie-Josée was confronted by her doctor's similar misunderstanding of the value of walking over wheeling. In a follow-up discussion on Facebook Messenger, she shares with me bitter memories about her childhood and early adolescence. She remembers that on shopping trips with her mom, for example, she was carried in a stroller until the age of 13. Walking long distances was too difficult and she did not have a wheelchair. She hated the stroller and as a result she avoided going out as much as possible. "Rendue à 13 ans, j'avais mal au coeur à chaque fois en poussette," she recalls. Sometimes her parents would carry her in their arms. "Je me demande encore comment j'ai pu supporter ça. [rires] Je peux bien avoir eu une grosse crise

d'adolescence!", she exclaims. When she finally got a prescription for her first wheelchair, her doctor told her she was subjected to the admonition to walk: "Je te prescris le fauteuil, mais je veux que tu marches."

Marie-Eve's and Marie-Josée's testimonies echo Mike Oliver's (1990) claim that the medical rehabilitation industry, comprised of doctors and various healthcare professionals, does not value the use of a wheelchair. Oliver argues that the personal choice of not walking "threatens the power of professionals, it exposes the ideology of normality and it challenges the whole rehabilitation enterprise." (as cited in Sapey, p. 494) Marie-Eve's and Marie-Josée's testimonies point to a lack of understanding on the part of this industry in Québec, their power over disabled people, and the lack of autonomy and agency experienced by disabled children and teenagers in the decision of whether to use a mobility device or not. Neither Marie-Eve nor Marie-Josée were informed about the potential benefits of using a mobility aid.

Scholarship on children's mobility has explored how they navigate their environment and the obstacles they face (Barker et al., 2009; Murray, 2009). However, most of these studies have been on the population of able-bodied children. For example, Robin Kearns and Damian Collins (2003) argue that increased car use and intensifying traffic have reduced the number of children travelling between school and home independently. Literature on disabled children does not look at their mobility in their environment, but more broadly focuses on their lived experiences as young disabled individuals (Connors and Stalker 2007; Jahoda et al., 2010; Rabiee et al 2005; Goodley & Runswick-Cole, 2013) and their participation in leisure activities (Shikako et al., 2014). In a study on disabled children's perceptions of technical aids, Lisa Skär (2002) interviewed eight children aged six to eleven years old using either a wheelchair, walking trolley or crutches. She found out that they did not consider their technical aids as barriers in play and as something external to their bodies. Likewise, Barbara Gibson (2016) argues that "young children do not necessarily perceive disability in negative terms. Instead they are curious and welcoming of differences. Those who use walkers and wheelchairs may take special pride in their devices, and other children may want to try these out or "go for a ride."

In the case of the participants in my study, Pierre started using a wheelchair earliest in life. At age three, he used a scooter designed for adults. A footrest made of wood was added to accommodate his short legs. At age five, he was given his first power wheelchair just in time to

start kindergarten. He vividly remembers that he used to play with his friends and cousins and that his wheelchair was fully integrated into their games:

C'était intense, mais écoute, c'était mes meilleures expériences. C'est ce qui m'a permis d'aller à l'extérieur et tout le kit. C'était loin d'être parfait. Écoute, je suis tombé à de multiples reprises. Ce n'était pas aussi sécuritaire que ce l'est maintenant. [...] C'est dur à croire que j'avais le droit d'utiliser ça, mais tu vois, j'en suis pas mort donc ça a quand même bien marché. Ça me permettait de sortir dehors. J'habitais à Drummondville, mais plus un peu à l'extérieur de la ville, donc je pouvais aller dans le bois. Je pouvais aller me promener quand même pas mal avec ça pis suivre mes parents, ma mère en vélo.

Pierre's story is unusual because even though research shows that using a power wheelchair does not compromise the development of motor skills and that independent mobility is beneficial for the development of disabled children (Douglas & Ryan, 1987; Paulsson & Christoffersen, 1984), the use of manual wheelchairs generally is favoured by health professionals over the use of power wheelchairs.<sup>26</sup> I ask Pierre why and how he got his first power wheelchair at such a young age. He does not know. Later in the interview, while reflecting on his happy childhood and his everyday life as a young adult, Pierre claims that without his parents he would not be where he is today. He explains that his parents worked hard to make sure he had all the services and support he needed. When he moved in Montréal at age 22, he already had a lot of experiences as a wheelchair user. This helped him to explore the city and he quickly felt at ease wheeling wherever he needed to go.

Isabelle has had a very different experience. She explains that the government only accepted to cover her first power wheelchair when she started to attend a regular high school, suggesting that the preference to prescribe manual wheelchairs is embedded in the public insurance system, as well as in cultural values within the medical system:

De 0 à 14 ans, je ne pouvais pas sortir toute seule. J'étais vraiment dépendante de ceux qui me poussaient. J'ai eu mon électrique à cause que j'ai été acceptée à l'école secondaire régulière. Là, le gouvernement a accepté de m'en donner un. C'est sûr que, honnêtement, je ne m'en passerais plus.

She argues that she had very little independence with her manual wheelchair and constantly relied on her mother. "J'ai tout le temps été éduquée à être dans les poches de ma mère. Ça vient aussi de là le fait que je n'ai pas été rapidement à l'aise de circuler tout seule. Elle m'a beaucoup

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<sup>26</sup> In a journal article published in 1987, Jo Douglas and Martina Ryan explain that some disabled infants as young as eight months old can increase their mobility experiences by using power wheelchairs.

protégée, surprotégée,” she remembers. Isabelle explains that her power wheelchair increased her autonomy at school but did not significantly change her everyday life mobility in everyday life:

Au début, quand j’ai eu ça à l’école secondaire, c’est le TA qui venait me chercher et qui venait me porter. Je n’étais pas du tout, pas du tout libre. On ne m’avait pas appris à circuler librement dans la ville. Pour moi, c’était juste aller à l’école et revenir. Pis quand je sortais en famille, c’était pour aller au Biodôme, aller voir des musées, mais pas pour circuler librement.

Isabelle’s story recalls the research of Cheryl Missuana and Nancy Pollock (1991), who found that disabled children are more often in presence of adults than able-bodied children. They explain that this can “increase their need for help from adults and make them less socially competent.” (as cited in Skär, 2002, p. 32) Isabelle states that the lack of experience in her youth delayed the moment that she started to wheel the city by herself. She remembers how scared and excited she felt the first time she used the sidewalk with her wheelchair.

The differences between Pierre’s and Isabelle’s childhood mobility experiences and their capacity to navigate Montréal independently as young adults are significant. Even though Isabelle and Pierre both had disabilities that affected their motor skills, they have experienced different journeys in the process of acquiring a power wheelchair and in the development of their skills as wheelchair users. This points to several entangled factors influencing this process, such as parents and healthcare professionals’ perspectives on the mobility of children, and the environments in which children live (e.g., regular school versus specialized school, rural area versus urban area), and the values embedded in the present public insurance system.

### *The bumpy road of internalized ableism and physical obstacles*

Kéven told me that he first realized he was different from other children when, at a very young age, he struggled to follow his friends who suddenly all climbed a set of stairs. He got his first manual wheelchair when he was about ten years old. He did not have any specific memories about the event. He was neither excited nor unhappy about the manual wheelchair. To explain the subdued nature of his reaction, Kéven suggests that he was well prepared for the arrival of his manual wheelchair by his family and doctor. Using it simply happened naturally. Marie-Eve, Marie-Josée and France had very different stories to tell. They remember resisting, to various degrees, the use of a wheelchair.

Barbara Gibson (2016) argues that “over time kids learn that their differences can negatively mark them as different or “just not good enough.” The attention of well-meaning parents, health professionals and teachers who try to “fix” difference sends this message loud and clear. When Marie-Eve got her first manual wheelchair in her first year of high school, she was delighted to discover that, with the help of her family and friends, she could get around without physical pain. She started using her wheelchair full-time, and within two months she was not able to stand up anymore. After many surgeries, she went through a very difficult rehabilitation process to regain the ability to walk. She associated this experience with a failure and felt guilty. At school, Marie-Eve used a manual wheelchair. However, she could not push herself and always needed assistance. When someone working at her high school recommended that she use an electric wheelchair to be more independent, she completely rejected the idea. “J’étais super réticente. [...] Je ne voulais rien savoir,” she says. At her graduation ceremony, Marie-Eve could not bring her wheelchair for a practical reason<sup>27</sup> and she walked on the stage to get her diploma without thinking about how it could be perceived. She got a standing ovation and quickly realized that her classmates and teachers, who only knew her as someone who uses a wheelchair, were thrilled to see her walking to get her diploma. “Je me suis dit qu’ils m’applaudissent parce que je marche. Ils me trouvent inspirante dans le sens qu’ils pensent que j’ai réussi. Ça a renforcé ce sentiment là. Tsé, marcher c’est réussir sa réadaptation,” she remembers.

Janice McLaughlin (2017) explains that “avoiding social stigma is one aim of the disabled young people’s compliance with medical procedures. They sought a body that interacted with others in expected ways—for example, by being able to walk rather than use a wheelchair.” (p. 249) At the age of 27, Marie-Eve finally agreed to get a mobility scooter, which her occupational therapist highly recommended to her. “Je n’ai pas mis les freins. J’étais comme ‘ok on va essayer ça’ en me disant qu’au pire, je ne l’utiliserais pas. On s’en fout,” she says, explaining that throughout her life healthcare professionals have prescribed her assistive devices that she has never used because it was not practical for her.

Marie-Eve describes discovering a world that had been out of her reach:

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<sup>27</sup> Her best friend Sabrina, who was a full-time wheelchair user, was going to her graduation ceremony. However, Marie-Eve’s mother’s car could only fit one wheelchair. Because Sabrina could not walk at all and needed her wheelchair, Marie-Eve had to leave her own wheelchair at home.

Ça a été toute une découverte pour moi parce que je ne me souviens même pas d'avoir été genre au dépanneur du coin, même par moi-même, tsé. Je n'ai jamais fait une commission. Je n'ai jamais fait une marche dans le but de prendre une marche. Je n'ai jamais fait tous ces trucs là, que les gens qui n'ont pas de limitations ou de maladies chroniques, peuvent faire. [...] Quand j'ai eu mon quadriporteur, j'ai passé ma vie au Parc La Fontaine! ([see video Veilleux-3](#))

While her scooter changed her life for the better, driving the scooter hurt her elbows. Two years later, her new occupational therapist told her that her scooter was not appropriate for her body and prescribed an electric wheelchair. “Elle m’a dit que tu ne prescrites pas un quadriporteur à quelqu’un qui fait de l’arthrite. Comme si c’était une évidence. Mais en même temps, je pense que j’avais besoin de cette marche là pour accepter le fauteuil,” she admits. Marie-Eve adds that making new friends who are using power wheelchairs has been a source of motivation. Using a power wheelchair also has had an impact on her relationship with her parents, who have been separated since she was a child. She remembers that she used to feel very frustrated when her mother pushed her manual wheelchair, which affected their relationship. She argues that this reliance on her mother made it difficult for her to become independent. Being able to get around without her mother’s help helped her to grow and make decisions without constantly needing her mother’s approval:

C’est elle qui était pognée pour me pousser la plupart du temps. Dans tous nos voyages, ça affectait énormément notre relation qu’elle me pousse et que je sois complètement prisonnière de ses décisions tsé. Elle décide de tourner à gauche, on va tourner à gauche. On s’est vraiment engueulées des fois. C’était vraiment intense à quel point ça m’irritait. [...] J’ai de moins en moins besoin de son approbation pour chaque décision que je fais. Avant, je l’appelais pour chaque maudite décision. Je pense que ça m’a permis, et c’est aussi ce qui permet ma mère, d’avoir une vision plus positive et de se joindre à nos, à mes revendications. Par exemple, de dire que ça a pas d’allure qu’il n’y ait pas de métro accessible.

Marie-Eve confides that the situation is different with her father. He hopes that she will get surgery and be able to get rid of her wheelchair. “C’est super important pour lui de remarquer. [...] Le fauteuil, il l’appelle ma charriette. Ma charriette de feu comme dans je ne sais pas quel film. Je pense pas qu’il voit les cotés positifs et tout ce que ça m’a donné,” she sighs.

France was introduced to the world of disability abruptly at 17 years old after a dramatic dive that broke her neck. Since her legs were paralyzed, she had no choice but to use a wheelchair. Although she received two wheelchairs from the RAMQ—a manual and an electric one—she chose to store her electric wheelchair in a closet. For eight years, she refused to use it.

“C’était vraiment une question d’orgueil. Je ne voulais pas embarquer dans mon fauteuil électrique. Donc oui, il était dans un garde robe et il ramassait la poussière,” she admits. At the time, France felt that an electric wheelchair made her look more disabled, something she absolutely wanted to avoid.

These three testimonies indicate a desire to not be identified as disabled or at least severely disabled. For example, after blaming her doctor and her parents’ lack of knowledge for not having a wheelchair before the age of 13, Marie-Josée formulates a hypothesis. “Peut-être aussi que je n’en voulais pas de fauteuil roulant. J’étais très rebelle et je ne me voyais pas handicapée,” she suggests. These are, perhaps, manifestations of internalized ableism. Fiona Kumari Campbell (2008) explains that similar to internalized racism, internalized ableism is not the result of a single event but of repetitive experiences.<sup>28</sup> Penny Rosenwasser (2000) defines internalized racism as:

an involuntary reaction to oppression which originates outside one’s group and which results in group members loathing themselves, disliking others in their group, and blaming themselves for the oppression—rather than realizing that these beliefs are constructed in them by oppressive socio-economic political systems. (p. 1)

Campbell (2008) argues that “internalized ableism utilizes a two-pronged strategy, the distancing of disabled people from each other and the emulation by disabled people of ableist norms” (p.155). Furthermore, internalized ableism affects disabled youth in a particular way. As Bill Hughes, Rachel Russell and Kevin Paterson (2005) suggest, disability and youth are at odds in consumer culture:

Youth signifies beauty, hope, potency, vigour, and strength. These “ideal-typical” traits suggest that youth as a concept embodies everything that is not anomalous as well as everything that one might desire to represent one’s identity. In fact, the category of youth, as a desired attribute of identity, implies the erasure or transcendence of anomaly. Disability is a signifier of ugliness, tragedy, asexuality, invalidity and frailty. [...] Youth and disability, as signifiers, in a culture of consumption in which the “external territories” of the body are paramount, are opposite and incompatible. These binaries position youth and disability as “categorically” incompatible. There is no way in which one can square the difference because the opposites repel rather than attract. Disability and youth are in profound tension and the logo centric imaginary is unable to bring them into harmonious relationship. (pp. 12–13)

In addition to having to deal with shame and ableism when getting a wheelchair or a scooter, some participants talked about the new obstacles they encountered when they

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<sup>28</sup> I explore the concept of internalized ableism in greater detail in Chapter 6.

transitioned from either walking to wheeling or from wheeling with a manual wheelchair to wheeling with an electric wheelchair.

Nabila recalls how her first electric wheelchair gave her much more freedom and independence than anything she had experienced before. However, throughout the interview, she shares several stories of exclusion and discrimination based on the inaccessibility of the built environment. “C’est une liberté, mais en même temps avec ce que tu me racontes, c’est une liberté nuancée,” I tell her. Nabila replies:

C’est ça qui fait mal parce que l’on se dit avec le miracle d’un fauteuil motorisé, de faciliter, de faire les choses, mais en même temps, tu te retrouves bloquée à cause d’une marche, d’un trottoir, d’un transport. C’est ça. Ça devient un outil négatif.

France remembers that she had decided to start using her electric wheelchair because of her love for an outdoor university class on the history of Montréal. She had to visit different neighbourhoods and quickly realized that she could not ask her companion to push her wheelchair and take notes at the same time.

Once France started using her electric wheelchair, it never went back into the closet. Not only did France have to come out, but she also experienced a grieving process:

Il a fallu, quand j’ai commencé à être en fauteuil électrique, que je fasse le deuil, par exemple, de tous les commerces qui avaient une marche parce que quand tu es en fauteuil électrique dès qu’il y a une marche, c’est un obstacle. Mon fauteuil électrique doit peser autour de 300 livres donc c’est impensable de demander l’aide à quelqu’un dans la rue. [...] C’est léger un fauteuil manuel donc tu peux sortir. Tu peux aller partout. J’allais même dans des bars au 2<sup>ième</sup> étage. Je me faisais transporter. Ça, ça été vraiment un changement de vie.

She explains that getting a power wheelchair changed her relationship with Montréal. Some of the places she used to go on a regular basis disappeared from her personal map. She had to rediscover her city and the places she would be able to navigate. In addition, France needed to learn *how* to wheel. She recalls the following challenge of crossing at a light:

Au coin d’une rue, la lumière était verte et on dirait que j’avais de la difficulté à estimer s’il me restait encore assez de temps. On dirait que je ne comprenais pas la vitesse à pied pis la vitesse en fauteuil. [...] Je vivais un peu d’angoisse de traverser des grosses artères comme St-Denis, des rues ou tsé des boulevards comme le boulevard Taschereau. [...] Ça ça me faisait vivre des émotions. Ça me faisait vivre du stress alors qu’aujourd’hui, c’est tellement naturel la conduite.

In terms of people's attitudes towards her, France says that most people do not make a distinction between manual or electric wheelchairs. Moreover, she vividly recalls the great pleasure she felt during her first strolls. With nostalgia in her voice, she says: "Je faisais mes rides à 100 miles à l'heure pendant quatre heures de temps juste parce que j'étais libre." The first summer she had her motorized wheelchair, she went up and down the Mount Royal numerous times. She especially enjoyed gaining as much speed as she could on her descent. She remembers:

J'avais l'impression de faire du jogging ou d'être complètement être investie de tout mon corps, de tout mon esprit alors que je poussais une manette. C'était tellement libérateur de pouvoir aller vite. J'ai fait ça pendant trois étés de temps, je pense. Je faisais ça pour rouler. Juste pour rouler.

Christian's debut as an electric wheelchair user went smoothly than that of some of the other participants. He admits that although becoming an electric wheelchair user meant that he no longer had access to regular public transit—the network was completely inaccessible at that time—that he did not see his new wheelchair as an obstacle. He explains with humour, the transition:

La transition s'est bien faite. En fait, je ne voyais pas cela comme un obstacle de plus, mais davantage comme un bien fait. Cela me demanderait moins d'énergie et j'allais faire moins de chute, donc me blesser moins et... me coûter moins cher en jean!

For Christian, the advantages clearly outweigh the disadvantages.

Caroline has fond memories about her first days using a motorized wheelchair and claimed that wheeling brought her pleasure from day one. Prior to using a wheelchair, Caroline could only walk short distances. The pain of walking was unbearable. When I asked Caroline how she felt when she got her first power wheelchair nine months prior to the interview, she replied with enthusiasm:

J'ai sauté de joie! J'étais tellement heureuse. C'est drôle de se faire dire ça hein? [...] Pour moi, ça a été une délivrance face à la maladie. [...] Je suis vraiment contente. Je me promène partout. Je fais mes commissions. Je me sens libre de faire ce que j'ai le goût de faire. ([see video Goyette-1](#))

Geneviève spoke of the inaccessibility of the city and she confides that she anticipates getting a mobility scooter in the future. As time passes and the condition of the sidewalks in Montréal seems to be worsening, using a manual wheelchair is harder on her body. Considering that wheelchair access is extremely poor in Montréal, she is aware that she will not be prohibited from entering into even fewer places. "C'est une aide et c'est une nuisance parce que ça va

t'empêcher de faire autre chose," she says, noting that this assistive device both allows her to be mobile, yet also impedes access. Geneviève's hesitation to procure a mobility scooter, as well as other participants' reflections on the compromises they make to attain freedom and independence, shows that the limitations experienced by mobility aid users is not disconnected from the environments in which they move.

### ***Conclusion***

This chapter not only provides some context to situate the participants' stories, but it raises several issues. In terms of a historical context, I believe I have conducted wheeling interviews at a particularly significant moment in terms of the history of disability rights. The movement today is at an important crossroad and faces enormous challenges. For example, the lack of home support jeopardizes some disabled people's right to live at home, outside of institutionalized settings, and the right for disabled parents, like Caroline, to care for their own children. This crisis has forced some disability organizations to organize protests to raise public awareness and to try and pressure governments to make change (Duchesneau, 2017; Raymond, 2018). Unfortunately, the Francophone media's coverage of these actions is generally poor. In terms of accessibility issues, the "milieu associatif" can take pride for making "accessibilité universelle" a familiar concept amongst city officials and for gaining recognition in urban planning projects and policies. However, the concept is regularly misused with alarming regularity. On several occasions, for example, I have witnessed political parties indicate that their event is "accessible universellement" even though the only accessibility feature is a ramp at the entrance. Furthermore, the concept itself is, in my opinion, confusing: it implies that it is possible to design a space that will meet all individuals' needs and that everyone can navigate a space without assistance. Aiming for high standards of accessibility is important and necessary. However, individual accommodation and interdependence between human beings is essential and should not be overlooked. Moreover, there is a tendency to push for accessibility on the pretext that it is good for everyone: from parents with prams to travellers with suitcases. While this is true, this argument erases the fact that accessibility is not just something that's "nice to have" for those who have other options, or for whom accessibility is a temporary condition connected to a specific activity. Accessibility is a necessity and a right for disabled people.

The gap between disabled people's concerns and wishes and the discourses and priorities of disability organizations cannot be ignored. The issue of legislative change testifies to that. One of Justin Trudeau's commitments during the 2015 federal election was to enact a federal law to ensure the rights of disabled Canadians by 2017. In 2016, the Government of Canada organized public consultations on this law in various Canadian cities with the objective of obtaining a better understanding the preoccupations of the disabled population coast to coast. I attended the consultations in Quebec City and Montréal.<sup>29</sup> Most of the issues raised by the numerous participants, including healthcare, education and transportation, fall under provincial jurisdictions, which means they will not be addressed in the new federal act. People who intervened in the consultations by asking questions or sharing their experiences were clearly in favour of strong legislation. Their exasperation with obstacles and discrimination was clear. One would think that these consultations would have convinced the leaders of some disability organizations of the need for a new disability law at the provincial level, but so far, no such law is on the agenda of the movement in Québec. In the meantime, disability laws have been adopted in the past few years in other provinces such as Ontario, British Columbia and Manitoba (Bradley, 2017).

Furthermore, the Québec disability rights movement needs to question how it represents the diversity of disabled people. Despite the work of organizations such as Action des femmes handicapées de Montréal (AFHM) and Association multiethnique pour l'intégration des personnes handicapées (AMEIPH), the complexities of disabled people's lives are rarely considered by larger disability organizations (e.g., disability issues in First Nation communities and additional obstacles faced by queer and racialized disabled people), while other communities and movements continue to regularly exclude disabled people from their spaces and their battles and do not consider ableism to be a form of oppression (Parent, 2017). For example, the Confédération des organismes de personnes handicapées (COPHAN) wrote a brief about the *Charte des valeurs* proposed in 2013 by the provincial government of Pauline Marois. Although COPHAN opposed the *Charte*, it did not adopt an intersectional analysis that took into account race and gender, for instance (2016). Instead, it analyzed the issue from the point of view of secular disabled people by omitting that the consequences of how such a *Charte* would be

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<sup>29</sup> The Montréal consultation was particularly well attended. I had never seen that many disabled people and allies in the same place.

different for, for example, Muslim women with disabilities wearing the hijab and men with disabilities wearing the turban.

The brief overview of the politics of obtaining a mobility aid in Québec, through the experiences of the people I have wheeled with in Montréal, indicates the ways that disabled people are in a highly political, uncertain terrain when navigating this process. Although mobility aids are covered by Québec's public health insurance, access to these aids is influenced by social, political and cultural issues. Different actors such as health care professionals and parents, in the case of children, are involved in the process. For participants who obtained their mobility aids during childhood, some health care professionals have facilitated the process while other have been resistant to assisting people to make decisions. As geographer Yi-Fu Tuan writes, "standing and walking—these characteristically human activities—require encouragement and coaching from adults." (p. 67)

In the case of participants using wheelchairs and scooters, both children and adults have independently learned how to use their mobility aids and incorporate them in their everyday life. These first experiences using such a device have been an important moment in the participants' lives and has impacted how they have learned to wheel and even how they navigate the city today as what Tim Cresswell (2006) would call "prosthetic citizens." It is important to note, for example, that even though Laurence and Luc do not use wheelchairs or scooters they use mobility aids, i.e., a white cane and an assistance dog. The use of these aids mediates their relationship with their environments.

In the next three chapters I will explore in depth the themes that are most discussed by the participants, what it means to get around Montréal today, and the different tactics used by disabled Montrealers in a city that constantly constrains their mobilities. In doing so, I will engage with participants' childhood memories because the obstacles they encounter generally have changed over their lifetimes.

## Chapter 4

### Wheeling Montréal: navigating the uneven geographies of the ableist city

*The easiest way to wheel to Pierre and Marie-Eve's condo from my place is to take the bike path along the railroad separating Rosemont–Petite-Patrie and Plateau Mont-Royal. It is about a 10-minute ride. The bike path is gravel and there are some holes here and there, but it is quite flat and smooth. There is no traffic light to stop you. Since the bike path is located between the railroad and warehouses, it is a nice little gateway from the action of the city in the city itself. It is one of my favourite places to wheel in Montréal... during the day.*

*One summer night, I decided to take the bike path to go back home. I had never taken it at night before. I expected to be a bit scared because of the dark, but thought that should not stop me from saving a few minutes and avoiding uneven curbscuts and sidewalks. I did not imagine it would be this dark. I could not see the ground at all. I had to use my phone to light the ground I was wheeling on. Wheeling into a hole at full speed could be dangerous. And then there was the sound. The sound made by the contact of my wheels on the gravel. I had never heard it like this before. Rationally, I knew it was just the sound of my wheels on the gravel but, in the dark of the night, it sounded like someone was following me. Joggers and pedestrians walking their dogs had deserted the bike paths. For the exception of a few cyclists, I was alone.*

*Well, was I? All I could do was to keep going to the next exit and hold my phone tight in my hand.*

*I ended up making it out safely but I never took this bike path again alone at night. One evening, before leaving Marie-Eve and Pierre's, I told them that I wished I could take the bike path to go home but that I was too scared. Marie-Eve immediately acknowledged my fear and said she would not wheel on the bike path either, while Pierre claimed that he would without even hesitating. Marie-Eve turned to me and said that Pierre did not understand the fear that we, as women, sometimes experience. Pierre admitted he never had to fear for his safety in Montréal because he is a man. Even though I wished Marie-Eve and I lived in a world where women did not have to worry for their safety, a part of me found comfort in being able to point out a particular situation where my experience as a disabled woman was different from the experience of my disabled male friend.*

*Disabled women's experiences are rarely recognized and put forward in our fight against ableism in Montréal. Reclaiming our identity as disabled women is not self-evident.*

—February 7, 2017

The concept of walkability is regularly used in order to design environments that are friendly for walkers. “Objectively, walkability is hard to quantify. True walkability takes a combination of mixed land uses like shopping and homes, plus great urban design like safe sidewalks and welcoming architecture,” writes Dan Malouff (2018). Walk Score is a Seattle-based company that developed a measurement method to rank cities according to their walkability. For Walk Score, walkability means that stores and services are easily accessible for

pedestrians.<sup>30</sup> Essentially, a walkable area is an area where walking is considered practical, pleasant and safe. Even though this method is not perfect and has faced criticism (*Ibid.*), it is one of the most accessible resources available online. Walk Score ranks Montréal third out of the ten largest Canadian cities in terms of walkability (Walk Score, 2017). However, walkability scores vary greatly from one neighbourhood to another.<sup>31</sup> Creating more pedestrian-friendly neighbourhoods is a recurrent issue in Montréal politics (Bérubé, 2015; Ville de Montréal–Opposition officielle, 2016), where accidents involving pedestrians are increasing (Chouinard, 2017). Developing active transportation, such as cycling and walking, and reducing car dependency were two of the main objectives of the transportation plan adopted by the city in 2008 and in the *Charte montréalaise des droits et responsabilités* adopted in 2006 and modified in 2011 (Ville de Montréal, 2008; Ville de Montréal, 2011). It was one of the issues in the last municipal electoral campaign in November 2017 and it is now one of the priorities of the new Projet Montréal administration.

On its website, the City states “Il est facile et agréable de marcher à Montréal, tant dans les rues piétonnes, le réseau souterrain, les grands parcs et les places publiques vivantes” (Ville de Montréal, 2017a). But is it really that easy for all Montrealers? Is the typical individual that Montréal wants to see use active transportation instead of private motor vehicles able-bodied? I am interested in Montréal’s “walkability” from the perspectives of the people I have wheeled with, as this has been the heart of our discussions. By considering mobility (and in this case, “walkability”) as a “resource distributed unequally among social groups” as proposed by Jordan Frith (2012, p. 134), I uncover “uneven geographies of oppression” (Massey, 2008, p. 260). The concept of differential mobility helps to identify the politics behind every set of stairs and lack of audio-signal traffic lights. As Kim Sawchuk (2014) has written, “differential mobility addresses the relations of power that hinder or enable movement, a system of preferential access to space that discriminates against those who have an ‘impairment’” (p. 414). This does not mean that all participants experienced the same level of discrimination when moving in the city, rather the opposite.

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<sup>30</sup> Public transit is one of the services considered important to have access to in the study. Issues pertaining to public transit will be covered in Chapter 5.

<sup>31</sup> Plateau Mont-Royal is the city’s most walkable neighbourhood, with a Walk Score of 93. Pointe-aux-Trembles–Rivières-des-Prairies comes in second, with 44 points on its scorecard (Walk Score, 2017).

The stories shared reveal that participants' perspectives on barriers and their impacts are not homogenous. As disabled scholar Tanya Titchkosky (2011) argues, access is an "interpretative relation between bodies." (p.3). In this chapter, I begin by exploring the obstacles in the built environment that demonstrate the lack of accessibility legislation in Montréal and Québec and manifestations of power in the architecture. Solutions put forward by disabled people to eliminate these barriers are also briefly presented. Following this, I engage with the dangers encountered by the participants to demonstrate how their experiences are largely ignored, still, by different regulatory bodies and institutions such as the Ministère des Transports and the Ville de Montréal. Finally, I turn to Montréal's winter since the cold season occupies an important part of what it means to live in Montréal and has numerous impacts on participants' everyday mobilities. I claim that winter is not only a meteorological reality but a political issue.

### ***The ableist city and the obstacles of the built environment***

*Over the past decade, my neighbourhood has become one of Montréal's trendiest neighbourhoods. In January, the New York Times recommended five places to go in Montréal. All of them were in my neighbourhood. This kind of attention from the New York Times does not go unnoticed. Many in the Montréal media reported on it and local politicians were thrilled. Before even reading the Times article, I figured that most recommended places would be out of reach for me, as is the case for most restaurants, cafés and bars in my neighbourhood. I was right. Only one of them is wheelchair-accessible.*

*In my city, I expect places to be inaccessible. I also expect this lack of physical access to be ignored. This is the city I am familiar with.*

—March 20, 2017

During the wheeling interviews, the inaccessibility of the city has been much more discussed than its accessibility. All participants identify numerous barriers and obstacles while only six participants talk about accessible places. Two things might explain this. First, participants have a desire to show me the troublesome situations they face in their everyday life. At the beginning of the interview, Nabila asks me if I am comfortable with going to see the obstacles she typically encounters. "Ma sortie est justement pour montrer tous les obstacles que je rencontre quotidiennement, mais je suis mal à l'aise que tu vives ce stress avec moi," she says. I tell her that that I am ready to encounter obstacles and stressful situations with her. In fact, I have

an obvious academic and activist interest in exploring these issues. After wheeling for 14 years in Montréal, I feel like I was well prepared for such a stroll. It will not be my first. Furthermore, lack of accessibility occupies a major place in the wheeling interviews because, like in many regions of the world, it is a critical issue in Montréal.

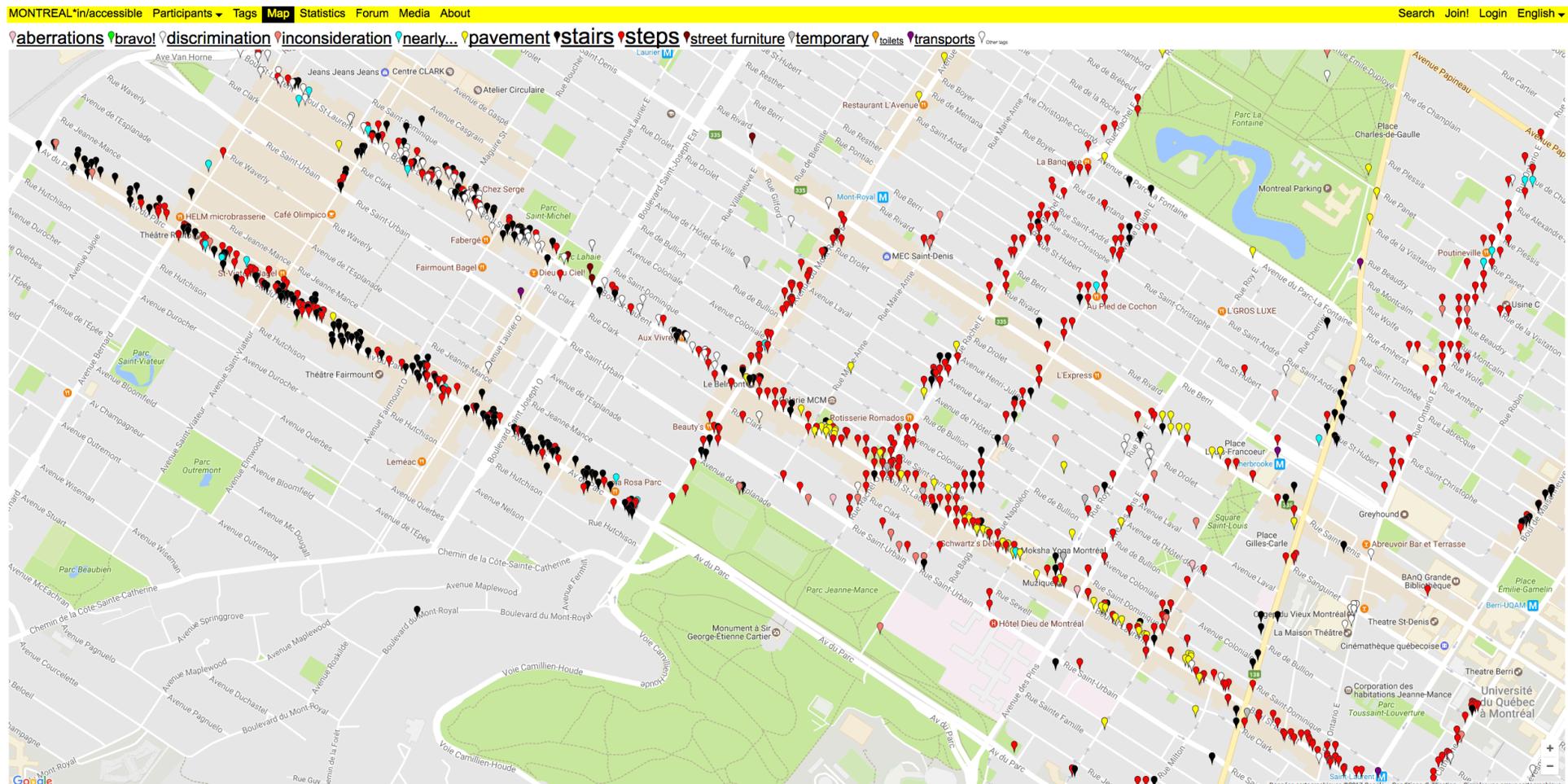


**Figure 5:** Photo of a new inaccessible café in Rosemont–Petite-Patrie. The café is located in a new building. There is one step. A sign indicates “Venez nous dire bonjour. Café gratuit” I took the photo on April 2, 2017.

For example, in 2012, I worked on a project called Montréal \*in/accessible, which very clearly showed the overwhelming presence of barriers in Montréal.<sup>32</sup> Disabled people using mobility aids, myself included, took photographs of obstacles we encountered in the city with our cellphones. The numerous barriers were geo-located on a map to visualize the extent of the discrimination experienced by these members the disability community (Megafone.net, 2012). The pins on Figure 6 indicate obstacles on major streets in Rosemont–Petite-Patrie, Plateau Mont-Royal and Ville-Marie. Areas without pins are not barrier-free but have simply not been explored by the participants. People with low vision or who are blind stumble on various barriers such as street furniture on sidewalks and pedestrian crossings without audio-signal traffic lights (Houde-Roy, 2013, Lopez, 2017). The presence of obstacles when navigating sidewalks is one of

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<sup>32</sup> The project was originally the idea of Barcelona artist Antoni Abad.



the most recurring themes in the wheeling interviews and is explored in more detail later in this chapter. According to the accounts of participants' who live, work and volunteer in ten different boroughs of Montréal, obstacles and barriers can be found almost everywhere in the city.

Before we leave France's home for the interview, her feet slip from her footrest. I try to help her but do not succeed. She calls one of her care workers on the telephone for help. They agree to meet at a café nearby, where her worker is studying. This detour is necessary for us to continue the interview safely, since it was dangerous for France to be wheeling with her feet off her footrest. When we arrive at the café, we are unable to get inside because of a step at the entrance. France does not have her care worker's phone number to inform her of our presence. Instead, we wave to catch her attention without success. We end up asking a passer-by for help to let her know that we are there. Inaccessible places such as this Plateau Mont-Royal café are not unusual but rather an integral part of the Montréal's landscape for many disabled people. Geneviève claims that about three quarter of Rosemont–Petite-Patrie's stores are not wheelchair-accessible. Laurence, an Ahuntsic resident, goes even further and states that the only accessible places in her neighbourhood are the pharmacy and the Caisse populaire. She explains that the doors of most places are difficult to open, making it extremely challenging for her to get in with her assistance dog. Marie-Josée also identifies the lack of automatic doors as a major barrier to almost every store in Villeray and other neighbourhoods she frequents. I ask her what she does when she cannot open a door by herself. She explains that she is used to asking for assistance. "Si je ne le demande pas, il n'y a personne qui va m'aider. Si je ne le demande pas, ben je ne peux pas sortir. Je ne sortirais pas," she exclaims. This shows that disabled people often find themselves in situations where they have no other options than to ask strangers for assistance. Local stores providing full access are rare.

Marie-Eve became surprised by the lack of accessible places when she started dating Pierre. Unlike Marie-Eve, Pierre cannot leave his wheelchair behind him and walk short distances. Prior to this, she would lock her wheelchair outside when going out with able-bodied family members and friends. "J'ai réalisé qu'il n'y a pratiquement rien d'accessible," she admits. Marie-Eve points out that larger franchises such as McDonald's own most of the accessible places while smaller places with unique cachet—which Montréal is known for internationally—are generally inaccessible. Geneviève explains that she and her non-disabled boyfriend David prefer local businesses to superstores but that very few of them have accessible entrances. Most

times, David gets what they need while she waits for him in their car. Sometimes when there are less than three steps, she walks while he lifts her wheelchair. While she used to do this more often when she was younger, she says she does not like to do this anymore because it is physically demanding and people stare at her. “Ça me gosse. J’aimerais ça y aller tout seule. Je le fais par dépit parce qu’à un moment donné il faut ben que tu rentres un peu quelque part,” she sighs. Nabila also frequently finds herself in a similar situation with her daughters as she waits for them outside of stores while they shop. Unlike for Geneviève, climbing up steps is not an option. She underlines that she experienced the lack of access to stores differently in her hometown of Algiers. “Ça n’arriverait jamais à Alger. Ils [les commerçants] feraient tout pour que je rentre. Le côté humain est différent,” she argues before adding “chaque pays a ses avantages et ses inconvénients.” She explains that if entering the store was impossible, the seller would at least come to her to facilitate her shopping.

The barriers in the built environment identified by the participants are not limited to stores and restaurants but also include places like schools, workplaces and daycares. Nabila talks about her the shock she had when she immigrated to Montréal. Her daughters’ school is inaccessible, as is the training centre in which she had to register in the hopes of finding a job. She points out that many of the places she could have worked at had one step or a flight of stairs. These obstacles add up to the other difficulties immigrants may face when arriving in Montréal. Immigrants are therefore more at risk of being unemployed and taking part in their new community life.

Unlike other participants using wheelchairs, Isabelle shows me a great number of accessible places during our interview, near her Nuns’ Island apartment. She points out that the area is frequented primarily by wealthy people. She also explains that almost every place in her neighbourhood is physically accessible to her, as the buildings in the area are newer than in the rest of the city.<sup>33</sup> That is, however, not true of the closest neighbourhood daycare. Even though Isabelle does not yet have a child, she notices that obstacle. “On verra en temps et lieu comment je ferai pour entrer,” she says. ([see video Boisvert-1](#)) Reflecting back on her childhood and adolescence in Rosemont–Petite-Patrie when barriers were just a fact of her everyday life, Isabelle confides that her life would have been very different if lack of access was not an issue. “Si tout ça avait été adapté et accessible facilement assez vite et que j’avais grandi avec ça,

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<sup>33</sup> In 2011, the average income of Nuns’ Island resident was 108% higher than the city’s average income (Boulianne & Guilbault, 2016).

j'aurais absolument été plus autonome beaucoup plus rapidement,” she claims. It is interesting to note that most participants never expected Montréal to be more accessible than it actually was and is today. This suggests that the presence of obstacles in the built environment has been normalized for a long time.

### *The flaws of accessibility legislation in Québec*

Most of the buildings in the neighbourhoods the participants and I have wheeled through were built before 1976 (Rocha, 2017). In 1976, Québec adopted its first building code, *Construction Code*, that included accessibility requirements (Benard, 2017). An overwhelming number of buildings built before 1976 were only accessible by steps or stairs. The *Act to secure handicapped persons in the exercise of their rights* adopted in 1978 stipulated that the agencies who are responsible for public buildings built before 1976 had to submit a plan to provide access to disabled people. However, many types of buildings were exempted (*Ibid.*). In 2000, new accessibility requirements were added for buildings undergoing major renovations (*Ibid.*). Despite these regulations, many buildings continue to be built and renovated without being made accessible (Benard, 2017; Lamarche, Leshyner & Gauthier, 2015).

Article 69 of the Act to secure handicapped persons in the exercise of their rights with a view to achieving social, school and workplace integration, adopted in 2004, requires the Ministère du Travail to submit a report on the accessibility of government buildings by 2006 to develop regulations to eliminate barriers (Benard, 2017). To date, such regulations have not been made public. Pierre remarks that most buildings on Masson Avenue, for example, one of the most commercial streets in his neighbourhood, have only one step each. “Ils pourraient facilement être accessibles,” he claims. Melanie Benard (2017) and Lucie Lamarche, Andrey Leshyner and Linda Gauthier (2015) explain that Québec’s regulatory and legal framework for accessibility is not sufficient and weakened by multiple exceptions. The list of exceptions is so long and complicated that one must have a deep understanding of law and architecture to understand what must be made accessible according to the Construction Code. During our interview, Geneviève and I wheel by an inaccessible building, which is only about four years old. A single step separates us from the two stores on the ground floor. I tell Geneviève that I have contacted the borough’s mayor about this and that he has told me that the building complied with Construction Code regulations at the time. Geneviève, who has studied urban planning at the graduate level, explains:

C'est tellement compliqué le Code [*Construction Code*]. [...] Je pense que des fois il y a des gens qui ne le maîtrise même pas, comme notre maire. Pis je veux dire, c'est difficile de l'utiliser. [...] Il y a des gens aux permis qui sont censés connaître ça. C'est à eux de l'appliquer en fait. C'est leur responsabilité. Est-ce qu'il le connait? Je pense que non. Je pense que personne ne le connait. Les rampes d'accès ne sont jamais conformes. C'est sûr que personne ne le connait. C'est grave.

For his doctoral thesis research, David Hick (2015) has conducted a literature review and surveyed 200 motorized mobility aid users in the UK, the Netherlands and Canada. He finds that that many infrastructure-related barriers restrict the mobility of these users as well as their participation in society (p. 2). He also observes that Canadian participants are less likely than British and Dutch participants to feel that their needs are being considered by city planners and city councils (p. 123). Hick even notes a difference between English-speaking and French-speaking Canadians. He explains:

While the English-speaking Canadian sample were fairly evenly distributed, there was a resounding dissatisfaction amongst those in the French-speaking Canadian sample, with all but one respondent giving a score of 1, 2, or 3. This would seem to indicate that there is either a problem with the process of citizen involvement in Quebec, or that a particular aspect (such as accessible public transport, perhaps) is so dissatisfactory that they feel that all their needs are being ignored (*Ibid.*).

Melanie Benard (2017) and Lucie Lamarche, Andrey Leshyner and Linda Gauthier (2015) note that the gap between the rights protected by the *Charter of human rights and freedoms* and the accessibility regulations included in the *Construction Code*. They demonstrate that the Charter offers a wider protection than the Code. Melanie Benard (2017) argues that one of the main weaknesses of the *Act to secure handicapped persons in the exercise of their rights with a view to achieving social, school and workplace integration* is that it lacks enforcement mechanisms, which results, notably, in an inefficient removal of barriers in the built environment. Therefore, it is not surprising that, in the past years, the largest category of complaints received by the Commission des droits de la personne et des droits de la jeunesse is related to disability discrimination (Commission des droits de la personne et des droits de la jeunesse, 2015).<sup>34</sup> However, it is notable that the proportion of disability-related complaints is much higher in other

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<sup>34</sup> In 2014–2015, 71 complaints were related to access to goods and services, 45 to access to transportation and public places and 25 to housing accessibility issues (Commission des droits de la personne et des droits de la jeunesse, 2015, p. 51). Melanie Benard (2017) explains that this statistic does not indicate the number of complaints that have been rejected and successfully resolved.

Canadian provinces and territories (Canada Human Rights Commission, 2015, p. 27).<sup>35</sup> Melanie Benard (2017) points out that in 2015 the average delay to assess a complaint in Québec was 398 days. It is difficult to measure the impact of such delays on disabled people, but the *Canadian Human Rights Commission* has issued a warning on the subject in a report on the *Implementation of the United Nations Convention on the Rights of Persons with Disabilities in Canada*. “Barriers to accessing human rights justice may result in persons with disabilities underreporting their experiences of discriminations,” warns the Commission, which lists delays in resolution amongst the main barriers (Canada Human Rights Commission, 2015, p. 27). Furthermore, as Melanie Benard claims, because of the flaws of the legislation regarding accessibility the burden is placed on disabled individuals to report each and every obstacle that they encounter. Most participants have never filed a complaint at the Commission des droits de la personne et des droits de la jeunesse.

Marie-Eve, one of the four participants who has tendered a complaint to the Commission, explains why she rarely reports obstacles:

Je ne porte pas plainte pour tout parce que ça prend du temps que je n’ai pas et parce que c’est un processus assez difficile et stressant. Chaque fois qu’on me demande pourquoi je pense que X est de la discrimination, je me mets à douter. C’est lourd. Et aussi parce que je crois que les individus ne devraient pas porter le poids de tout ça.

The processes for issue a complaint are heavy, stressful, time consuming and the outcomes are not guaranteed.

The flaws of the *Construction Code* and the accessibility legislation at the provincial level have pushed activists to demand the involvement of the Ville de Montréal, which also has the power to regulate the built environment on its territory (Robichaud, 2014). However, these demands have had very limited success so far. For example, a motion proposed by the political party Projet Montréal was rejected by Denis Coderre’s administration (Robichaud, 2014; Ville de Montréal, 2014). The motion was aimed at forcing the city to evaluate the accessibility of all of its projects. The City claimed that it was not necessary because changes would be coming soon. Nearly three years later, nothing has changed with the exception of a regulation enforcing the

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<sup>35</sup> In Québec, from 2009 to 2013, the proportion of disability-related complaints was 31.5%. For the same period, it was 54% in Ontario and 48.1% in Alberta. Québec is the only jurisdiction where disability-related complaints represented less than 40% of the total complaints (Canada Human Rights Commission, 2015, p. 27).

accessibility of summer terraces in a few Montréal boroughs following human rights complaints brought about by RAPLIQ (Parent, 2011b).

Behind the absence of a strong accessibility legislation in Québec lie ableist attitudes that allow this situation to continue at a governmental level, combined with an administrative strategy that places the onus on individuals to quite literally “fight city hall.” Geneviève’s words explain how a systematic lack of access becomes normal, is rationalized, and is thus normalized. She explains that people often say “c’est normal que tu ne puisses pas entrer, tu es en chaise.” She adds that building owners or tenants generally believe that making their businesses accessible to disabled people is unreasonable and too costly. On numerous occasions, she was told that nobody has asked for access before her and that wheelchair users can get inside with their help anyway.

#### *Fixing inaccessibility: Solutions in tension*

To address these systemic problems of access, some disabled people, inspired by other initiatives in Canada such as Toronto’s Stop Gap, have launched non-profit organizations such as AXCS and J’accède au Québec with the objective of building portable ramps for stores that have a single step (Bruemmer, 2015; Gaoir, 2015). The Ville de Montréal applauds these initiatives, yet they have had a mixed reception from the Montréal disability rights movement (Gaoir, 2015). The Regroupement des activistes pour l’inclusion au Québec (RAPLIQ) argues that accessibility is much more than an accessible entrance and that permanent measures need to be taken instead of temporary ones (*Ibid.*) Sandra notes that such initiatives seem great but, since they have to be installed every time a person needs them, she wonders, “will the ramps be actually used?”. “I see the problem if it is left inside. People don’t know where it is, or what if the front door of the location is closed,” she continues. Sandra’s worry leads to another concern raised by RAPLIQ: the possible obstacles that these ramps could pose for blind people.

I ask Luc about his take on this issue. He says that portable ramps are not a problem if they are installed only when someone asks for it. “Je suis non seulement prêt, mais même content de savoir que quelqu’un a pu entrer là où il ne pouvait pas entrer autrement là tsé,” he explains. Sandra’s and Luc’s perspectives conflict. For the ramps to be useful, Sandra needs them to be in place at all times; Luc argues that the opposite is necessary to avoid creating new barriers for blind people. Nabila has mixed feelings on the issue. She explains:

L’idée en soit n’est pas mauvaise, mais ne devrait pas être une solution permanente. [...] De plus, les rampes amovibles ne sont pas sécuritaires et n’assure pas notre autonomie.

Ceci dit, dans certaines situations, je préfère qu'un commerçant me l'offre plutôt que de retourner chez moi bredouille.

Given her concerns about their safety, Nabila adds that a better solution would be for the government to encourage businesses to become accessible.<sup>36</sup>

In January 2017, the Ville de Montréal made an announcement on this issue. The City launched a program with a budget of \$1.6 million for a period of five years to help businesses to become accessible (Ville de Montréal, 2017b).<sup>37</sup> The Programme d'aide à l'accessibilité des commerces (PAAC) covers 75% of the costs up to \$10,000. The City estimates that about 40 projects will receive funding every year.<sup>38</sup> Again, this announcement did not get unanimous approval among disabled people and the community. RAPLIQ notes that the budget is ridiculously small. "Pour changer les choses, ça va prendre beaucoup plus que ça. C'est comme mettre un sparadrap sur une plaie," argues Linda Gauthier, president of the organization (Schué, 2017). In another interview, she states her fears: "Je pense que c'est juste pour tenter de nous faire fermer la boîte un peu. Comme on est en année électorale, on va avoir l'air plus fou de chialer devant les gens qui n'ont pas de limitation." (Radio-Canada, 2017a) Martin Beauregard, the founder of AXCS, has declared that it is good news for disabled people. "Peut-être que c'est pas beaucoup d'argent, mais on avance vers quelque chose. C'est juste une bonne nouvelle pour moi," he states.

While working on this chapter, I contacted a few participants to ask them what they thought about the City's new program. Christian and Marie-Eve replied on Facebook Messenger. As Marie-Eve states while it is not enough to rectify this enormous problem, there may be a way to make this first small gesture more useful—by launching an accompanying campaign:

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<sup>36</sup> In June 2018, the Government of Québec announced the launch of a new program to support small businesses in becoming accessible (Cabinet de la ministre responsable de la Protection des consommateurs et de l'Habitation, 2018). The program Petits établissements accessibles is administered by the Société d'habitation du Québec. Interested businesses must contact their city to apply. Even though the program started on June 18, 2018, there is still no information available on the Ville de Montréal's website.

<sup>37</sup> Here is a breakdown of the total budget: \$300,000 per year from 2017 to 2021. \$100,000 in 2022 (Ville de Montréal, 2017).

<sup>38</sup> On June 4, 2018, the Government of Québec announced the creation of a subsidy program to help small businesses wishing to become physically accessible (Cabinet de la ministre responsable de la Protection des consommateurs et de l'Habitation, 2018). Even though municipalities are responsible to administer the program, four months after the launch of the program, there is still information available online on the Ville de Montréal's website.

Tant mieux si la ville a compris qu'il fallait investir pour aider les commerçants à rendre leurs bâtisses accessibles, mais ça me paraît peu pour une ville aussi grande et inaccessible que Montréal. Et j'espère que cette annonce vient avec une bonne campagne de publicité pour que les commerçants l'utilisent. Ça serait dommage qu'on se retrouve un an plus tard avec seulement une portion du budget utilisé parce que le programme n'est pas connu.

Her fear is that if businesses do not participate, it will give the wrong impression that the issue is not a priority.

Similar to RAPLIQ's position, Christian replies that the program is more of a band-aid to the accessibility problem in the city than anything else. However, he adds:

Je ne crois pas que ce soit juste à l'État de financer des infrastructures accessibles. La société doit faire sa part, il doit y avoir de la contrainte, une réglementation qui les oblige. Au mieux, j'irais vers un crédit d'impôt ou de taxe s'ils font des réno, mais jamais subventionnés. J'irais plus vers une obligation de mise en accessibilité quand la vocation d'un local commercial change.

Like the position of RAPLIQ, he stresses the need for accessibility to be obligatory, and some of the onus to be on both society and the business community.

In October 2018, the city published a report of the first of PAAC. Only 11 demands were received by the city between April 2017 and April 2018, and seven projects were authorized (Ville de Montréal, 2018b). While the annual budget is \$350,000, only \$50,586.75 was spent (*Ibid.*).

Participants' testimonies demonstrate that the issue of the accessibility of the built environment is far from being a part of our past: it is embedded in the everyday experience of the city for many disabled Montrealers in the present. Over time, participants using mobility aids have developed a map of the places where they know they can get in and have become accustomed to having to deal with obstacles. They also have strong feelings about the need for greater efforts on behalf of both government and civil society to assume responsibility for the implementation of policies, rather than having the burden fall back on them, as individuals. They are aware of how this situation has an obvious impact on their mobility habits in the city—and they are articulate about this. In the following section, I turn to the multiple dangers participants reported before even getting to their destination while wheeling or walking Montréal streets and sidewalks.

***Danger and fear in the city: The gap between new state regulations and disabled peoples' life experiences***

*Random person yelling at me: As-tu ton permis de conduire? Tu vas vite avec ça!!! Fais-tu des courses?*

*This is generally followed by a burst of laughter. Some people also add that I should slow down. I am expected to smile and, ideally, to laugh as well. Since moving to Montréal, I have heard this over and over. I used to force a quiet laugh or at least a smile but in the last few years I generally stay stoic as I pass by them or I outwardly show that I'm annoyed. Sometimes I notice that my reaction pisses them off. I am learning not to care. The maximum speed of my wheelchair is 10 km/h, which is slightly faster than the average jogging speed. It only looks fast from the point of view of a pedestrian standing still and staring at me.*

—February 5, 2017

While wheeling with Marie-Eve, I ask her if she remembers people making comments about her mobility aid when she started using a motorized scooter on Montréal sidewalks a few years ago. She answers:

*Je n'ai jamais eu de commentaires. Tsé les gens sont comme toujours en train de se tasser, tsé pour nous donner la priorité. C'est cool là. C'est pratique, mais en même temps je ne comprends pas toujours. Des fois, il y a en masse de place tsé. T'as pas vraiment besoin de te tasser plus pis de te mettre super écrasé dans ton coin! [...] J'ai l'impression que les gens ont peur.*

This fear, overtly expressed by some pedestrians, is something I have witnessed myself countless times as I wheel on city streets. Furthermore, on several occasions, I have heard people saying that motorized mobility aid users are dangerous and reckless. In the media, I have seen stories about the nuisance caused by motorized mobility aid users as well as accidents and cases of drunk driving (Bonenfant, 2015; Bertiaume, 2014; Lafontaine, 2014; Radio-Canada, 2009). Negative media representations, ableist understandings of what it is like to get around using a mobility aid, and an increase in mobility scooters users on Québec roads, bike paths and sidewalks in the past decade are all part of the story about the rising concerns and potential dangers posed by motorized mobility aid users to other street and sidewalk users. The growth of motorized mobility aid users is associated with the aging population and the rise of the costs of car ownership (Magner et al., 2006; SAAQ, 2006). In 2009, the Société de l'assurance automobile du Québec and the Ministère de la Santé et des services sociaux mandated that the Institut national de santé publique du Québec (INSPQ) document the mobility habits of

motorized mobility aid users to assess their level of dangerousness to ensure the safety of all road users and to determine whether they should be considered pedestrians or vehicles<sup>39</sup> and where they should be allowed to circulate. A committee mainly composed of government institutions, such as the Ministère des Transports du Québec, the Ministère de la Santé et des services sociaux, the Office des personnes handicapées du Québec and the Société de l'assurance automobile du Québec, was created to support this research. However, there were no mobility aid users sitting on the committee.

At the time my research was being conducted, motorized mobility aid users were considered pedestrians and therefore not allowed to circulate on the streets and on bike paths. However, many of them were already using these infrastructures. From 1996 to 2009, 19 motorized mobility aid users were killed in accidents on Québec roads (Institut national de santé publique du Québec, 2011, p.31). Fourteen of them included a motor vehicle. Motorized mobility aid users were found responsible for half of these accidents (p.34). Coroners who have investigated these accidents have concluded that 1) motorized mobility aid users should have the opportunity to acquire better mobility skills through training and awareness and 2) heavy vehicles should be equipped with cameras to cover their blind spots (Veilleux, 2014). No regulating measure targeting motorized mobility aid users were mentioned. Even though these statistics and coroners' recommendations are far from alarming, the concern about the danger of these motorized mobility aid users is shared by many people sitting on the research committee. Several questions targeting these users were raised. Should a driving license be mandatory to drive a motorized mobility aid? Should these users take driving lessons? Should the use of powered mobility aids be reserved only for people who have a medical diagnosis proving that they need one? Should these mobility aids be licensed? Should these users still be allowed to circulate on sidewalks? Should they be allowed to circulate during winter and at night?

Meanwhile, there is no legislation ensuring the accessibility of sidewalks and outdoors spaces in Québec (Benard, 2016; OPHQ, 2017). This problem has just been acknowledged recently by the Office des personnes handicapées du Québec (OPHQ) (2017):

Actuellement, le Québec, comparativement à d'autres législations, ne s'est toujours pas doté d'un outil législatif ou réglementaire permettant d'assurer l'accessibilité des espaces

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<sup>39</sup> In May 2009, a Québec Superior Court judge decided that motorized mobility aids are motor vehicles and that people injured by them should be compensated by the Société de l'assurance automobile du Québec (Radio-Canada, 2009)

publics extérieurs de manière uniforme et harmonisée sur l'ensemble de son territoire. [...] Cette absence de normes unifiées, harmonisées et prescriptives dans les pratiques occasionne la conception d'aménagements extérieurs qui ne sont pas accessibles et qui ont pour effet de briser la chaîne de déplacement des personnes handicapées.

However, no action has been taken to remedy this problem.

In 2011, the INSPQ published its report and recommended that motorized mobility aid users be allowed on sidewalks, roadways and cycling infrastructures among other measures. To be allowed on the sidewalks, the users are required to carry with them an identification card attesting a medical diagnosis limiting their walking capacity (p. 100). To follow-up on this report, the Table québécoise de la sécurité routière has suggested more detailed research on motorized mobility aid users in Québec because of the scarcity of literature available on the subject and the complexity of the issue (p. IX). The mandate has been given to Jean-François Bruneau, the main author of the INSPQ report. During the summer of 2012, 64 motorized mobility aid users were interviewed in four Québec cities: Montréal, Sherbrooke, Victoriaville and Magog. I was one of them. A member of the research team came to my house and attached a GPS camera to my wheelchair. I was told to go where I usually go without changing my habits. The camera had about two hours of recording capacity. I do not remember what I did and where I went but I recall feeling a bit uneasy about my participation in this research as I was worried that the findings could lead to the adoption of legislation restraining my mobility and my rights.

On June 1<sup>st</sup>, 2015, the government of Québec implemented the *Projet-pilote relatif aux aides à la mobilité motorisées* (Projet-pilote) before the publication of the findings of the research in which I had participated. The preliminary results of the research demonstrated that motorized mobility aid users are not putting pedestrians in danger and are circulating at the average speed of 6 km/h, which is similar to the average pedestrian walking speed (Bruneau, 2016, p.6). The *Projet-pilote* has changed the status of motorized mobility aid users in the *Highway Safety Code*. From that day forward, these users are no longer considered pedestrians. A new category of road users has been created especially for them. They have become motorized mobility aid “drivers” instead of “users.” While they have obtained the right to use bike paths and some roads<sup>40</sup> (the far-right side of the roadway or the shoulder of some roads), their right to circulate on sidewalks like

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<sup>40</sup> The use of motorized mobility aids is prohibited on limited access roads, such as highways and their access and exit ramps, the roadway of roads where the speed limit is over 50 km/h and the roadway of roads with more than one lane in each direction (Québec, 2015).

any other pedestrians, however, is significantly reduced. The new regulation stipulates that, in addition to the rules already existing for pedestrians, motorized mobility aid users must comply with new rules. One of the new rules makes their right to use the sidewalks conditional. Electric wheelchair and scooter users are allowed to use the sidewalks only if they do not compromise the safety of pedestrians and other users. Another rule makes it mandatory for users to have their mobility aids equipped with reflectors on all four sides. Having a grocery bag attached to a wheelchair handle hiding one of the reflectors, for example, becomes unlawful.

Section 12 of the *Projet-pilote* prohibits users from carrying another person on their laps or their back. An exception is made for children younger than five years old. However, only the legal guardians or the person caring for the young child are authorized to do so and must use a restraint system. These three regulations create significant differences between motorized mobility aid users and pedestrians who do not use such aids (including manual wheelchair users) under the *Highway Safety Code*. A motorized mobility aid user failing to comply with one of the many requirements is liable to a fine from \$30 to \$60. There are no similar regulations for pedestrians who do not use motorized mobility aids. The safe and responsible behaviour of pedestrians is expected but not regulated nor subject to fines.

In the disability community, the *Projet-pilote* has been critiqued by some organizations and individuals (COPHAN, 2014; COPHAN, 2015; Motricité et moelle épinière Québec, 2015; RAPLIQ, 2014; Veilleux, 2014). They argue that when using the sidewalks, motorized mobility aid users should be subject to the same rules as other pedestrians. The Confédération des organismes de personnes handicapées du Québec (COPHAN) argues that using the term “drivers” refers to the idea of driving a vehicle and that by considering motorized mobility aids as transportation vehicles, the *Projet-pilote* creates inequalities between pedestrians (2015, p.4).

On the Facebook group *Transport mésadapté*, disabled people have reacted to the new regulation. “En lisant ceci, je réalise à quel point je n'ai aucun, mais AUCUN jugement pour assurer ma sécurité et celles des autres qui partagent la “route” avec moi. Come on!”, writes, with irony, Marilyne Turcot (2015), a young disabled woman using a motorized wheelchair. In an open letter, Marie-Eve Veilleux (2014) points out that to protect vulnerable road users such as pedestrians and cyclists, Québec public authorities are starting to target motor vehicle drivers' behaviours and are improving the design of roads, bike paths and sidewalks. She explains that instead of regulating motorized mobility aid users' behaviours on sidewalks and framing them as

a potential threat to other users, the government should address the multiple obstacles and sources of danger they face, which are very similar to pedestrians and cyclists, on Québec streets and sidewalks.

Throughout the wheeling interviews, participants have shared perspectives on danger and safety on streets, sidewalks and bike paths. In NVivo, I have created the node “danger and fear” to identify situations in which participants feel unsafe or scared. All participants have at least one story to share. I have identified a total of 93 citations, which demonstrates the recurrence of this theme. The lack of accessibility to public transit is also one of the main worries when we talk about danger and fear. Chapter 5 is fully dedicated to this particular issue.

The analysis of the theme “danger and fear” indicates that participants’ testimonies challenge many of the INSPQ’s findings. For example, the INSPQ report indicates that in Montréal, the majority of mobility device users use the sidewalks while in other cities they prefer to wheel on roads or bike paths (p. 88). The preference for bike paths over the streets or sidewalks is generalized to the urban and rural populations (p. 90). The only significant obstacle identified by the researchers are sidewalk joints, which they say cause pain and discomfort to many users. In my research, participants also mention sidewalk joints as a nuisance and cause of pain. France explains that when she started using a power wheelchair, she had to get used to feeling each joint:

Toutes les petites craques de trottoir, ça c’est vraiment insupportable parce que c’est comme si c’est comme si ce n’est pas fluide. C’est comme si tu avais un mini nid-de-poule à chaque, je sais pas moi, à chaque mètre. Ces trottoirs là, avec des petites craques, souvent ça provoque des spasmes. Comme moi, dans mon cas, ça m’en provoque. Quand ça te provoque des spasmes, tes pieds débarquent de ton appui-pieds. Ça, c’est une autre réalité à laquelle j’ai dû m’habituer.

Sidewalk joints, however, are far from being the only important obstacle encountered by the Montrealers with whom I wheeled. Sidewalks in poor condition as well as construction projects are identified as the principal reasons why most of the participants regularly or occasionally avoid the sidewalks. Some participants mention not using or limiting their use of bike paths, which challenges the consecration of bike paths as the ideal infrastructure for the motorized mobility aid users. Furthermore, disabled women have spoken about other sources of danger such as violence and street harassment. In this section, I will include the stories of participants who are

not using motorized mobility aids. However, most of the stories that will follow come from participants using such devices.

### *Sidewalks in poor condition*

The INSPQ report states that some municipalities do not know whether or not their sidewalks are in good condition and accessible to mobility aid users while others claim that about 80% of their sidewalks are accessible (p.89). In other words, little is known about the accessibility of the sidewalks and the dangers encountered by disabled people when using public infrastructure. Participants, on the other hand, have a lot to say to say on the state of sidewalks. Many of them consider that the sidewalk situation is worsening year after year.

Marie-Josée and I wheeled for more than one hour in the area of Université de Montréal campus and Côte-des-Neiges métro station. Marie-Josée chose this neighbourhood because when she moved to Montréal in 2004, she was living on Université de Montréal campus. At that time in her life, she would never venture out alone where we were wheeling. “Je ne sortais pas beaucoup donc ce n’était pas vraiment un problème, mais là présentement ce serait un problème,” she says. I ask her what has changed since then. “La confiance en moi, l’autonomie, le désir de plus d’autonomie. Avant, je me contentais de peu, mais là je veux élargir encore plus mes horizons,” she replies.

Since then, with the assistance of a mobility therapist, Marie-Josée has developed some techniques for navigating the city; nonetheless, she still struggles. She identifies three things that make her feel unsafe; heavy traffic, traffic lights that are too pale to see and uneven sidewalks. While we were on a particularly bumpy sidewalk, Marie-Josée complained “c’est cahoteux! Ouch! Ayoye! Ahhh my God! Mais c’est l’enfer ici. Ça n’a pas d’allure.” Later in the interview, she exclaims “je pense que quand je vais revenir [chez moi] je vais être fatiguée. Oh boy!”. “Est-ce que ça te donne aussi des douleurs?”, I ask her. She responds yes without hesitating. Many participants using mobility aids also complain about the pain and discomfort that is caused by sidewalks. “Il y a plein de bosses. J’ai mal au dos et au cou. Ce n’est pas du repos. Pour moi le repos est d’aller dans un jardin et de rouler tranquillement, mais pas en ville,” Isabelle explains. Marie-Josée says that the most difficult thing for her is constantly watching for holes on the sidewalks and that this is extremely tiring. Geneviève also shares her frustration about being forced to always watch out for holes and cracks when she wheels:

Quand les trottoirs sont dégueux, on regarde toujours par terre tsé. On a pas la même, je sais pas... La même appréciation du paysage. Je peux pas vivre pis être la tête en l'air pis regarder les oiseaux tsé. Je regarde le trottoir parce que je vais peut-être me retrouver la face par terre si je regarde pas par terre.

In other words, Geneviève must be vigilant at all times to avoid a bad fall. She explains this to me while wheeling cautiously on an uneven sidewalk.

Kéven, who uses a manual wheelchair like Geneviève, confides that he has bad falls about every four months because of the sidewalks. As we are wheeling on Jean-Talon street near Chateaubriand, he divulges that “la semaine passée je me promenais ici avec Christiane. On s'en allait au bar tsé. Elle m'accompagnait, pis je me suis méga planté par en avant, dans un nid-de-poule. J'ai eu au mal au genou pendant trois jours.” He does not report these incidents to the city or the police.

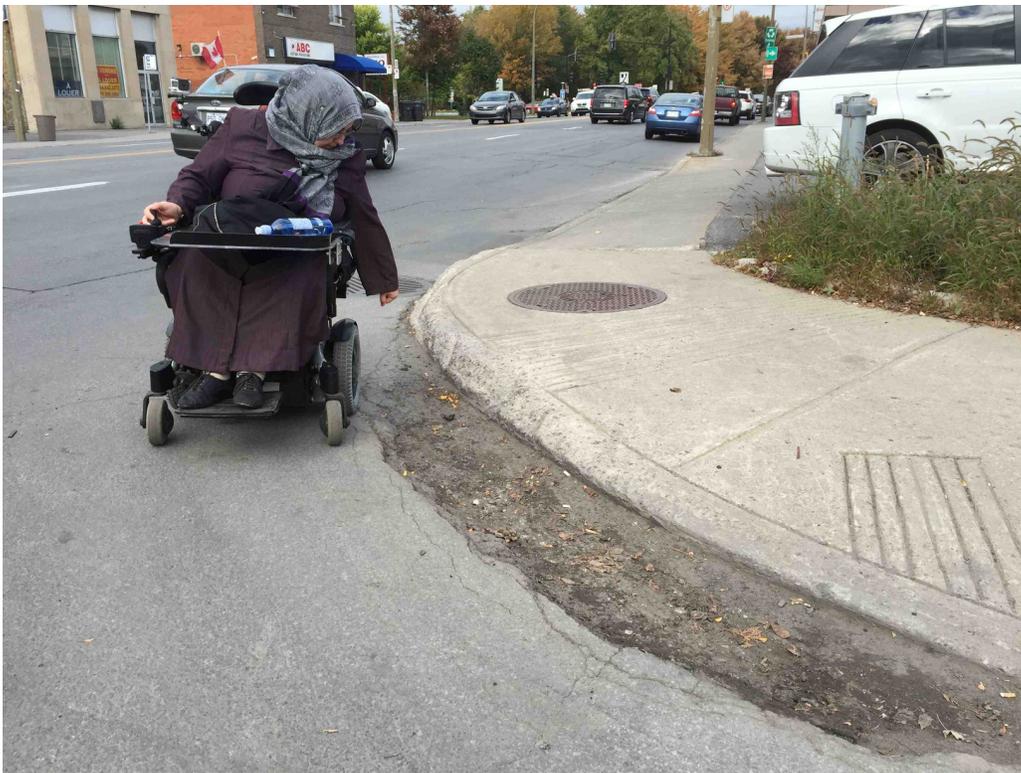
When I met with Nabila she was still affected by an incident she had experienced a few months earlier and she says that she lives in fear of going out of her home. She explains that her mobility is limited because she restricts her outings:

Je n'ose plus aller à Côte-des-Neiges. La route est tellement mauvaise. Il y a tellement de trous avec les travaux actuels. Si je sors, je vais prendre un gros risque. J'évite au maximum. Si je programme mon transport, je sors, je vais magasiner ou faire quelques activités. Mais, sinon, des sorties comme ça, des sorties comme ça, irréfléchies. Non. J'évite au maximum. Je sais que ça va me prendre du temps pour m'en remettre.

Despite the stress involved with going out, she wants to wheel with me because she says that she firmly believes in the power of telling our stories to change things. A few months before, at the corner of De Nancy and Jean-Talon, in her neighbourhood, her wheelchair got stuck in a big hole breaking one of her wheels. “C'est la peur de ma vie. Je commençais à avoir peur parce qu'il n'y a presque personne qui passait. J'étais vraiment coincée,” she says as we stop at the same corner (Figure 7). On the day of this incident, Nabila was rushing to get ready to fly to Algeria the next day. Her mother had just died and she was going to the funeral. She was devastated and did not have time to call the city to complain.

Wheeling with me, Nabila goes back to this intersection for the first time since her traumatic incident. We immediately notice that the hole had not been fixed. While this curbcut is in particularly poor condition, it is not the only problematic one we encountered as we wheel together. In fact, I note that the sidewalks in Nabila's neighbourhood, Côte-des-Neiges-Notre-

Dame-de-Grâce, are among the worst I had seen in Montréal. It feels like the neighbourhood does not belong to the pedestrians but to the motorists. On a few occasions, we are forced to wheel on the street due to inadequate sidewalks and pedestrian crossings and found ourselves in dangerous situations. I had a similar experience with Sandra, who lives in another area of the same borough. Like Nabila, Sandra's main preoccupation regarding the accessibility of her neighbourhood is the terrible condition of the sidewalks. She presses me on this issue several times. Because of the condition of the sidewalks, she describes being forced to wheel on the streets and make detours. She argues that things are not getting better. The only improvement she has noticed was that the city changed the railroad tracks a few years ago. She used to get stuck in the tracks. That is very dangerous. Nabila confides that she prefers wheeling in the Town of Mount Royal, a wealthier



**Figure 7:** Nabila shows me the hole where she got stuck. I took this photo with my cellphone.

borough bordering her own. Christian also admits that he loves to wheel in Town of Mount Royal. Like Nabila, he enjoys its quiet streets and the good condition of its sidewalks, where he can wheel without too many significant obstacles. “Je préfère prendre les rues de Ville Mont-Royal. C’est plus sécuritaire. Les trottoirs sont meilleurs. Peut-être que leur ville est plus riche? Je sais pas! [rires] Peut-être qu’ils paient plus de taxes? Je sais pas!”, suggests Nabila with a

laugh. Nabila's suggestion is not far-fetched. In 2011, the average income is \$33,071 per capita in Côte-des-Neiges-Notre-Dame-de-Grâce and \$83,804 in Town Mount-Royal (Radio-Canada, 2014). In the sector of the borough where Nabila lives, the average income is 19% lower than the city's average income (Boulianne & Guilbault, 2016). Further research is needed to assess the level of accessibility of sidewalks and to investigate whether or not there are differences between richer and poorer areas. However, as my wheeling interviews demonstrate, there is a reason to believe that cracks and holes in the sidewalks may be distributed unfairly across the city.

Obstacles that are encountered by participants on the sidewalks are not determined only by the quality of the concrete surfaces. Laurence, who does not use a mobility aid but walks with the assistance of her dog, invites me to walk with her on her quiet residential street. She explains why:

C'est pas légal, légal. Je n'aime pas marcher sur les trottoirs. Comme j'ai des problèmes d'équilibre, des fois je marche comme une personne saoule. [...] Pour moi marcher dans la rue, c'est plus facile parce que c'est plus large tsé. J'ai pas trop à me préoccuper si je ne marche pas droit et il y a moins de dénivellations. ([see video Rousseau-2](#))

For Laurence, sidewalks not only need to be as flat and smooth as possible, they also need to be large enough. Since this is rarely the case, she often walks on the streets. However, as explains, she cannot walk on busy streets, especially downtown where she works. For this reason, she feels more comfortable in residential neighbourhoods such as hers. The condition of the sidewalks is not the only obstacle mentioned by Laurence. On garbage and recycling days, she hates to walk in her neighbourhood. On these days, even walking her dog is a challenge. She explains that street cleaners throw empty bins all over the sidewalks and the street curbs, which creates countless additional obstacles.

Jacynthe and Luc admit that they do not go on leisurely walks because of all the obstacles they must deal with when they do so. "Pour moi prendre une marche, c'est pas synonyme de loisir ou de détente. Si je vais circuler quelque part, c'est vraiment parce que j'ai un endroit où aller ou quelque chose à faire," says Jacynthe. Other pedestrians often slow her down because she wheels faster than they walk, which makes her impatient. Luc has a different explanation:

Les seules raisons pourquoi je marche seul, c'est pour me rendre du point A au point B et je prends le chemin le plus court ou le plus sécuritaire. Je ne suis pas le genre à sortir pour aller marcher parce que ça reste du travail. [...] Des fois, les gens disent « ah, il a fait beau hier, je suis allé prendre une marche ». Je ne fais jamais ça moi-même [...] Il faut quand

même que tu comptes les rues. Il peut y avoir des poubelles. Il peut y avoir des enfants en rouli-roulant.

In the few months prior to the wheeling interview, Luc acquired his first smartphone and he started going places by himself more often. He now finds his outings to be more pleasurable. He uses some apps that are designed for blind people. These apps are extremely useful to guide him to his destination but are not designed to warn him of upcoming obstacles. Luc confides that walking in the city can be scary but that he pushes himself to do it. “Si je commence à pas y aller parce que j’ai la chienne, je vais me replier sur moi-même,” he says. Luc draws a clear connection between the obstacles he encounters and the risk he faces of becoming socially isolated. His testimony, along with the other testimonies presented here, demonstrate that the INSPQ has a very narrow and limited understanding of sidewalks’ accessibility.

### *Construction sites*

In the past few years, the number of construction sites on Montréal roads has increased significantly. These sites are so numerous that traffic cones have become the city’s new symbol (Ball, 2016; Bisson, 2016). Many projects were carried out to prepare the city for its 375<sup>th</sup> anniversary in 2017. Construction sites are expected to multiply and be omnipresent over the next ten years as the Ville de Montréal will increase repair projects on its roads, sewers and water system (Corriveau, 2016). When I conducted wheeling interviews during the summer of 2015, the participants and I encountered many obstacles created by repair projects. The main problems faced by disabled people were inaccessible temporary detours and signage that jeopardized their capacity to get around the city and even prevented them from reaching their destination (Gaïor, 2015; Ugolini, 2016).

I contacted the Ville de Montréal and the Ministère des Transports du Québec to get information about the rules and regulations for pedestrian crossings on construction sites. I learned that contractors must follow norms created by the Ministère des Transports (Transports Québec, 2016). For example, norms indicate that when a sidewalk is blocked, construction workers must place a sign and create a one-meter wide corridor. None of these norms, however, are related to accessibility. It is assumed that all pedestrians navigate these temporary spaces in the same way. Pedestrians are expected to be able-bodied. Therefore, it is not surprising that participants have reported many barriers at construction sites.

The consequences of construction obstacles vary from one person to another. Some participants explain that construction projects are a source of inconvenience but that they have no choice but to deal with them. As we are approaching a sidewalk blocked by a barricade, Christian stops to type a message. “Se déplacer en fauteuil roulant, c’est toujours avoir à l’esprit un ou deux coins de rue à l’avance pour prévoir les obstacles,” he says to me on Facebook Messenger. We continue wheeling. No accessibility measure is in place. To get around the obstacle, Christian decides to wheel on the street in the opposite side of the traffic to the next intersection. I follow him. We have both done this countless of times. Other participants, including Isabelle and Marie-Josée, explain that such barriers have greater consequences on their mobility. Isabelle states that her sense of direction is really poor and that she can easily get lost if she faces a detour:

La semaine passée, il y avait deux trottoirs de barrés, je me suis dit « ah je vais prendre un autre chemin ». Je suis habituée à de Maisonneuve, mais c’était barré en fin de compte à un moment donné. Fait que là j’ai pris un détour pis c’était encore barré. Pis au bout d’un deuxième detour, j’étais perdue, mais complètement perdue alors que j’étais juste à deux coins de rue de mon arrêt d’autobus. Mais c’était trop pour moi.

Marie-Josée and I have found ourselves in the middle of a massive construction site on Côte-des-Neiges. As we are talking and wheeling, I am able to foresee the obstacles. Marie-Josée has a different perspective. When we get to a fence blocking the access to the street, she is surprised. “Je ne le voyais pas. Ce n’est pas indiqué pour les gens qui ont des problèmes visuels. On ne voit pas toujours la clôture. Bon là on s’en va où?”, she asks (Figure 8). She is worried. “Ça me stresse beaucoup,” she says. I reassure her by telling her we will find a way. “Non, non, je sais. Tu es là. Déjà ce n’est pas accessible pis en plus des travaux, c’est encore pire,” Marie-Josée responds in an exasperated tone. She explains that these types of situations upset her and are very frustrating because there is no information available about accessible paths. Marie-Josée is right. I have never seen such information on Montréal’s construction sites. I regularly have to wheel back or take detours. I guide her to the alternative route for pedestrians only to discover that this route was not wheelchair-accessible. We turn around and head to another intersection. Again, we hit an identical obstacle—the temporary crossing path is not wheelchair-accessible. It looks like we will have to make a very long detour to circumvent the construction site, which spreads over several blocks along Chemin de la Côte-des-Neiges. I decide to ask to a construction worker responsible for pedestrian safety if there is an accessible way to cross the street we had been trying to cross. After consulting some of his colleagues, he comes back towards us and

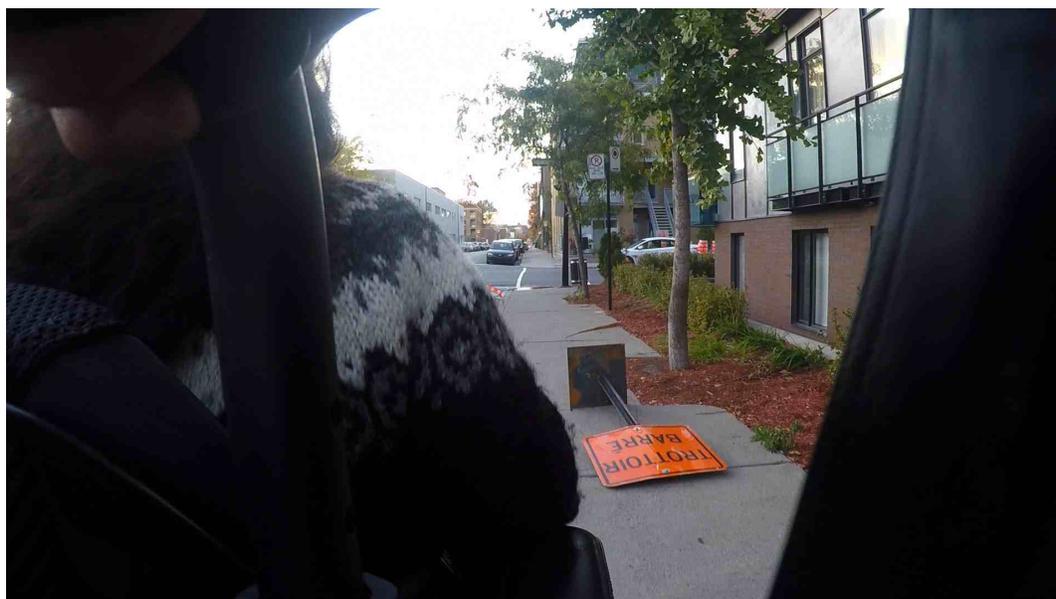


**Figure 8:** Marie-Josée stopped in the front of the fence blocking the access to the street. This photo was taken with the GoPro camera mounted on her wheelchair.

offers to escort us. We end up crossing the construction site in a zone where pedestrians are not authorized. At one point, Marie-Josée’s wheels get stuck in the uneven surface and the construction worker has to push her wheelchair to get her back to safety. Even though we make it out safely, Marie-Josée expresses that the experience confirmed her worries about getting around the city by herself. “Comme je te dis c’est un quartier que je ne voudrais pas vraiment faire toute seule,” she explains.

When I wheel with Luc, we navigate no less than five construction sites and encounter several barriers. On the first construction site, we are forced to turn back because the temporary sidewalk is not wheelchair-accessible. A few minutes later, on another construction site, he rips his pants and hurts his leg on a sharp construction sign out of the way that is on the ground, blocking the sidewalk (Figure 9). ([see video Fortin-1](#)) He had just told me earlier that these signs are dangerous because they have sharp edges and are hard to detect with a white cane. Nevertheless, these signs conform to the Ministère des Transports guidelines (Transports Québec, 2016). Luc has injured himself on unsafe construction sites more than once. Once he fell in a hole because there was no safety barrier. At Square-Victoria métro station, he hit his forehead on a scaffold. “La canne passe en dessous, mais mon front ne passe pas,” he says sarcastically. I ask Luc if he has noted changes in the city since the apparition of countless construction sites. “Je ne sais pas si c’est à cause des travaux, mais on dirait que les gens s’en permettent un petit peu plus

aussi,” he replies. Luc explains that since he was making more money this year, he often chooses to take a taxi to work in order to avoid having to navigate the city and being exposed to physical obstacles or unsafe behaviours from other people, which, he feels, is more frequent than usual. Furthermore, Luc finds that getting access to real-time information on construction sites is extremely difficult and that most obstacles are not even listed. With the expected increase of construction projects across the city in the next decade and the absence of accessibility regulations to ensure pedestrian detours, it seems like disabled Montrealers’ troubles will not be over any time soon.



**Figure 9:** Luc and I are approaching the sign that is on the ground and blocking the sidewalk. Luc holds on the right handle of my wheelchair. The photo was taken with the GoPro camera mounted on my wheelchair.

### *Bike paths*

In the past few years, Montréal has solidified its reputation as one of the most bike-friendly cities in North America (Babin, 2015; Ripplinger, 2012). The kilometers of bike paths keep increasing every year (Camera, 2016). According to the INSPQ report, this should be great news for motorized mobility aid users. As mentioned earlier, the INSPQ report identifies bike paths as the ideal infrastructure for motorized mobility users. The report even claims that all users surveyed for the report agreed with that statement and always chose bike paths over streets and sidewalks. It also indicated that motorized mobility aid users do not have any issue with sharing bike paths with cyclists and that the cyclists are courteous towards them (2011, p. 90).

Through the wheeling interviews, participants share more nuanced perspectives on their experiences of Montréal bike paths. France expresses a clear preference for bike paths on quiet one-way streets over sidewalks. She explains that in most instances she can reach many of her favourite destinations by using bike paths. France says she always has used them, even when this was not permitted by the Ville de Montréal. She rejoiced when the adoption of the *Projet-pilote* legalized the presence of motorized mobility aid users on bike paths:

J'étais vraiment contente quand ils ont fait la loi pour donner accès aux fauteuils roulants. Des fois, j'aimerais qu'il y ait des signes sur la piste cyclable pour que les gens soient vraiment conscients parce que même s'il y a une loi, les gens dans leur tête, ceux qui n'ont pas de gens près d'eux en fauteuil roulant, ils ne le savent pas tsé. [...] On a le droit à Montréal d'être sur les pistes cyclables maintenant...même si le commun des mortels ne le sait pas et nous regarde avec flèches parce qu'on va pas assez vite. ([see video Geoffroy-1](#))

France has argued that in the past two years, Plateau Mont-Royal's bike paths have become overcrowded and this has impacted the attitudes of some cyclists towards wheelchair users. On two occasions, she was told that she should not be on the bike path.<sup>41</sup> Louise does not like bike paths at all. They even scare her. "Me faire pousser dans le dos, j'aime pas ça", she says. ([see video Blouin-1](#)) Her boyfriend Christian wheels on bike paths depending on the traffic. "C'est sûr que je me tiens loin des autoroutes genre la rue Boyer dans le jour... Je roule croche et c'est dangereux pour moi et les autres. Mais, je vais dans celles qui sont moins achalandées," he explains. Marie-Eve points out that she could take the bike path on De Maisonneuve to get to work but that she prefers another route because wheeling with numerous cyclists passing is too stressful. She specifies that their speed is stressful and that constantly being passed by cyclists is too much to handle, especially in the morning.

### *Dangers at the intersections of gender and race*

Many studies have demonstrated that disabled women are more isolated and more likely to be abused than able-bodied women (Barile, 2006; Chouinard, 1999; DAWN-RAFH Canada, 2013; Women in Cities, 2010; Human Rights Watch, 2015). However, most of this research focuses on domestic and institutional violence and there is little literature on the experiences of women in urban environments. In 2008, Action des femmes handicapées de Montréal (AFHM) partnered with Women in Cities and became involved in a participatory research project on

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<sup>41</sup> Most motorized mobility devices do not go faster than 10 km/h, while most cyclists have an average speed of 20km/h. This means that nearly every cyclist overtakes wheelchair users.



**Figure 10:** France and I are wheeling on a bike path. The photo is taken with the GoPro camera mounted on my wheelchair.

women's safety in Montréal. Isabelle was one of the participants. With a group of disabled women, she identified spaces where she felt either safe or unsafe. She tells me that she realized that she does not have the same fears as the other women in her group:

Je me suis vite rendu compte que j'ai moins de crainte que d'autre monde. Il y a beaucoup de femmes qui mentionnaient le fait qu'elles avaient peur des itinérants, de la noirceur, des gangs de rue. Mais moi, ce n'est pas le cas. Les gangs de rue un peu plus, mais les itinérants j'ai pas cette crainte là parce que je sais que malheureusement la plupart des agresseurs sont des gens qu'on connaît. Donc ma vision de la sécurité était : la sécurité c'est aussi comment on se déplace. J'ai aussi remarqué que les femmes en situation de handicap sont souvent plus sécures quand on connaît les lieux, quand on a un contrôle grâce à un fauteuil ou à une aide quelconque vraiment adaptée. [...] Moi je me sens en sécurité quand j'ai le contrôle de mon fauteuil. Je me sens en sécurité quand je connais où je m'en vais.

The authors of the report resulting from this project echoes Isabelle's thoughts on feeling safe when she uses her wheelchair and knows where she is going. They write that:

for women with disabilities, safety goes hand-in-hand with universal accessibility. Safety, in this sense, encompasses a broader meaning because it is not only about avoiding acts of violence. It also means moving around without impediments and being able to access the city alone at any hour, without constraint. (Women in Cities, 2010, p. 22)

Jacynthe remembers that when she lived downtown, she never feared for her safety, even though the area did not have the best reputation:

Le fait de vivre dans le coin ça fait que tu rencontres souvent les mêmes itinérants, les mêmes punks sur le coin de la rue. Il y avait des gens qui dormaient dans le portique des résidences universitaires. [...] Une fois, par exemple, j'étais avec une de mes amies et un monsieur nous a dit : « eille, ça te déranges-tu de surveiller mon bicycle? Il faut que j'aille voir quelque chose en dedans ». [...] Tsé il n'y avait pas ce rapport là de crainte ou de méfiance. Je pense aussi que si tu gagnes la confiance des gens qui vivent dans la rue et qui connaissent le mieux la rue dans ce coin là, dans le centre-ville, tes arrières sont protégés. À mon avis! Je pense que si j'avais eu des problèmes, je serais allée vers ces gens là et ils m'auraient défendue.

She claims that she had developed an understanding of the neighbourhood and its politics. Knowing a neighbourhood and its inhabitants helps to critically examine prejudices and stereotypes about the area.

Throughout the wheeling interviews I continued to raise issues of safety to the participants in the hope of going beyond the dangers posed by the lack of accessibility and tackling, as well, the difficult topic of violence and street harassment that is experienced by disabled women. France admits that when she was younger, she used to feel totally safe in her neighbourhood. She would wheel back home late at night without worrying about her safety. “Je suis même rentrée à des trois heures du matin toute seule chez moi en fauteuil électrique. Pas accompagnée, avec ma sacoche sur mes jambes là! Avec 75\$ dans ma sacoche,” she recalls. France remembers that she thought that no one would attack a wheelchair user. However, a crime that happened in Parc La Fontaine changed how France felt about being out at night alone. A few years ago, a wheelchair user was beaten, and his attackers took his wheelchair from him. France explains how that event changed her habits when going out at night:

Moi j'habite à coté du Parc La Fontaine et c'est là que j'ai compris que j'étais vraiment vulnérable. [...] Depuis cet évènement que j'ai vu dans les médias, c'est un pensez-y bien. Quand je sors pis qu'il est tard, je vais plus prendre des artères, des rues où il y a plusieurs personnes qui circulent. Je ne prendrai plus des petites rues, des petites ruelles. Je deviens peureuse.

Even though France realizes that disabled people are not safe from being attacked, she says that she thinks that Montréal is a fairly secure city. Furthermore, France said that she feels vulnerable, not because she is a woman but because she is disabled.

Nabila is the only participant who said that she fears for her safety on a regular basis. Nabila confides that she has been verbally harassed because of her identity as a Muslim woman wearing the hijab. One day, at the intersection of Côte-des-Neiges and Côte-Sainte-Catherine while she was on her way to CLSC Côte-des-Neiges, a man came up to her to insult her. “Il s’est rapproché en continuant à m’insulter. Il s’est rapproché très, très près de moi. D’ailleurs, je pensais qu’il allait me frapper. Mais, finalement, il est parti,” she painfully remembers. Nabila explains that even though this event was particularly scary, it was not the only time she has been targeted because of her gender and religious expressions. Nabila identifies a precise moment in Québec’s recent history when she started experiencing hostile attitudes towards her religion: in 2009, when debates on the *Charter of Quebec Values* started appearing in the public space. She confides:

Disons que les réactions bizarres des gens quand tu es une femme voilée c’est sûr que j’en connais depuis mon arrivée [en 2009]. Disons cette histoire de Charte<sup>42</sup> ça a augmenté. D’ailleurs, quand je parlais de mon agression... Je n’ai jamais, jamais été agressée, du moins pas verbalement depuis mon arrivée à Montréal. Jusqu’au jour où ils ont provoqué un problème avec la Charte. Pour être franche, j’ai évité au maximum possible de sortir amplement depuis cet événement. Et puis voilà, ensuite je me suis dit parfois je n’ai pas le choix, il faut que je sorte.

Nabila continues to talk about the dangers she faces when going out and she draws a connection between her fear of suffering racist attacks and her fear of getting stuck in one of the numerous holes due to the sidewalks’ terrible conditions. Even though these two fears come from two different political issues, for Nabila, they are both intimately intersecting. All the experiences have the effect of limiting her capacity to get around with her daughters. Whenever possible, she prefers to protect them from these dangers. They either use Transport adapté or travel separately.

Considering that most women participants did not talk about fearing for their safety, does it mean that they do not experience violence, abuse and harassment in public? Some disabled women have called out their non-disabled sisters and claimed that they were left out of the important discussions on street harassment, which have gained a lot of attention in the past few

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<sup>42</sup> The Charter of Quebec Values (French: *Charte de la laïcité* or *Charte des valeurs québécoises*) has caused heated debates in Québec in 2013 and 2014. The Charter was proposed by the Parti Québécois government in September 2013. One of the most controversial elements of the bill concerned a prohibition of public sector employees from wearing overt religious symbols such as turbans, burkas and hijabs (CBC News, 2013). In April 2014, the Quebec Liberal Party won the elections and did not follow up on the proposed bill. Even though the bill was never adopted, it remains in Quebecers’ minds.

years.<sup>43</sup> In her blog post titled “Nobody Catcalls the Woman in the Wheelchair,” Kayla Whaley (2016) explains:

Despite the best of intentions, the way feminists tend to discuss street harassment as a given reinforces ableist ideas of womanhood, because it’s only a given if your body is seen by the patriarchy as a sexual object. Mine isn’t. Moreover, this assumption ignores a different form of harassment faced by those who are disabled. Harassment, after all, isn’t actually about sex, but about power — and my harassers hurt me through the power of desexualization. They use the same voice with me that they’d use with a 3-year-old. They pat my head like they would a dog. They stare at my chair while shushing their childrens’ innocent questions. It’s ableist rather than sexist street harassment (from all genders) that I experience. This desexualization makes me vulnerable to abuse as well. While disabled women aren’t often seen as sexual objects, we’re more likely to be raped and sexually abused than our abled counterparts.

In her opinion letter “Longing for the Male Gaze”, Jennifer Bartlett (2016) shares her perspective as a disabled woman on not being harassed and catcalled on the streets of New York City. She writes:

I also do understand what it feels like to get attention from the wrong man. It’s gross. It’s uncomfortable. It’s scary and tedious. And in certain cases, traumatic. But I still would much rather have a man make an inappropriate sexual comment than be referred to in the third person or have someone express surprise over the fact that I have a career. The former, unfortunately, feels “normal.” The latter makes me feel invisible and is meant for that purpose. I like it when men look at me. It feels empowering. Frankly, it makes me feel like I’m not being excluded.

Whaley’s and Bartlett’s thoughts on street harassment help to identify moments when participants were harassed or had to navigate the complicated politics of disability, gender and sexuality. Similar to Bartlett, Marie-Eve experienced the desire to receive attention from men when she was in her twenties. “Je n’ai jamais été ‘catcallée’ ou suivie, mais j’ai déjà vu des gars fixer ma craque de seins. C’était dans le temps où je me disais qu’en montrant ma craque de seins, on ne verrait pas mes mains laides”, she confides.

Marie-Josée, Isabelle and Caroline’s testimonies reveal manifestations of street harassment that do not typically fall into what has generally been considered as street harassment. When wheeling across Université de Montréal campus with Marie-Josée, we pass by a small group of students dressed up as Japanese anime characters. It is late August, the time of annual initiation

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<sup>43</sup> The video *10 Hours of Walking in NYC as a Woman* went viral in the fall of 2014 (Rob Bliss Creative, 2014). The video shows 24-years-old actress Shoshana Roberts walking in the streets of New York City and encountering various forms of street harassment by men.

for new university students. Marie-Josée is amused by their appearance and laughs heartily. However, a few minutes later, she tells me that she generally tries to avoid coming on campus during this time of the year. A few years ago, she was on her way to class when a group of students started taking pictures of her and mocking her. It looked like it was part of their initiation. Even though Marie-Josée is used to being stared at in public, generally by children, she remembers this event as particularly hurtful. This type of harassment has been documented by Lesley Ellis (2017). Ellis conducted two research projects in the United Kingdom that revealed that people with dwarfism have their photograph taken by strangers in public. She argues that the rise of smartphones equipped with cameras has made this form of violation even more common. Caroline shared two experiences when people had harassed her verbally and were hostile to her disability. “Avant d’avoir ma chaise roulante, à un moment donné, je suis allée dans un dépanneur pis la fille elle m’a regardé pis elle m’a dit « tabarouette t’es donc ben maganée toé », ” she recalls. On another occasion, a bus driver refused to give her time to sit before starting his vehicle. He argued that she was not truly disabled because she could walk. This happened when Caroline was with her young daughter. In addition to the humiliation of the driver’s remarks, she feared not only for her safety but her child’s safety as well. Caroline explains that she was more exposed to these attitudes prior to using a wheelchair. “Ça passe mieux quand tu as un fauteuil,” she argues. Since she has started using a wheelchair, she has felt more protected from ableist comments and attitudes on how she moves in the world as a disabled woman. Other disabled scholars and activists have argued that their assistive devices somehow help them to be seen as “legitimate” disabled individuals. In her piece “Seeing Is Be(liev)ing,” Deborah Peifer (1999) explains why she decided to use a white cane: without a cane, people did not believe she had a visual impairment. These stories of harassment experienced by disabled women demonstrate how ableism, racism and sexism intersect and create conditions for unsafe and unwanted interactions with other pedestrians.<sup>44</sup>

There are other sources of danger and fear that have not been mentioned in this chapter. For example, Marie-Eve speaks of her fear of being run into by pedestrians who do not look where they are walking or are absorbed by their phones. Sandra discusses being forced to use the streets due to the sidewalks’ conditions yet she fears cars. As we are both wheeling on a street, she confides that her boyfriend, who is also a power wheelchair user, has been hit by a car twice. At a busy intersection deserted by pedestrians, we came across a pedestrian crossing button that

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<sup>44</sup> Encounters with other pedestrians will also be explored in Chapter 6.

neither of us could reach. “I can’t press it. I hate it. I have to wait for somebody,” she explains. Marie-Josée claims that she avoids areas where there is more traffic. “L’Université Concordia oublie ça, je ne vais pas là. C’est difficile avec ma vision. Il faut quasiment avoir six à huit paires de yeux. Même dans mon quartier, j’ai déjà vu une auto qui était quasiment à deux pouces de moi même si j’étais sur la bonne lumière,” she recounts. ([see video Blais-1](#)) I had expected that participants would have talked more about how their experiences with cars and the difficulties this poses but they had more pressing issues to talk about. It may also be explained by the fact that most of them live in neighbourhoods with high pedestrian traffic, with the exception of Nabila and Sandra, who live in areas where cars are predominant.

I conducted the wheeling interviews just a few weeks after the adoption of the *Projet-pilote* relatif aux aides à la mobilité motorisées, however most participants were not aware of its details. Marie-Eve told me that more than a year after the implementation of the *Projet-pilote*, she has started to use the bike paths and the streets much more often. However, it is hard to say whether or not it has impacted other participants’ habits. Overall, if there is one thing that is clear from the wheeling interviews regarding danger in the city it is that the new regulations imposed by the *Projet-pilote* do not address disabled people’s main preoccupations regarding their safety as well as the safety of the people with whom they travel (e.g., disabled mothers and their children). In their everyday lives, most participants live with the fear of encountering obstacles. In some cases, these obstacles cause pain and injuries that often go unreported. Unsurprisingly, fear and stress are the two most common emotions identified by participants, whether they use a mobility aid or not. Some participants also claim that, despite all the obstacles they encounter, they derive pleasure from wheeling. This is a reminder that the emotional dimension of mobility is central to the question “what does it mean to wheel/walk in Montréal as a disabled person?”<sup>45</sup> Finally, to answer this question and better understand “walkability” from the perspectives of disabled people, the impacts of winter on participants’ mobility must be explored. Most of them have indicated that they experience danger and fear that is specific to Montréal’s notorious winters.

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<sup>45</sup> The emotional dimension of mobility will be explored further in chapter 6.

### ***Montréal winters: The city and disabled people's mobilities redesigned***

*March 2003. It must have been my first winter in Montréal. I suppose my last class of the day ended earlier than expected and my Transport adapté trip home was not scheduled for a few hours. I remember being in the CÉGEP bathroom and zipping my winter coat that I always had difficulty zipping up on my own. I had decided not to wait for my TA ride and to wheel home instead. I remember being in the bathroom, trying to zip up my winter coat and preparing for a long ride back home; at that time of my life, wheeling home was not something I would do, especially during winter. I relied almost exclusively on TA to travel the six kilometres between my apartment and CÉGEP. Wheeling home was not yet a string in my bow. Wheeling home was not yet the best tool in my survival kit.*

*A snowstorm had hit Montréal a few days before, but I was ready to take a chance since it was not too cold outside and, perhaps most importantly, I could not wait for the TA. I started using TA a year prior, and I had already spent too much time waiting for it. I just could not handle it. So, I left.*

*I remember wheeling on St-Denis, which I had probably chosen hoping that the sidewalks would be cleared of snow. However, they were still covered in snow and I was constantly at risk of getting stuck. I was controlling my joystick carefully and trying to make the right decision at every second. I had to find the best speed and the best angle. The curbcuts were the trickiest to navigate. At some point, I got stuck but people quickly came to help me out. It was the middle of the afternoon and people were outside, going on with their lives. I remember getting stuck like this two other times on my way home—at the exit of St-Hubert overpass, where I had to wait a little bit before someone passed by, and at the corner of Bélanger and De la Roche. Coming back home must have taken me over an hour and had not been easy but I felt satisfied somehow.*

*I don't have other memories of getting stuck in the snow multiple times between home and school. Just like I don't have other memories of zipping my coat to wheel home during winter. It is not because I didn't do it again.*

*It is because I did it so many times that it became ordinary.*

—February 16, 2017

One of the first decisions I made about this research was to not conduct any interviews during the winter. I briefly thought about trying but quickly decided against it. I knew how difficult it would have been since, despite all my winter experience in Montréal, a simple trip to the grocery can sometimes be impossible for me. I thought that conducting interviews in the summer would be ideal. However, many wheeling interviews took place during a mid-August heat wave.

France and I meet at her apartment on one of these days. We decide to do part of the interview inside to limit the time we would spend in the suffocating heat. In her kitchen, fans are turning full speed. The temperature is barely tolerable. I am a bit traumatized after nearly passing out the day before while wheeling with Sandra, so I brought an icepack with me. However, I drop it on France's kitchen floor, and neither of us can reach it. It stays on the floor. France and I

discuss about how she became disabled and how she learned to get around the city with her wheelchair. At one point, I realize that we are talking about the city as we see it: when there is no snow. I ask her about her memories of learning to manoeuvre her wheelchair in the snow. “Oui, bonne question! J’avais oublié l’hiver en cette canicule,” she replies. She immediately follows up and describes some of the impacts of winter on her everyday life. Even though winter feels so far from us at that very moment, her memories are fresh. This was the case with all participants, making “winter” one of the most popular themes of the interviews.

Participants had no difficulties recalling their winter experiences when I would bring the topic up. This would probably be the case for every Montrealer, of course. Montréal has a reputation as having one of the most severe and snowy winter seasons in North America. It receives an average of 209.5 centimeters of snowfall within a typical year usually between December and April (Environment Canada, 2016). The cold season is undeniably an integral aspect of Montréal, Québec and Canadian identity. “Mon pays ce n’est pas un pays, c’est l’hiver,” sings Gilles Vigneault not only expressing nationalism but also a profound importance of winter in Québec. Jody Berland (1994) claims that weather plays an important role in the definition and construction of cultures. “We can begin to understand how every culture defines itself differently as a human community in relation to natural and invisible forces by exploring how it explains and interacts with the weather,” she argues (p.111). “Its rhythms and irregularities, and the rituals we construct around them, shape what it means to be part of the social, both within a particular time and space, and across to other times and places, as we imagine or remember them,” she adds (p. 99).

Winter has shaped Montréal in different ways. The métro, for example, was built to ensure its functioning without disruption from Montréal’s rigorous winters (Clairoux, 2001). Montréal’s downtown is characterized by 32 kilometres of underground tunnels called “the underground city.”<sup>46</sup> Adam Gopnik (2011) describes Montréal as a place where pedestrians can choose between the winter street and the underground city:

One walks, coat on arms, quite literally for miles, without stopping to think that outside is bitter and hostile. Once again, the possibility of walking below, in comfort, gives the city back to the walker, whose natural mode is curiosity. (p. 200)

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<sup>46</sup> Most of the underground city remains inaccessible due to the absence of step-free access (Hagg, 2009).

The reality is that very few Montrealers can live without having to confront the climate. The underground city connects a very limited portion of the city. The significance of winter is also reflected in Montréal's cultural life. The city has winter-specific cultural events such as the festival Montréal en lumières and Igloofest. However, according to many design and urban planning experts, Montréal has yet to embrace its nordicity (Meloche-Holubowski, 2017). Spaces are rarely designed with winter in mind despite the season's disturbance to city space.

Every year, snow removal becomes a heated political issue and gets a lot of media attention (Normandin, 2017; Pineda, 2016; Shields, 2015). While poor snow removal is an inconvenience for most people, it can have much more serious consequences for disabled people and the elderly. A few disabled Canadian bloggers have also written about the impacts of winter on their everyday lives and their bodies (Martin, 2015; Williams, 2017). “Just like everyone else (okay—except for winter sports enthusiasts who no one really likes), we Super Crips hate the cold, the damp and how short the days are. The difference is that for us, winter complicates our already difficult daily negotiations with the world,” wrote Renee Martin, a disabled woman living in southern Ontario.<sup>47</sup> Every winter, there are news stories of disabled Montrealers confined at home for several days because of the tremendous difficulties getting around the city (Boulanger 2015; Boulanger, 2016; CBC News, 2017). This is the case of many disabled Montrealers who are trapped in their homes—myself included—as I am writing these lines in the middle of winter after a 20-centimetre snowfall. (Figure 11)

In 2013, I conducted interviews with six wheelchair users living in Montréal to document their winter experiences in the city and wrote a paper titled *The Politics of Snow*. The paper explored the impacts of winter on their professional, scholarly, social, urban lives as well as their sentiment of feeling trapped in their own homes. I have argued that snow is not only a meteorological phenomenon but also political. In 2013, only a small amount of literature on disabled people's winter experiences existed. Four years later, the Canadian literature on the subject has grown somewhat. It added to, in part, the research on the impacts of winter on the elderly, a population at high risk of falls because of icy sidewalks (Li, Hsu & Fernie, 2012).

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<sup>47</sup> Interestingly enough, Renee Martin and Spencer Williams live respectively in southern Ontario and Vancouver, two of the least snowy regions in Canada (Environment Canada, 2016).



**Figure 11:** I took this photo on February 16, 2017. This street intersection is not clear and is therefore inaccessible.

Sally Lindsay and Nicole Yantzi (2014) interviewed young wheelchair users aged 15–22 living in an urban area in southern Ontario. They found out that youth encounter several obstacles and safety concerns restricting their ability to participate in a variety of activities. These circumstances isolate them from their peers and increase their dependence on adults. Overall, winter is identified as a severely disabling phenomenon. Furthermore, the authors note a gendered difference—the women stayed at home more than men. The type of mobility aids used by participants also influenced the barriers they encountered. Participants using motorized wheelchairs reported fewer obstacles. The obstacles are more significant for people using manual wheelchairs or walkers. Sally Lindsay et al. (2015) have conducted similar research that compares the winter experiences of disabled and non-disabled youth living in two Canadian

cities.<sup>48</sup> In *Disablement as Inveterate Condition: Living with Habitual Ableism in Prince George, British Columbia*, Jessica Blewett and Neil Hanlon (2016) argue that the northern British Columbia city of Prince George reproduces the exclusion of disabled people with its ableist winter design. For example, heavy or spring-loaded doors that are used to prevent cold air from entering buildings are inaccessible to many disabled people. Ernesto Morales et al. (2014) has studied design solutions for facilitating the accessibility of Quebec City's sidewalks during winter since the presence of snow and ice has forced many disabled and elderly people to stay at home. They claim that winter is the "public enemy #1 for accessibility." (p. 29) The research involved disabled people, city representatives, designers, urban planners and occupational therapists.

Considering that research should pay attention to the particularities of geographic locations since the impacts of winter vary from one city to another, as argued by Sally Lindsay et al. (2014), it is troubling to note the absence of literature on disabled Montrealers' experiences of winter. During the wheeling interviews, participants talked about how their relationships with time and space in the city change in winter, which stresses the importance of the temporal dimension of ableism. For all participants, except Luc, winter adds another layer of barriers and dangers to the city. Even though most claim to reduce their outings during winter, all of them regularly go outside either for work, school, social or family reasons. This finding challenges the claim made in other studies regarding whether or not disabled people stay inside most of the winter. Unlike other cities, Montréal's winter is long and thus unavoidable. Many participants are preoccupied with the differences between Montréal boroughs regarding snow removal operations, as well as the psychological impacts of winter.

### *The politics of snow removal*

At the time of the interviews, snow removal operations<sup>49</sup> were the responsibility of each of Montréal's boroughs. This means that the operations are not launched at the same time and that the amount of snow on streets and sidewalks can vary across the city. Every winter, there are stories about snow removal issues in different boroughs (Béland, 2011; TVA Nouvelles, 2015c).

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<sup>48</sup> The cities are not specified. One is in Québec and one is in Ontario.

<sup>49</sup> Snow removal operations are divided in four stages: salting, plowing, loading and disposal (Ville de Montréal, 2015).

<sup>50</sup> Luc spoke about the differences in snow removal he notices between boroughs. He explains that the sidewalks in the downtown, where he worked at the time of the interview, were cleared rapidly, while his neighbourhood's sidewalks in Mercier–Hochelaga-Maisonneuve were not. In August 2015, former Mayor Denis Coderre announced a new snow removal policy that completely changed the organization of snow removal operations in the city. The opposition voted in favour of the policy. Boroughs lost the power to decide when and how snow would be removed on their territory. This decisional power was transferred from the boroughs into the hands of the City. The policy included a short section on universal access, which only provided a definition of universal access and a statement indicating that the policy responded to the concerns expressed by the local disability rights movement (Ville de Montréal, 2015, p. 10). However, there is at least one important accessibility issue absent from the policy. While it states that priority should be given to clearing snow from bus stops, there is nothing in the policy about paratransit pickup and dropoff points. Since the wheeling interviews took place before the implementation of this policy, I do not know how it has impacted participants' mobility. On Transport mésadapté, some participants have commented on the obstacles they encountered during winter. Geneviève explains that she has noticed that many curb cuts, which are mostly located on street corners, were not cleared even when sidewalks were cleared (Vanier, 2016).

### *Different season, different city*

Participants powerfully explain how their relationship with time and space changes during winter. The cold season adds a layer of complexities to the city and to their mobility. France

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<sup>50</sup> For example, in 2009, Le Plateau-Mont-Royal stopped clearing snow on weekends and increased the amount of snowfall required to launch clearing operations (Béland, 2011). The borough claimed that it needed to make difficult choices due to budget constraints and that plowing the sidewalks would be sufficient to ensure the mobility and safety of pedestrians. During plowing operations, the snow was moved to the sides of streets and sidewalks, which creates snow banks. In order to get to their vehicles, people were expected to climb over the snow banks or to shovel the snow by themselves—two physically demanding activities that cannot be performed by many disabled individuals. According to the borough, pedestrians had to either use public transit, such as the métro or the bus, or be able to get to their cars on their own. The borough's initial definition of pedestrian safety did not include people who use Transport adapté, taxis or personal vehicles due to the inaccessibility of the métro and the bus. Following demands from the Regroupement des activistes pour l'inclusion au Québec (RAPLIQ), the borough implemented a program in 2013 that offers disabled residents assistance with clearing snow from the entrances of their homes (Cabinet du maire, 2013). The program still exists and serves a few dozen individuals. To my knowledge, Plateau Mont-Royal is the only borough with such a program.

shows me the route she takes to go to work not only because it is part of her everyday life but also because she loves it... during summertime. She reflects:

Chaque fois que je vais travailler là en roulant par moi-même, je me dis « mon dieu si je vivais dans un pays où c'est l'été ou du moins où il n'y a pas de neige là...». Écoute, j'irais travailler tout le temps à pied. Ce serait merveilleux ma vie. C'est fou!

Our trip begins in the alley behind her home. She prefers the alley to the sidewalk because she can avoid sidewalk joints and wheel without being slowed down by sidewalk users. However, her habits change during winter. The alley is cleared for cars, but the space is often unsafe for her because France's wheels can get stuck in the snow. The path made by car tires is not wide enough for her wheelchair. She explains:

C'est toujours l'angoisse justement quand je rentre chez moi dans ma petite ruelle où il n'y a pas nécessairement de personnes qui vont passer. Il n'y a pas un flot de personnes comme sur la rue Mont-Royal par exemple. Je sais qu'une fois je suis restée embourbée pis après ça toutes les autres fois que je passe là l'hiver, je pense à cette fois-là où je suis restée prise. C'est ça. Je ne m'aventure pas nécessairement dans ma ruelle quand qu'il y a trop de neige où qu'il vient de neiger tsé. J'analyse la situation avant d'aller dans ma ruelle.

France recounts that she has been stuck in the snow in Montréal so many times that she has become used to it. Fellow pedestrians are generally willing to help her out. The particular issue with the alley behind her home is that she could have to wait for a long time before getting assistance from a passer-by. While the absence of pedestrians is an advantage most of the year, as it enables her to wheel as fast as she wants without interruptions, it becomes a source of danger when there is too much snow on the ground. Being immobilized in the snow exposes her to the cold, which does not mix well with tetraplegia. She must limit her time spent outside to avoid frostbites, which means that on extremely cold days, every minute counts. When we arrive at France's dance studio, she tells me "c'est mon terrain de jeu ici," strongly affirming her attachment to the route we have just wheeled and the surroundings of the dance studio where she teaches. She immediately follows this comment by telling how the same space is difficult to navigate during winter. Pointing to the Transport adapté pick-up point, she says "L'hiver, souvent, il y a des gros bancs de neige là. C'est épouvantable pour les étudiants. Leurs transports viennent ici, mais ils ne peuvent pas loader plus que deux personnes. [...] C'est vraiment mal déneigé." Because of all the obstacles created by winter, France admits that mild winters elate her:

À Montréal, des fois il y a des hivers où il pleut, où les gens se plaignent parce qu'ils ne peuvent pas faire des sports d'hiver. Mais moi j'applaudis quand il pleut l'hiver! Parce que

ça m'évite justement... Ça enlève tout ce stress là qui est le stress relié vraiment à une difficulté de circuler, de circuler dehors.

Sandra, Laurence, Isabelle and Marie-Josée also speak of how the spaces they move in change during winter. Sandra loves to be out in her neighbourhood, but she explains that snow accumulation makes it very difficult during winter. She limits her outings to a minimum. Laurence says that during winter she sometimes has to take a taxi for distances as short as 500 meters. While she can usually walk that distance without much effort, it gets too dangerous when sidewalks are icy. Accomplishing daily tasks, such as grocery shopping, can be extremely difficult. Luckily, she can rely on her parents' support to do most of her errands. Her mother lives in the apartment above hers. Isabelle has a similar arrangement with her mother, who lives in the same apartment building as her. Her mother takes her car to shop for both of them. Isabelle does not wheel much outside during winter because the routes she is familiar with are always at risk of being disrupted by snowy sidewalks. "Il suffit qu'il y ait un tronçon qui ne soit pas déblayé pour que je sois complètement perdue pis pas capable de me rendre," she explains. She adds that she does not have any resistance against the cold. Therefore, she has to make sure she will get to her destination in a reasonable time. When explaining why she did not go out when she was living on Université de Montréal campus during winter, Marie-Josée not only mentions the snow-covered sidewalks but also the topography of the area and the built environment. She argues that the hills that characterize the campus, which are built on the northern slope of Mont-Royal, are more dangerous during the winter because of snow and ice. To that, she adds that most buildings in the neighbourhood are inaccessible. Places to go to are rare; reasons to go out are limited. In addition, places to find refuge from the cold are hard to find. While not being able to get inside stores and restaurants is a problem all year long, it is even more critical during winter.

The arrival of winter, however, is not perceived as threat to the mobility of all participants I wheeled with. After his guide dog died, Luc made the choice to learn how to get around the city using his white cane. He remembers that even though he anticipated winter, he was surprised to discover that the cold season generally did not create obstacles for him. In fact, Luc argues that winter could be a facilitator. Luc explains that even though using his white cane in sticky snow is challenging, most of the time the snow works in his favour. His white cane slides better on frozen surfaces. Furthermore, sidewalk snow plows create beaten paths and cover obstacles such as standpipes, poles and mailboxes. "C'est plus facile l'hiver pour ça que l'été parce que tout ce qui est obstacle est généralement hors du sentier battu," he says. For Luc, the interaction of nature

(snowfalls), the built environment and the city's snow removal techniques creates sidewalks that are temporarily—and unintentionally—easier to navigate.

### *Winter distress*

Previous research indicates that disabled people are more likely to suffer from isolation during winter (Lemaire, 2010; Lindsay & Yantzi, 2014). However, none of these studies specifically report cases of depression. Researchers have called for more research on the issue. Even though talking about the psychological impacts of ableism and inaccessibility proved to be challenging during the wheeling interviews, discussing winter opened a door into difficult emotions. Some participants clearly state that winter causes harm to their mental health.

Under unusually scorching August sunrays, France and I are talking about snow removal problems. She tells me “Dire que l’été achève. C’est tellement triste. Toi tu as-tu un down?”. Relieved that I am not the only person anticipating winter in August, I answer in the affirmative. “C’est tellement pas drôle. C’est la fin du monde,” she adds about the upcoming end of summer. France explains that she does not go out as much as she would like during winter mainly because of the cold. Sometimes she forces herself to go out to change her mind and preserve her mental health. She points out that she knows many disabled people who stay home all winter and are incredibly isolated and suffer from it. France argues that the city should take this seriously and she gives an example of a pilot project that was put in place in her borough to remove the snow at a certain number of disabled individuals’ home entrances. While she acknowledges that this was a good idea, she ironizes that it would be not be of much help if sidewalks and curb cuts are not cleared more efficiently. Nabila talks about the winter activities her daughters miss out on because she does not have reliable and safe transportation to get there. She explains that having to wait outside for a late Transport adapté trip is much more dangerous in the winter because of the cold. Most of the times, there are no indoor places where they could wait for their ride. This not only points to a transportation issue, which will be further explored in the next chapter, but also to the place of winter in family life and more broadly to what it means to live in Montréal. Nabila wants her children to enjoy going to Fêtes des Neiges, skating, skiing and regretted not being able to offer that to them. It matters to her as a mother and an immigrant. “Je m’en veux. Je me dis qu’à cause de moi, elles n’ont pas vraiment vécu leur enfance alors que c’était ça le premier souhait en venant ici. Je n’ai jamais pensé que j’allais être prise, limitée,” she confides with deep emotion. I am gripped by such emotion that I find myself

at a loss for words. I manage to tell her that it must be very hard to live with that guilt. She responds that it is indeed very difficult and continues talking about how lack of access has an impact on her daughters.

Geneviève is the only participant who has mentions depression specifically. She explains that at work some of her colleagues tell her that winter must be hard for her. “Je ne dis pas toujours oui. J’essaie de contourner. Je ne suis pas un être déprimé. Je ne veux pas que tu viennes me voir chaque jour de l’hiver pour me dire combien c’est triste,” she stresses. Geneviève argues that she hates these kinds of comments because she does not want to belong to the group of people who hate winter and complain about it. She wants to have an active life and have things to share on Monday mornings but, more often than not, she does not have much to tell her co-workers because she has spent the weekend at home reading. Going outside is taking too much time and planning. Just thinking about it feels heavy and complicated. She confides that she was diagnosed with a depression once during winter. She never knew whether winter played a major role in her depression, but she says that it definitely contributed to the difficult situation in which she found herself. It was not possible for her to find ways to change her mind. She felt trapped. While her car offers her the possibility of getting around the city quite easily, winter regularly makes it challenging and sometimes even impossible since getting to her car and removing the snow poses major barriers.

### *Taming winter*

Although participants’ stories show that winter creates additional obstacles for many, participants have developed knowledge and skills that help them to tackle winter conditions and navigate the winter city. Sally Lindsay and Nicole Yantzi (2014) found that youth who had more experience using their mobility aids (more or less 10 years of experience) were more confident about their ability to wheel on snow and ice. They had developed skills by themselves because most of them did not receive any training. Similarly, Montréal participants had to learn on their own. Winter experience plays an important role for many; however, it cannot be measured by the number of years you have as a wheelchair user. Winter experience has much more to do with knowledge and skills about a particular route and about how to wheel in winter conditions.

Pierre had been getting around using a power wheelchair for more than 20 years when he moved to Montréal. He and his wheels had already seen snow and ice. During his childhood, he spent a lot of time playing outside with his friends and he experienced rough terrains. Despite his

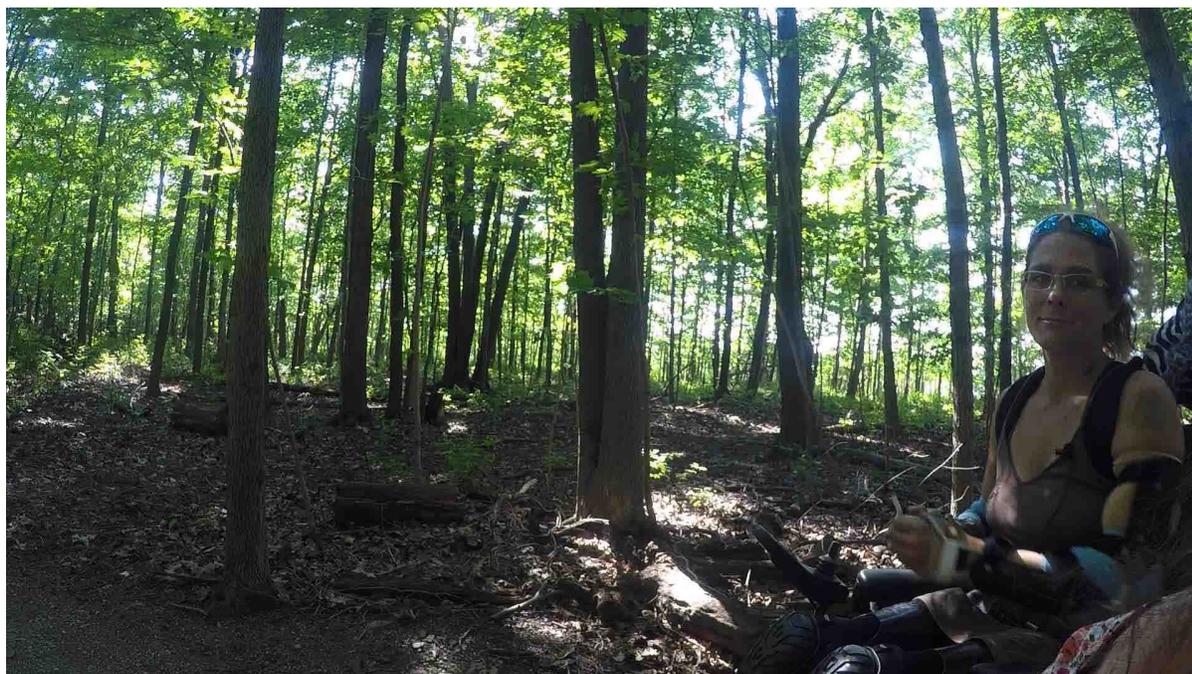
experience, however, he remembers that he did not wheel much outside during his first winter in Montréal. He took Transport adapté even for very short trips in the city. Pierre did not know if he could wheel these distances in winter conditions. In the spring and summer that followed, Pierre discovered Montréal sidewalks and became familiar with his surroundings on wheels. During his second winter, he wheeled to school even where there was snow on the ground.

I ask him if he wheeled to school in all winter conditions. “Non, non, non. Quand c’était trop intense, je prenais un TA, mais là j’étais beaucoup moins chicken,” he admits. Winter was not as intimidating as it was when Pierre first moved to Montréal. Having a better understanding of the city and of the impacts of weather on his mobility allowed him to determine when he could wheel to school and when it was safer to use Transport adapté. Pierre’s years of experience in Drummondville and Sherbrooke are clearly helpful to him but could not replace the experience he has gained in Montréal. What it means to wheel on snow and ice varies from one city to another.

Unlike Pierre, Caroline only has had one winter of experience at the time of the wheeling interview. She brought me to her favourite place in her neighbourhood—a path located in a small forest. (Figure 12) Before I could even ask her, she proudly tells me “Je viens ici l’hiver! T’imagines-tu?”. She explains that on cold days, the path is wheelchair-accessible because the snow is packed and the surface is hard. Aware that there is always a possibility of getting stuck, she only ventures on the snow-covered path when accompanied by a friend. A nature lover, Caroline spent a lot of time in Abitibi’s woods during her youth when she was walking. Her knowledge of nature and winter conditions, coupled with her sense of safety in the woods, have contributed to her confidence to wheel in her neighbourhood’s forest the first winter she used a wheelchair.

France identifies several things she has learned over the years to mitigate the effects of winter on her life. She explains that as a director of a dance company she often must go to studios that are only accessible by the alleyways, which are generally not cleared by the city. On several occasions, she has needed the help of her assistants or colleagues to clear the snow and to be able to get in. France also avoids booking shows during winter months. She states:

J'essaie vraiment d'éviter décembre, janvier, février et mars. Souvent, on ne choisit pas parce que ce sont les diffuseurs qui choisissent. Alors, ça aussi, c'est toujours un pensez-y bien parce que tu es à la merci de la température. Tu as bien beau vouloir être ponctuelle, organisée, fluide, efficace, mais quand tu te lèves pis qu'il est tombé 35 centimètres de neige, ça se peut que tu arrives en retard à ta répétition et ça se peut aussi que tu ne puisses même pas y aller. Ça aussi, c'est vraiment un défi.



**Figure 12:** Caroline in the small forest. The photo was taken with the GoPro camera mounted on my wheelchair.

Winter produces challenges that are, at times, unavoidable. No amount of organization or preparedness can erase the consequences of a 35-centimetre snowfall. Moreover, no amount of previously acquired skills will prevent getting stuck on uncleared snowy sidewalks. Isabelle argues that wheelchairs should be better designed to deal with snow. “Ça ne prend pas grand-chose pour rester pris,” she emphasizes. France explains that having new tires helps. A few years ago, a wheelchair mechanic advised her to change her tires before the beginning of winter. They have better grip, which can make a major difference on snowy and icy surfaces. “C’est tellement drôle parce qu’on pense à prendre notre douche pis à faire nos trucs du quotidien. Mais là oups c’est vrai, j’ai un fauteuil roulant! Mes pneus ne sont pas éternels,” she laughingly says. For France, taking care of herself includes taking care of her wheelchair and taking into consideration the climate that she lives in.

## ***Conclusion***

Despite the significance of winter in Montréal and its numerous repercussions on the everyday lives of disabled people, research remains to be done and practical measures put into place to ensure the mobility and safety of disabled people during this season. Considering that weather is an integral part of how a culture represents itself, as Berland (1994) argues, the exclusion of disabled people from Montréal's nordicity says a lot about the deep roots of ableism in the city. Two of the major infrastructures offering Montrealers refuge from the hazards of winter conditions, the métro and the underground city, were built to meet non-disabled people's needs. While the participants and I talked about the arrival of winter and what this means for their mobility, we did not talk much about the end of this season. I contacted a few participants by Facebook Messenger on March 20, 2017, which happened to be the first day of spring and the warmest day since the biggest snowstorm the city had seen in five years (Météomédia, 2017). I asked them how they feel at the arrival of spring and what spring means for them. Marie-Josée immediately answered my questions with: "Librrrrrrre! Heureuse! Ça représente beaucoup le printemps. Pu de neige, pu de banc de neige... Je peux reprendre le transport en commun. Je peux sortir sans avoir peur. Je peux aller faire mon épicerie (me déplacer) avec mon accompagnateur." Sandra replied in capital letter "FREEDOM" and added "especially after last week" [referring to the snowstorm that hit Montreal]. Kéven claimed that spring means he gets back his mobility:

Moi, je retrouve ma mobilité. Je ne considère pas que c'est sain de se déplacer porte-à-porte, en auto, chaque jour. C'est bien pratique dans des situations précises, même essentiel. Je suis choyé d'avoir ce luxe, mais quand j'ai le choix de déambuler dans les rues, je préfère de loin cette option. C'est pour ça que je suis venu à Montréal. Pour explorer des rues, avec un itinéraire changeant, pouvoir m'arrêter spontanément dans une boutique, rencontrer des gens dans la rue, etc.

Spring marks the participants reunion with the city they have missed during winter. It makes me think about a song I listen to every spring. In *Heureux d'un printemps*, recorded in 1977, Québec singer Paul Piché argues that the joys of winter and summer belong to the elite whose members do not go into debt to heat their house and can go on vacation during summer months instead of working by the sweat of their brow:

Heureux d'un printemps  
Qui m'chauffe la couenne  
Triste d'avoir manqué  
Encore un hiver  
J'peux pas faire autrement

Ça m’fait d’la peine  
On vit rien qu’au printemps  
L’printemps dure pas longtemps.  
[...]  
Assis su’l’bord d’mon trou  
J’me creuse la tête  
J’pense au bonheur des gens  
J’sais ben qu’ça va pas durer  
Ç’a l’air qu’ça prend des sous  
Pour faire la fête  
À qui appartient l’beau temps  
L’hiver, l’été durant

The feelings of happiness and freedom expressed by Marie-Josée, Kéven and Sandra, which I also experience every spring, seem to fade away within a few weeks. As it has been demonstrated through this chapter, participants encounter obstacles all year long. Maxime D. Pomerleau (2014), a Montréal-based disabled artist and journalist, has written an open letter in which she explains that the end of winter does not mean that all obstacles disappear. “Quand on est handicapé, l’hiver dure pas seulement l’hiver, il dure toute l’année. La marche de béton devant le commerce, le restaurant, le dépanneur, elle ne fond pas avec la neige,” she argues. In these circumstances, it appears clear that *l’beau temps* [good weather] is political and does not belong to disabled Montrealers.

In this chapter, I have demonstrated that Montréal’s enviable “walkability” score as determined by WalkScore is based on the norm of able-bodiedness and does not take into consideration the experiences of disabled people. Throughout the wheeling interviews, participants have identified obstacles threatening Montréal’s “walkability.” Not only is Montréal not built with disability in mind but the city and the government of Québec also continue to adopt ableist policies and regulations that perpetuate barriers to the city. There is still no strong accessibility legislation in place. The city is built for non-disabled people, and the exclusion of disabled people continues to be normalized through these policies and regulations. Throughout the stories told in this chapter, I have highlighted the complexities of the relationships the participants have with the obstacles they encountered in the city as well as various walking and wheeling practices they have developed and integrated into their everyday life. These walking and wheeling practices can be understood as forms of resistance.

Sally Lolley (2017), an able-bodied writer-in-residence at CBC News,<sup>51</sup> argues that distance in Montréal is “always shifting” and that “everyone’s mile is different.” “Construction crews or a clear street, a cold snap or a break in the rain, a protest, a street festival or a Bixi station without a single docking station free: you never know what will cause a Montreal mile to shrink or to expand,” (*Ibid.*) she writes. Considering the multiple layers of obstacles that are encountered by disabled people in this city, the distance of a Montréal mile is subject to change.

The obstacles found in Montréal must be understood within their context. For instance, sidewalks in poor condition have a greater impact on disabled people in the inner-city neighbourhoods, where sidewalks are an integral part of the city infrastructure and are used by nearly everyone in one way or another. Furthermore, the various perceptions of accessibility and inaccessibility as well as their different impacts on participants’ everyday life demonstrate how mobilities are embodied and differential. In other words, the inequalities present in space and time are lived differently from one individual to another and point to issues of power and privilege. To quote Tim Cresswell (2006), “difference as not absolute but relational” (p. 17). For example, France and Nabila are both disabled women using motorized wheelchairs. However, lack of access has different impacts on their professional lives. France, as the director of her own dance company, has the power to arrange her schedule to minimize the chances of encountering obstacles (e.g., she avoids planning shows during winter, she only goes to dance studios that are wheelchair-accessible, her main studio is not far from her home). Nabila, for her part, explains that finding work as a disabled immigrant woman is extremely difficult. Many of the places she wants to apply to for employment are not wheelchair-accessible and they are far from her home. Moreover, in the event that she does get a job, it is quite unlikely that the position will have flexible working hours.

Finally, in light of participants’ stories in this chapter, I feel compelled to say that “public enemy #1 for accessibility” (and “walkability”) is not winter, as claimed by Ernesto Morales et al. (2014), but ableist practices deeply rooted in Québec legal, political and cultural structures. These practices will be under further investigation in the next chapter, which is dedicated to one of the most controversial disability issues of the past decade in Montréal: the accessibility of public transit.

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<sup>51</sup> I am assuming that she is able-bodied because she never mentioned anything about disability in her writing. She also writes that she is “teleported” by the métro indicating that this mode of transportation is easily accessible to her (Lolley, 2017).

## Chapter 5

### Public transit in Montréal: The complicated intersections of the métro, the bus and Transport adapté systems

*On my first day in the city, I tried to meet up with my best friend who had just moved near Place-des-Arts métro station. From Petite-Patrie, it would be an easy feat. But it wasn't. I couldn't use the métro—all stations were inaccessible. My mom and my aunt came with me at the bus stop. Just to make sure everything would go smoothly. I had never taken a bus with my wheelchair before.*

*Everything did not go smoothly.*

*What would come to happen so many times for years to come, happened—the ramp did not work properly and the driver seemed annoyed by my presence. On the top of that, once on board, I realized I had taken the wrong bus. Instead of bringing me to the Quartier Latin, it would only bring me to Rosemont métro station. Three stops from where I had just boarded. This was a simple mistake that anyone new in the city could make. However, taking another bus to continue my trip felt impossible. Most buses were not accessible and their frequency was low. I quickly discovered that there were not many buses running along métro lines. People are expected to use the métro.*

*I think I got off at Rosemont and called my friend from a public phone. We decided to meet on Mont-Royal Avenue instead. I can't remember how I got there. I guess I wheeled.*

*This is how I was abruptly initiated to the problem of accessible transportation in Montréal. My friend, who is able-bodied, and I were both new to the city and shared the same aspirations—we were looking forward to everything that the city had to offer young people—but suddenly it became clear that we would not have access to the same things. It was a fact that I somehow managed to rationalize. I was unable to measure the impact that this would have on my everyday life and, more importantly, I did not have the words to write and talk about it.*

—October 15, 2016

Although new technologies are evolving and changing how we live and interact with one another, the need for being mobile and meeting in-person is not decreasing. John Urry (2003) argues that “these moments of physical co-presence are crucial to patterns of social life that occur ‘at-a-distance’, whether for business, leisure, family life, politics, pleasure or friendship” (p. 156). Therefore, who is able to move, by what means, and in what amount of time are all critical issues for disabled Montrealers. A large part of the disabled population relies on public transit to get around the city. Out of the 15 participants, 12 do not own a car and are entirely dependent on public transit. Disabled Canadians are about twice as likely as their able-bodied peers to live with low income (Prince, 2014). Moreover, disabled people must also shoulder a number of extra costs

associated with disability.<sup>52</sup> Considering this economic disadvantage, owning a car, and especially an adapted van, is out of reach for many.<sup>53</sup> Furthermore, some disabled people simply cannot drive due to their disabilities. That being said, it is interesting to note that the automobile was the most used mode of transportation by disabled people in Québec in 2006 (Institut de la Statistique du Québec, 2010, p. 182). The fact that the participants live in Montréal, the city with the most extensive public transit network in Québec, certainly contributes to their use of public transportation. Many regions across Québec do not offer public transit services to their populations.

Montréal is known in North America for the quality of its public transit network, which is composed of 68 métro stations and 220 bus routes. According to a study conducted by Walk Score, a private company that provides walkability information based on the distance to various amenities, Montréal has the second-best transit system in Canada. In 2010, the Société de transport de Montréal (STM) won the American Public Transportation Association award for Outstanding Public Transportation System in North America. While Montréal has an enviable reputation, its underground transit system is one of the least accessible among European and North American cities with over one million inhabitants (Société Logique, 2001; Woods, 2016). In 2015, at the time of the wheeling interviews, only nine métro stations—all on the orange line—were wheelchair-accessible (see Appendix D and E). At the rate that accessibility retrofits were advancing, the system will not be accessible before 2085 (RAPLIQ, 2010b). In the past eight years, many disabled people and disability rights organizations have denounced the poor accessibility of Montréal's public transit system in the media and at Montréal City Hall (RAPLIQ, 2010b; Ouatik, 2011; Bachelder, 2014, Breton & Parent, 2015; Radio-Canada, 2016a; Radio-Canada, 2016b). Budget cuts to the paratransit service operated by the STM have also been criticized (Ex Aequo, 2014). In 2011, 17 disabled individuals filled complaints at the Québec human rights commission against the STM (Radio-Canada, 2011). I was one of the plaintiffs. In 2015, the Regroupement des activistes pour l'inclusion au Québec initiated a class

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<sup>52</sup> A 2014 study conducted in Québec indicates that these additional costs harm disabled people by jeopardizing their social and professional inclusion (Dumais, Prohet & Ducharme, 2014).

<sup>53</sup> It is important to note that the Québec government has a program that covers the cost of the modifications required to make a vehicle accessible to a driver with disabilities. However, in order to qualify for this program, the individual must buy a brand-new minivan, which costs about \$30,000. Considering that the average income of a disabled person in Montréal is \$16,452, getting an adapted car is simply not possible for many.

action lawsuit against the STM.<sup>54</sup> On October 11, 2016, the STM announced a plan to make 14 stations wheelchair-accessible by 2022 (Société de transport de Montréal, 2016).<sup>55</sup> For the first time in its history, the STM also announced its intention to make the entire network accessible and set a year for the project's completion: 2038. On November 5, 2017, Projet Montréal, a political party that made public transit a priority and promised a fully accessible métro by 2030, won the majority of seats at City Hall. Despite a more accessible bus fleet, access to buses remains difficult for any disabled person (RAPLIQ, 2011; Breton, 2015a; Montreal Gazette Editorial Board, 2015) due to ramp malfunctions, as well as discriminatory attitudes and insufficient training of employees. The STM plans on having 100% of its fleet equipped with front-door ramps by 2025 (Société de transport de Montréal, 2017).<sup>56</sup>

Since I have been actively involved in this fight for public transit accessibility in Montréal, all the people I have interviewed for this research were already aware of my keen interest in the issue. Moreover, many of them are also advocates for better transit accessibility, as getting around the city is a perpetual struggle in their lives. In most cases, just meeting up for the wheeling interviews involved having to use public transit. “Comment t’es-tu rendue ici? Comment ça s’est passé?” were among the first questions asked by the participants or myself. Issues around transportation unsurprisingly turned out to be the most discussed during the wheeling interviews in Montréal.

In the literature, the gap between the transportation choices available for disabled people and able-bodied people has been studied by many researchers (Jolly, Priestley & Matthews, 2006; Pfeiffer, 1990; Porter, 2000; Pyer & Tucker, 2017; Quinlan & Bates, 2012; Soorenian, 2013). It is often used as an example of how disabled people are spatially disadvantaged (Imrie & Wells, 1993; Gleeson, 1996; Kitchin, 1998). For example, Rob Kitchin (1998) argues that “disabled people often have to travel circuitous routes and are denied the same spatial choices as able-bodied people.” (p. 348) These research findings are primarily based on accounts of people living in Great Britain and in the United States. Disabled Montrealers face similar obstacles to the ones identified in the literature, such as a limited number of wheelchair-accessible underground

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<sup>54</sup> In May 2017, the Superior Court of Québec approved the class action lawsuit (Cohen, 2017).

<sup>55</sup> The stations were not chosen because of their ridership, but on the basis of how easy it would be to install elevators (CBC News, 2016). Some disabled activists, myself included, questioned that decision (Olivier, 2016).

<sup>56</sup> Buses have an operational life of approximately 16 years.

stations, problems accessing buses due to ramp issues, and lack of reserved space (Gaete-Reyes, 2015; Transport for All, 2016). However, the cultural, legal and political contexts differ greatly. For example, large sums of money were invested in accessible transportation in preparation for the 2012 London Paralympic Games (Beard, 2012; UK Government, 2012). Montréal has yet to experience a similar accessibility boost sustained by a major international event.<sup>57</sup> Moreover, the effects of winter conditions on the use of public transit by disabled people have been poorly documented so far. It goes without saying that Montréal and London winters have very little in common. When we think about the inaccessibility of public transit in Montréal, we generally approach it as a static spatial reality. There is a need for more literature that takes into account the impacts of the cold season on disabled peoples' transit experiences.

Unlike in Great Britain, disability activism for accessible transit and academic research do not intertwine significantly in Québec. Transportation issues have been at the heart of the development of disability rights movements in Great Britain and in the United States. The protests organized by the Disabled People's Direct Action Network and Transport for All in Great Britain and by the American Disabled for Accessible Public Transit (ADAPT) in the United States have marked the history of these movements and continue to be a point of reference and a source of inspiration for academics interested in disability and transportation. Even though public transit issues are among the priorities of disabled activists in Montréal and have attracted a great deal of media attention in the past few years, there is a dearth of literature on the (in)accessibility of public transit in Montréal and in Québec in general. The latest statistics available on disabled peoples' transportation habits in Québec are not very useful as they are quite general (i.e., no distinction is made between urban and rural areas) and completely ignore the presence of obstacles in transportation systems. A report published in 2010 indicated that a third of people with "severe disabilities" are limited in their mobility because of their condition (Institut de la Statistique du Québec, 2010, p. 191). I was only able to find two useful research reports. One report published in 2016 covers the social and economic benefits of Transport adapté (Association du transport adapté du Québec, 2016). Another report, published in 2015, investigates the social representations of different actors involved in the development of accessible public transit in Quebec City, such as disabled users, public transit administrators and

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<sup>57</sup> Paralympic Games were held in the same city as the Olympic Games in 1960 (Rome) and 1964 (Tokyo). In 1976, Montréal hosted the Olympics, while the Paralympics took place in Toronto. Since 1988 (Seoul), Paralympic Games have systematically been held in the same city as the Olympic Games. (McBride, 2012)

bus drivers (Boucher et al., 2015). The study is based on interviews conducted with 23 people, comprising 17 able-bodied bus drivers and public transit administrators, and six disabled users. The only information given about the disabled participants is their gender and type of disability. This means that not only are disabled people underrepresented in the group of participants, but also that the reader does not get a sense of the complexities of their stories—these people are abstract, disembodied and universalized. In my research, I explore how these complexities are lived and how the issues related to public transit change over the course of a person’s life. The interactions between space and time are also at the heart of my analysis. As argued by Mei-Po Kwan (2013), who has analyzed daily time-space trajectories, “time is a fundamental dimension that shapes people’s access to and use of urban opportunities.” (p.1082) This section is organized into three different parts, one for each of the modes of public transportation offered by the Société de transport de Montréal (STM): métro, buses and Transport adapté (TA for the insiders). They appear in order of frequency of use by participants, from least used to most used. This analysis of these three transportation systems gives an insight on how they connect even though they are not designed and intended to do so.

### ***The Métro***

*De 2002 à 2008, j’ai passé la plupart du temps hors de chez moi dans le Quartier latin et ses alentours. Pour mes études. Pour travailler. Pour voir mes ami-es. Pour sortir. C’est lors de mes multiples déplacements entre La Petite-Patrie et cette partie de la ville que j’ai développé une connaissance approfondie de l’inaccessibilité du transport en commun à Montréal. À cette époque, il n’y avait pas de station de métro accessible. Trois « options » s’offraient à moi : prendre le TA (tout planifier à l’avance et perdre un temps fou à attendre mon transport), prendre le bus (risquer de ne pas pouvoir monter à bord à cause d’une rampe brisée) ou rouler en fauteuil roulant (faire face aux différentes intempéries et aux divers dangers).*

*Depuis 2015, je peux me rendre à l’UQÀM en moins de 25 minutes en prenant le métro entre les stations Jean-Talon et Berri-UQÀM. 25 minutes. C’est moins long que la plage de 30 minutes du TA.<sup>58</sup>*

*Il m’arrive encore d’être fascinée par cette temporalité.*

*Parfois, je me demande :*

*« Si les stations Berri-UQÀM et Jean-Talon avaient été accessibles dès mon arrivée à Montréal en 2002, est-ce que je serais en train d’écrire cette thèse? »*

*Je pense que non.*

*J’aurais très peu connu le TA.*

*J’aurais pu éviter les bus plus souvent qu’autrement.*

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<sup>58</sup> The STM requires users to wait 30 minutes before reporting a late pick-up.

*Bien entendu, l'inaccessibilité des autres stations m'aurait posé problème, mais je me serais débrouillée. J'aurais fait avec. Mon fauteuil et moi pouvons faire fi de bien des choses. Nous avons l'habitude.*

*Je pense que j'aurais eu juste assez de privilèges pour vivre à Montréal sans trop ressentir le poids de l'exclusion.*

*Je pense que j'aurais eu juste assez de privilèges pour ne pas chercher à comprendre pourquoi les personnes handicapées sont marginalisées.*

*Je pense que j'aurais eu juste assez de privilèges pour faire partie des gens qui se plaignent qu'il fait trop chaud dans le métro.*

—July 11, 2018

It is impossible to ignore the métro system when writing about mobility in Montréal. The métro has a privileged place within Montréal's economy, politics and culture. "Le métro est à Montréal ce que les boulevards sont à Paris et les canaux à Venise," claims Québec historian Jean-Claude Germain (McLauchlin, n.d.). Not only is the métro central to the organization of the public transit system in Montréal, but it also is one of the major components of Montréal's identity and Québec's history (Clairoux, 2001; Deglise, 2008; Guimont, 2007). "The Métro is the heart of Montréal. The City needs it to breathe, to survive, to love and to be loved." (Parent, 2010) Inaugurated during the Révolution tranquille, the Montréal métro symbolizes the modernization of Québec society. For many, it was a dream come true and a new open door towards the future. Since its opening, the métro has received praise for its unique architectural design and public art displays (Société de transport de Montréal, 2002). All 68 stations are underground, which enables the métro to operate under the harshest of winter conditions. In 2017, the métro recorded a ridership of 260 million—a Montréal record. Montréal's métro has North America's third-highest ridership per capita, after New York City and Mexico City (Société de transport de Montréal, 2018b). Nearly a million passengers ride it every day (*Ibid.*). In the housing market, proximity to a métro station is a definite advantage. It is the second most important factor determining the value of a property (Dubuc, 2013). In everyday life conversations, the métro is regularly used to situate people in the city. For example, when Montrealers ask me where I live, I always say that I live close to Fabre métro station. It is the one landmark in my neighbourhood that people are most likely to know. However, I cannot use that station, because it is one of the 55 stations that are only accessible by stairs (see Appendix E and F).

Even though the Montréal métro is significantly behind most underground transit systems in North America and Western Europe in terms of accessibility (Société Logique, 2001), most historians, journalists and métro enthusiasts have failed to acknowledge the problem. With regard to accessibility, there is no shortage of issues to address. For instance, in October 1988, Montréal hosted the annual convention of the American Public Transit Association (APTA). Many disabled people and allies, mostly from the United States, staged a series of protests against the inaccessibility of public transit in North America (Parent, 2010). Maria Barile, one of the few Montreal protesters, claimed that the Office des personnes handicapées du Québec's officials "discouraged local disabled people from turning out at the demonstrations." (Semenak, 1988) She said that "some people were told they could lose their welfare cheques and others were told that things could get violent" (*Ibid.*). Over three days protests took place at APTA meeting locations and at some public transit sites, such as the Longueuil métro station.<sup>59</sup> Several arrests were made.

These protests forced the Montréal public transit commission to publicly comment on the inaccessibility of its services for the first time in its history. Louise Roy, the managing director of the transit organisation even declared to *The Gazette* that her organisation had "no intention of adapting buses or Metro stations to accommodate the handicapped" (*Ibid.*). For three days the protests gathered media attention. However, these events are neither part of the history of the Montréal public transit nor the Montreal disability rights movement. I learned about them only because of my friendship with Maria Barile. Maria had recorded all the television reports on a VHS tape, which she gave to me. While working on my master's thesis on the history of the inaccessibility of the métro, I was surprised by the lack of research on disabled people's experience with(out) the métro. In *Je Me Souviens: The Hegemony of Stairs in the Montréal Métro* (2010), I argued that ableism, as a system of oppression, has supported the exclusion of disabled people, whose mobility needs cannot be accommodated by stairs. The choice of focusing on stairs in this work stems from the fact that disabled people's experiences of the métro can greatly differ depending on how they move. In her research-creation film *Misfire, 'Mis'perform, Manifest: Disability and Everyday life*, Arseli Dokumaci (2014b) walked with Jérôme Plante, a blind man, and Anna January, a disabled woman who has difficulties using stairs and walking on uneven grounds. While Jérôme claimed that the métro is the most accessible means of transportation for blind people, Anna argued that the métro is very difficult to access and

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<sup>59</sup> On October 3, 1988, the judge Louis-Jacques Léger prohibited ADAPT members from protesting on the Island of Montréal (Semenak, 1988).

therefore is not an option for her. In the wheeling interviews, I was interested in people's relationships with the métro as well as in how their everyday lives were affected by its poor accessibility. This part of my research pays particular attention to issues of space and time.

### *Proximity and distance*

When looking for a place to live in Montréal, many people consider the proximity to a métro station as a deciding factor. This factor is particularly important for transit-dependent people. In my research, 11 participants who use mobility aids live near a métro station that they could, in theory, easily access by wheeling or taking a bus. However, only Kéven and Christian ride the métro frequently and are able to access one of the few wheelchair-accessible stations (see Appendix D).<sup>60</sup> Six participants have never used the métro with their wheelchairs. Isabelle is one of them, even though she is a Montréal native. Unlike most people who grew up in Montréal, she was not introduced to the system during her childhood or teenage years. “Je t'avoue que je ne sais même pas comment ça marche le métro,” she candidly admits when I ask her if she has tried to use it after a few stations were retrofitted with elevators.

In research conducted in Great Britain, Debbie Jolly, Mark Priestley, and Bryan Matthews (2006) have found that a lack of knowledge is an important factor limiting many disabled people's use of public transit (quoted in Soorenian, 2013, p. 1126). The low ridership among the participants points to the complex relationship between disabled people and the Montréal métro. Out of all the participants who have moved to a new place in the past decade, only one took into consideration the proximity to the métro, and this choice was motivated by the needs of the able-bodied members of the household. Before explaining the factors behind this, it is important to note that, while housing market studies generally consider that a location must be within 500 meters of a rapid transit line to be considered close (Avison Young, 2015), participants using wheelchairs and scooters tend to have different definitions of proximity. The 500-meter norm is based on a standardized above-ground walking distance for pedestrians. Kéven explains that wheeling 1800 meters to get to the Jean-Talon métro station is generally not an issue for him. “C'est à 15 à 20 minutes en roulant. Pour moi, marcher 20 minutes, c'est pas pire. Même si je passe devant une station inaccessible,” he says. However, Kéven adds that this has proven to be

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<sup>60</sup> Luc lives close to a station that does not provide wheelchair access, but that is accessible to him as he learned to navigate it. He has developed different tactics for navigating the métro system by himself. However, we did not use the métro, because the stations he uses between his home and his workplace are not wheelchair-accessible.

difficult and sometimes impossible in the past winters, due to snowy and icy sidewalks. Under these winter conditions, his perception of the proximity of Jean-Talon métro station changes. Nabila argues that the bad conditions of many sidewalks and the type of built environment have an influence on whether or not a space is close to her. Côte-Vertu, the nearest wheelchair-accessible station at the time of the interview, is located 2.9 kilometers from her home. In addition to this considerable physical distance, Nabila claims that going there is too difficult, due to the poor condition of the sidewalks and the fact that it involves taking detours to pass under the Métropolitaine, a major highway crossing Montréal Island. Kéven's and Nabila's perceptions of proximity are shaped by season and space, as their assessments of proximity are calculated not only in meters but also in minutes and in obstacles.

There are four main factors that explain why living near a métro station is not a top priority for disabled people in Montréal who need step-free access: 1) the limited options in terms of accessible and affordable housing; 2) the poor accessibility of the métro; 3) the fear of riding the métro; and 4) the absence of a long-term plan to retrofit stations with elevators. Moreover, Ex Aequo, a Montréal disability rights organization, claims that there is a permanent shortage of accessible housing for disabled people (Brassard, 2016). This means that it is harder for disabled people to choose in which area of the city they want to live. Furthermore, adapting a home is often quite a challenge. The government subsidy program for home modifications does not systematically cover all of the costs, which often forces disabled people to shoulder a large share of the costs.<sup>61</sup> In addition to the difficulties of finding an accessible place or making a place accessible, there are very few areas served by a wheelchair-accessible métro station. As mentioned in the introduction of this chapter, as of 2016, the STM had not planned which stations it would retrofit with elevators.<sup>62</sup> Without this information, disabled people could not anticipate where the next wheelchair-accessible stations would be located and make choices about the location of their home accordingly.

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<sup>61</sup> If they rent, disabled people must get the owner's permission to make the modifications they need. Owners have the privilege to refuse such modifications. Disabled people can apply for this funding only every five years and the amount is generally capped out between \$15 000 and \$20 000. Furthermore, austerity measures adopted by Québec's Liberal government have caused a great deal of uncertainty around this program. For example, the 2014-2015 budget indicated that the program will endure a 37% cut (OPHQ, 2015).

<sup>62</sup> Even though the October 2016 publication of the list of the 14 stations to be made accessible by 2022 was a first for the STM, many disabled people remain skeptical about this plan, as they have previously been disappointed by unfulfilled promises.

Take the example of Kéven. When he moved to Montréal for work in 2013 for works he did not worry much about how he would get around the city. He was sure that Montréal would treat him better than Sherbrooke in terms of access to public transit. Kéven did his undergraduate studies at Université de Sherbrooke and he explains that wheelchair users were not allowed on the city's buses. He even had been kicked off a bus at least once. "C'est un avantage que j'aimais à Montréal. Malgré tout, il y a une liberté pis une spontanéité qui n'est pas disponible dans les autres régions du Québec," he claims about the accessibility of Montréal's buses. Kéven found an apartment in Villeray, which is about six kilometers from his workplace, located downtown. He had a car but hoped he would not need it much. "Je n'aime pas prendre mon auto, fait que je cherchais une alternative," he confides. He assumed he would find a way to use public transit as much as possible. However, it did not take long before he realized there were few accessible métro stations. There are no wheelchair-accessible stations within a range of less than four kilometers from his home, and he has been forced to use his car to commute to work most of the time. He explains:

Je connaissais déjà la situation des métros. Je savais qu'il y en avait genre sept stations à l'époque, mais je ne savais pas à quel point c'était possible de se déplacer à Montréal en ayant juste sept stations de métro. Dans ma tête, c'était quand même possible. [...] C'est juste une fois sur place que tu réalises qu'avec sept stations tu vas nulle part. Et sur sept, il y en a trois à Laval.

Three years later, Kéven moved to Griffintown, a neighbourhood close to downtown. He was accepted in a new wheelchair-accessible housing cooperative after being on a waiting list for two years. Bonaventure métro station is located 1800 meters from his new apartment. He now lives much closer to his workplace, AMI-Télé. When weather permits, usually from April to November, Kéven can choose from different bus routes or simply wheel to work. This was not planned on his part, as he applied for this accessible and affordable apartment prior to working for the television channel. While he did not choose his job based on its proximity to accessible public transit, he admits that its location is a major advantage. Even though the métro is no longer a practical option for his daily commute to work, he still uses it to go to Quartier Latin, where he likes to go out for drinks.

The affordability of a place was a decisive factor for Caroline, Marie-Josée and Nabila, as they live on tight budgets. Additionally, Caroline and Nabila are mothers, which adds a great deal of stress to their finances. Caroline and Marie-Josée have found apartments kilometers away from the closest wheelchair-accessible station, while Nabila chose an apartment next to an inaccessible

station. The proximity to the métro is necessary for the mobility of her husband and their two daughters, all of them able-bodied, since the family cannot afford an adapted car and relies on public transit for their daily activities and obligations. Geneviève and Pierre both have bought property in Rosemont–La-Petite-Patrie. At the time of their purchase, there were only four wheelchair-accessible stations in Montréal, none of them in Rosemont–Petite-Patrie, their preferred neighbourhood. Having access to a step-free métro station was not one of their criteria, however easy access to grocery stores and shops was a consideration. Geneviève and her partner consider access to parking spaces a necessity. Due to the lack of accessible transit options, Geneviève’s only option for getting around the city—and making her daily commute to work— involves owning and driving a car. Pierre argues that there are so few accessible stations that the métro is not a practical means of transportation in the city. “On est à Montréal et on sait que le métro ça sert à rien [for wheelchair users],” sighs Pierre. Nabila also claims that riding the métro does not make any sense to her. I ask her whether or not she has ever used the métro. “Non! Le prendre pour aller où? C’est ça le problème!” she replies immediately, emphasizing the ridiculousness of the situation.

In addition to the scarcity of accessible and affordable housing and the very low number of step-free stations as reasons why living close to the métro is not something they value, most participants argue that the métro evokes fear and worry. Pyer and Tucker (2017) explore the concept of transport anxiety and demonstrate the importance of emotions in the study of transportation systems. They interviewed 69 British teenaged wheelchair users about their experiences of accessing leisure spaces. Most of the anxieties that are identified by the participants concern their personal safety and their fear of not being able to get to their destinations due to obstacles in public transit infrastructures, such as broken ramps and faulty elevators. The researchers note that these teenagers did not include interactions with fellow passengers as a source of transport anxiety. The research results do not mention the impact of public transit employees’ attitudes on their transit experiences either. While physical obstacles have been identified as a potential threat to their personal safety, many Montréal participants share accounts of transport anxiety that have included hostile attitudes from fellow passengers. They explain how personal safety is something that is felt, that is embodied, and that changes over time.

At the top of the stairs at the Côte-des-Neiges métro station, Marie-Josée points out different obstacles that contribute to her fear of using the métro alone and cause her transport anxiety. At the time of the interview, she had never used the métro with her wheelchair. On the few occasions that she did take it, she was walking and accompanied by a friend. The idea of riding the métro alone is out of the question when we meet:

Pour l'instant, y aller toute seule, oublie ça! À cause de ma déficience visuelle et ma petite taille. C'est mouvementé. Je suis désorientée, surtout quand on sort des wagons. [...] Il faut vraiment trouver des moyens pour ne pas se faire écraser. J'avais ma canne blanche pour indiquer aux gens de se tasser, mais souvent il y avait des gens qui ne se tassaient pas. C'était des gens pressés. Ce n'est pas quelque chose que je prendrais souvent.

Ironically, just as Marie-Josée is talking about how other riders are careless, an incredulous man approaches us and asks, "Comment allez-vous faire?", Marie-Josée bursts out laughing and tells him we already knew the station is not accessible and have no intention of going down the long flight of stairs.

Laurence identifies other passengers' attitudes as a problem. After riding the métro for many years, she has decided to stop and become a paratransit user. While wheelchair accessibility to the network has improved moderately in the past few years, Laurence claims that this did not facilitate access for her. She stresses that métro riders are not "civilized" and only rarely did they give up their seat for her:

J'ai commencé à ne plus le prendre pour une raison bien simple. La Ville de Montréal mettrait tous les ascenseurs du monde dans le métro, ce qui arrivera pas du tout on s'entend, ça ne changerait pas le fait que j'ai arrêté de le prendre parce que les gens ne sont pas civilisés. Tsé, je rentre dans le métro, j'ai une canne pis on ne me laisse pas la place. Les gens ne laissent même pas leur place aux personnes âgées la plupart du temps. C'est moi qui leur laissais ma place! ([see video Rousseau-1](#))

Forced to stand up during the ride, Laurence would be out of breath when reaching her destination: "Tu arrives à ta destination et tu es déjà épuisée. En tout cas, moi je suis comme ça. C'était vraiment pas idéal." She adds that maybe she would take it again sometime, if she was feeling brave, illustrating that riding the métro feels like a battle to her.

Geneviève's testimony shows that fear and worry can fluctuate over time and space. The first time she used an underground transit system was thousands of kilometres east of Montréal, when she spent a few months as an exchange student in Prague. She remembers that experience as a challenge, because of the numerous obstacles she encountered. At the age of 22, she was in

Europe for the first time in her life and wanted to prove that she could travel alone. To her great surprise, Prague's underground transit system was partially accessible. At that time, the Montréal métro did not have a single accessible station. It is, therefore, far from home that Geneviève was introduced to underground transit. While the closest station to her Prague home was not accessible, but many other stations were. Despite the lack of access at her station, Geneviève would sometimes use it by asking other riders for help taking the escalators. She explained that being abroad was different than being at home. "Je savais que j'étais là pour un petit bout. J'étais tout seule. Ce n'était pas ma vie normale de tous les jours," she remembers. As we continue talking, Geneviève reflects on how she has changed in the last decade:

C'était un peu extrême [using inaccessible stations]. J'étais plus jeune aussi. J'accrochais n'importe qui qui pouvait me monter. S'ils ne savaient pas comment faire je leur disais. Ça me dérangeait moins. J'avais moins peur de tomber. J'étais moins gênée. J'avais l'impression que mon autonomie passait par là pis c'était comme ça. Maintenant, j'aime moins.

I ask Geneviève if she uses the Montréal métro since some of its stations have been made accessible. She says she hasn't, and that she feels guilty about it. She then shares a memory of when she was a master's student at École de technologie supérieure only a few years ago. She had to go on a fieldtrip with her classmates in Laval. They were going to visit the Société de transport de Laval for a transportation systems management class. The meeting point was at Bonaventure métro station, near their school, a partially accessible station. In 2009, the STM installed elevators between the platform and the mezzanine level, but there is still no elevator to connect with the street level.<sup>63</sup> Geneviève remembers that she considered riding the métro with her classmates. However, she did not know whether or not she could navigate Bonaventure station with her manual wheelchair: "Je ne savais pas comment c'était à Bonaventure. Je me demandais si je survivrais. C'est ça. J'étais pas sûre combien il y avait d'escaliers." Asking for help was not something she was willing to do. It quickly became clear that driving there was the most efficient and safest option. The difference between her underground transit experiences in Prague and Montréal illustrates how attitudes and feelings toward the use of a space can change over a person's lifetime and are influenced by the specificities of the situation and the location.

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<sup>63</sup> The STM does not own the property where the elevators between street level and the métro station are located. The organization responsible for the installation of the missing elevators has gone through two major reorganizations in the last decade. Exo, the new transit organization responsible for the missing elevators, indicates that they will be in service during the 2019 winter, which is 10 years after the installation of two elevators by the STM (Exo, n.d.).

### *The spatiotemporalities of (not) riding the métro*

At the time of the interviews, Christian and Kéven had just recently started using the métro on a regular basis due to the opening of the elevators at Jean-Talon métro station, located at the border of Rosemont–Petite-Patrie and Villeray neighbourhoods. It had been less than three months since the station had become wheelchair-accessible. Before Jean-Talon was accessible, Kéven, who uses a manual wheelchair, would sometimes take the métro at Jarry station with the help of friends or even strangers, risking his own safety as well as that of his helpers. “Lever 120 livres dans les marches, c’est dangereux.” he said. Unlike Kéven, Christian was a métro rider before he began to use a wheelchair, about two decades ago, when he was 28 years old. The new elevators enabled him to rediscover a space he used to know well, while Kéven learned to navigate a space he was unfamiliar with. Prior to meeting for the interview, Kéven and I had agreed that I would accompany him on his way home and that this would involve riding the métro together from Berri-UQÀM to Jean-Talon. I looked forward to it, since I had only been in the métro a few times since the inauguration of the Jean-Talon elevators.

When we arrive at Berri-UQÀM métro station, Kéven says he needs to buy his monthly pass before going through the turnstiles. He searches for an accessible ticket machine, unsure where it is. I tell him that I still cannot navigate the station like an experienced commuter and that I feel like a tourist. Kéven replies that he initially felt the same way and that it is by wheeling through the space regularly that this feeling disappeared. Kéven argues that a few weeks after becoming a regular user, he already felt better in the métro than he did in a bus:

Dans l’autobus, il faut que je m’assure que le monde me laisse passer. Il faut que le chauffeur ouvre la rampe, qu’il n’y ait pas personne qui obstrue la rampe. Tandis que là, tu as un sentiment de liberté. Il y a un sentiment de liberté qui n’existe pas dans l’autobus. Il n’y a pas de place désignée. Tu montes où tu veux. À un endroit ou un autre. C’est vraiment un sentiment de liberté. Les gens ne comprennent pas à quel point c’est le fun prendre le métro pour nous.

Not only does he have more control over how he moves in the métro, but it also makes him feel more independent, since he does not have to rely on friends or strangers. “J’ai moins l’impression d’être un poids,” he confides. Riding the métro with his friends is now a positive experience: “Quand tu sors, tu n’as pas besoin de te séparer de tes amis.” (Figure 13) Even though Christian’s and Kéven’s transit options are still very limited, with a mere eight accessible stations out of 68, they both express how Jean-Talon métro station being made accessible has changed how they get around the city. They have developed strategies to benefit from the restricted access to the métro.

The issue of time is central to their experiences and strategies, and therefore cannot be ignored. Kéven usually chooses to commute to work by bus in the morning, because taking the métro does save him any time. The ride is quite smooth because there is no traffic and the bus is not crowded. However, he takes the métro to get home after work or after going out with friends. This allows him to avoid rush hour traffic, which buses can't escape, and he can go home whenever he wishes, as the métro runs more frequently than the bus:

[...] quand je prenais l'autobus 30 sur l'heure de pointe, ça pouvait me prendre une heure pour me rendre chez nous. Tandis que là, je fais Berri-UQÀM à Jean-Talon en max 10 minutes donc ça a un avantage. [...] Quand je sors avec des amis pis que je suis dans le coin du Quartier Latin, je peux partir n'importe quand sans avoir à checker l'heure.

Christian expresses his satisfaction about saving time when riding the métro in a manner similar to the métro's first riders on October 14, 1966 (Radio-Canada, 1966). When the métro was inaugurated, many Montrealers were fascinated by its speed. Riders were thrilled to be able to save time. Suddenly, neighbourhoods connected by the new stations became closer. John Urry (2000) explains that growing speeds and efficiency have compressed distances. This is echoed by Christian: "Et, je te dirais que l'arrivée de l'ascenseur à Jean-Talon a changé la donne! Je roule moins qu'avant pour mes déplacements! Oui, ça me permet de me déplacer plus rapidement," he exclaims illustrating how his perceptions and experiences of distances have changed. The métro is a new means of transportation that is part of what he calls the "*cocktail transport*." He chooses the transportation option that is the better fit for his destination. In addition, the métro enables him to discover new parts of the city with which he was not familiar before. "Avec le métro qui devient de plus en plus accessible, je peux aller déchiffrer des avenues que je connais un peu moins. Ces mois-ci, je découvre pas mal le West Island!", he writes. For Christian, the opening of "new" métro stations allows him to expand his knowledge of the city. It translates into new opportunities.

One métro habit shared by Christian and Kéven is that they mostly ride it alone. Nabila, a wife and the mother of two girls, has a different experience of public transit and the métro, as most of her trips involve travelling with her family, and in particular her two daughters. Her testimony shows that disabled people are not all equal before a flight of stairs, each of their everyday lives being affected differently by the inaccessibility of the métro system. As we left her apartment to start the interview, Nabila suggests wheeling to De la Savane métro station. She lives only a few metres from that station, which is only accessible by stairs. Even though she



**Figure 13:** Kéven and I riding the métro during the wheeling interview.

cannot use it, De la Savane métro station is part of her everyday life and transportation routine because of her able-bodied family members. At the entrance of the station, I suggest going inside to talk a bit. Nabila agrees. We enter the station and stop a few meters away from the top of the long stairways. “C’est ici que je quitte mes filles. Elles prennent le métro. Elles vont à la station

Côte-des-Neiges et moi je continue en roulant. [...] C'est vraiment frustrant. Tu peux t'imaginer à quel point c'est frustrant," she says, her voice full of emotion, just as we start talking. ([see video Nouara-1](#))

Despite the lack of intimacy attached to such a public space and the loud background noise of the métro's ventilation system and the métro cars pulling in and out of the station, we have a deep discussion about how the inaccessibility of the métro impacts her as a disabled mother. De la Savane métro station is a space where she has gone through multiple heartbreaks and felt—and continues to feel—the bitter taste of exclusion. Nabila explains that as a mother, she has transportation needs that go beyond her own, and include her daughters. She remembers:

Quand elles avaient 12 et 9 ans, ça m'ennuyait vraiment de les laisser partir seules comme ça. Elles étaient assez jeunes. Pour aller à l'école, elles devaient prendre le métro. Moi, je passais la journée en pensant au pire. Est-ce qu'elles vont rentrer à la maison saines et sauvées? ([see video Nouara-1](#))

She wants to be with them to make sure that they will be safe, and yet, she cannot.

This question of safety is brought home when she recounts, how, on one occasion, an older man took her eldest daughter in his arms against her will. Fortunately, her daughter was able to escape and call for help. On the days following the assault, Nabila's husband accompanied their daughters on the métro in the morning. However, he could not be there at the end of each school day because he was still at work. On snowy days or days following snowstorms, Nabila recalls that she was not able to accompany her children to the métro station despite its physical proximity to their apartment. At that time of her daughters' lives, not being able to ride the métro with them has caused Nabila serious anxiety regarding their safety. However, this has not affected her consistently throughout the years. Now that her daughters are teenagers and are used to the métro system, Nabila's fears have subsided. Nothing about the space has changed—the station is still inaccessible to Nabila—but the passing of time has changed how she experiences the space as a disabled mother.

At some point during our conversation, an elderly white man, who had just exited the station by using the stairs, approaches us and kindly asks, "How can I help you?" We tell him we are fine and are simply having a conversation. Fully aware that most métro stations are not accessible, he says the situation is unfair and that he fears the day he will no longer be able to ride the métro. We chat with him for about three minutes. Not long after our encounter, we leave the

station and head towards Côte-des-Neiges, where Nabila regularly goes shopping and grocery shopping. As we are wheeling, our conversation kept going back to the difficulties of getting around the city as family. Nabila touches upon another aspect of her family's mobility involving the intersections of space and time. When she goes out with her husband and their daughters, they have to part ways because of a rule preventing them from riding paratransit altogether. Nabila uses paratransit and her husband takes the métro. Nabila explains that her daughters now prefer to ride the métro with their father because they do not like paratransit. Waiting long periods of time for paratransit is something they prefer to avoid. Sometimes they choose to travel with her, but only because they feel bad about leaving their mother alone.

When they are separated by two modes of transportation, the family is not only divided by space, but are forced to operate on different times: regular and adapted transit times. Their times of departure and arrival regularly differ, as both transportation systems work on different schedules, speeds and routes. Nabila describes the difficulties in synchronizing these two times due to paratransit's unpredictability, lack of flexibility and infamous delays. They have to constantly factor extra time into their plans, which often results in limiting the duration of their activities and complicating each of their family outings. Since the family cannot afford mobile phones, they have no means of staying in touch and updating each other as their trips unfold, if needed. It is only by considering the combination of factors such as travelling as a family and not having enough money to have mobile phones that we can appreciate the impact of the inaccessibility of the métro on Nabila's everyday life as a mother and as a member of her family.

In the wake of Montréal métro's 50th anniversary celebrations, most of the people I have wheeled with have never ridden it or are only just starting to. Thousands of disabled Montrealers are literally not living in the same historical period as their able-bodied peers, as their experiences are still left out of the story of the métro that is told and celebrated. If the métro is conceived of as a space where the performance of certain abilities such as walking are mandatory, the complex experiences of disabled people who ride it, have given up on riding it, or wish they could ride it are missing. Disabled people's experiences of the métro illustrate the disparities of unequal, differential access. These inequalities compromise people's ability to get around the city. Christian's and Kéven's enthusiasm about becoming métro riders contrasts with the stories shared by many participants, in particular Nabila, Geneviève and Laurence, who are still unable to use the métro. While Christian and Kéven described the métro as a space of freedom and

possibility, while the system symbolizes uncertainty, danger and injustice for others. This points out to the subjectivities and differences between disabled people as well as the complexities of the concept of accessibility. Since completing the interviews in summer and fall 2015, a few of the participants have started to use the métro. Marie-Eve, who used to worry that her wheels would get stuck between the platform and the métro car, now feels confident enough to ride it alone. Marie-Josée has started using the métro with her friends and is reportedly enjoying it. Disabled people's interest in having access to the métro is undeniable and is likely to grow even stronger in the coming years as more stations become accessible.

### ***The buses***

*December 15, 2009. I was waiting for a bus at the corner of Beaubien and Papineau. I had just moved back to Montréal from Toronto and I wasn't sure if I had made the right decision. Should I have stayed in Toronto? How would it be to come back to a city that is less accessible than Toronto? Even though Toronto's subway and bus network is not fully accessible, it was so much easier to get around the city.*

*The bus arrived. The other passengers got on first. I was used to it. But this time the driver did nothing to activate the ramp so I asked for it. He replied that he couldn't open it today. The service was suspended for wheelchair users.<sup>64</sup> I couldn't believe it. "Mais la tempête a eu lieu il y a une semaine! Les trottoirs sont déneigés", I protested. The driver repeated the same thing. He said there was nothing he could do. I was not allowed on board. I watched the bus leaving, wheeled a few meters away from the bus stop and bursted into tears. It was only the second time of my life that I cried in public because of an accessibility issue, even though I have encountered countless obstacles.*

*I've never cried for that reason again.*

*A few days after that incident, I co-founded RAPLIQ, a disability rights organization. I became an activist. I became a spokesperson for my community. I developed arguments to fight for accessible transit. I had to be strong and convincing. I could not afford to shed even a single tear, and I must admit that this kind of restraint turned out to be quite easy for me.*

*As a disabled woman, I am always at risk of being labelled as too emotional and vulnerable. I am perfectly aware that I am an object of pity in the eyes of many.*

—October 25, 2016

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<sup>64</sup> A few days later, I filed a human rights complaint with the Québec Human Rights Commission. It was my first complaint to the Commission. I hoped my complaint could end this practice, but it didn't. However, in 2014, the STM stopped suspending the service even during the heaviest snowstorms. Since then, the STM posts alerts on its website recommending wheelchair users to be mindful when planning their day or to postpone their trips explaining that it could be impossible to deploy the ramp at bus stops.

In 1919, the first public buses made their appearance on Montréal streets. Almost 80 years later, in 1997, the STM started to integrate wheelchair-accessible buses into its fleet (Société de Transport de Montréal, 2004). However, wheelchair users were not welcomed to use these buses when they were initially put into circulation. In 1998, the STM conducted “controlled experimentation” on the new buses with people using mobility aids. The public transit organization also surveyed 3600 “regular clients” about their opinion on the accessibility of buses to wheelchair users. The results showed that 90% of the “regular clients” judged that the experience (of witnessing a person with a mobility aid using a bus) went well and that the time of boarding (between 69.5 and 92.5 seconds) and disembarkment (between 56.4 and 62.5 seconds) was reasonable (Société de transport de Montréal, 1998). The STM has not been the only transit agency concerned with the time needed to deploy the ramp and let a wheelchair user get on board. This was viewed as extra time that could compromise the speed and rhythm of the able-bodied riders. Pfeiffer (1990) explains that, in the 1970s and 1980s, U.S. transit agencies “fear[ed] that irregularities and delays in service resulting from the operation of accessible buses may have harmful effects on regular ridership.” (p. 162) In a press release dated July 9, 1998, the STM announced that, in the light of the positive results, it had decided to allow wheelchair users to use five bus routes as of August 24, 1998. The STM claimed that these routes met wheelchair users transit needs well (*Ibid.*) This statement points to a discriminatory, ableist understanding of disabled people’s mobility in the city. It is as if their transit needs are different from those of “regular clients.”

The introduction of wheelchair-accessible buses into the fleet did not go smoothly. The first generation of low-floor buses made in Québec received numerous critiques from users to transit experts. For example, Pascal Boissé (2010), an automobile journalist, criticized the buses’ poor reliability and their “strange design.” He claimed that these vehicles have a “comportement routier qui malmène violemment les passagers.” (*Ibid.*) For disabled people using mobility aids, the manhandling went even further—they were frequently denied access to the buses, mostly due to faulty ramps. From 1996 to 2007, the STM purchased buses equipped with rear-door ramps. However, this technology proved to be unreliable from the outset according to the testimonies of those who used it in the 1990s and early 2000s. Other transit agencies across Québec, such as the Réseau de Transport de la Capitale (Quebec City), deactivated the ramps claiming that they were

disrupting service (Boucher et al., 2015; Pelchat, 2010).<sup>65</sup> The STM chose not to deactivate the ramps, and for several years it has been the only public transit agency in Québec to offer the service to its clientele who use mobility aids. However, despite the significant problems with the functioning of the ramps, the STM did not test the ramps on a daily basis to prevent problems, arguing that they did not have enough space in the garages to proceed with such inspections. Other components of the buses, such as the doors, were checked every day to ensure the safety of the drivers and the users. The ramps were not considered to be among these essential components.

In 1998, France was living in the Plateau Mont-Royal close to the new accessible bus routes. She tried to get on a bus with her partner. She still vividly remembered how she was turned away by the bus driver:

Mon copain est allé voir le chauffeur et lui a dit « comment qu'on procède? ». Et le chauffeur a répondu « on procède pas » puis il a fermé la porte. Ça ça a été ma première expérience donc j'ai viré de bord. Pis je me sentais tellement comme une fourmi qu'on a juste envie de piétiner. Je me suis dit « Je ne prends plus jamais le transport ». Je ne m'essaye même plus.

From the introduction of accessible buses in the STM fleet, hostile drivers and malfunctioning ramps somehow became the norm and a part of disabled people's experiences riding them. Isabelle, for instance, says that drivers have told her that the ramp is not working without even trying it. She suspects that they either assume that the ramp will not work or that they are afraid of getting stuck if there is a problem. All of the participants who use buses have stories about missed and difficult trips evoking a variety of emotions such as anger and shame caused by ramp malfunctions. They say that the risk of malfunctioning rear-door ramps is so high that rather than coming as a surprise, these problems are expected.<sup>66</sup>

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<sup>65</sup> Montréal is the only city in Québec with buses that use the rear-door ramps. All the other transit agencies deactivated these ramps before putting the buses in service. Among those agencies are the Réseau de transport de Longueuil, the Société de Transport de Laval, the Société de transport de Sherbrooke and the Société de transport de Trois-Rivières. The arrival of buses with front-door ramps is fairly new in many cities. Some cities are still operating bus fleets that are completely inaccessible to wheelchair users.

<sup>66</sup> In August 2011, the Regroupement des activistes pour l'inclusion au Québec (RAPLIQ) tested 66 buses and found out that a third of these buses had non-functioning ramps while another third had major problems operating the ramps (RAPLIQ, 2011).

In 2009, the STM started buying buses with front-door ramps, which work much better thanks to better design. However, due to budget constraints, the process of replacing the buses with rear-door ramps has been moving slowly.<sup>67</sup> At the time of the interviews, about half of the fleet was equipped with front-door ramps (Société de transport de Montréal, 2017).<sup>68</sup> The distribution of these buses varies from one bus line to another. Today the STM operates 220 bus routes across the city. All of the people I have interviewed live close to at least one bus stop, like most Montrealers. Unlike the métro, the buses are part of the transit experience of most participants. The poor accessibility of the métro forces mobility aid users to take a bus for trips that are normally made by métro by other users. Ten participants use buses on a regular basis, and two have described themselves as occasional riders. France, Geneviève and Laurence are the only three participants who do not use the buses in Montréal. Yet, France is a frequent international traveller and enjoys riding public transit wherever she goes. She describes how it feels to travel by métro in other cities:

Je suis allée à Athènes, dans des pays millénaires. Et là, je circulais en métro! [...] Chaque fois que je voyage, quand je me ramasse dans un pays où le métro a 10 ans d'existence ou les infrastructures de transports sont assez récentes, je circule mieux que chez moi.

Geneviève and Laurence say that they were bus users in the past but have since stopped using them because of all the physical and attitudinal barriers they face. Laurence says that she used to take the bus when she was going to CÉGEP. She recalls how hard it was, especially during the winter, with the snow and ice. Walking to and from bus stops was a dangerous adventure. “Oh, mon dieu! Je ne ferais plus ça aujourd’hui [...] En marchant avec mes sacs à dos, mes livres, mes affaires, je ne referais plus ça,” she exclaims while remembering a time when she relied exclusively on the métro and bus system and rides from her parents.

Participants who use a mobility aid and are still bus users when we meet each had their own stories on how they were introduced to the bus system. As someone who tried to get on a bus on my first day in Montréal, I was fascinated to learn that many of them waited many years before starting to use them. Their stories remind me of the diversity of disabled people’s experiences,

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<sup>67</sup> In January 2018, the STM announced that 300 new buses will be added to the fleet by 2020. According to STM chairperson Philippe Schnobb, it will be the “largest increase of the fleet in the city’s history” (Magder, 2018). New buses will be equipped with a front-door ramp and two reserved spaces for people using mobility aids.

<sup>68</sup> Currently, in 2018, 60% of the bus fleet is equipped with front-door ramps (Société de transport de Montréal, 2018b).

perspectives and life courses. Lack of knowledge about the system as well as a profound sentiment of not being fit to use the buses, a manifestation of internalized ableism, are at the heart of most participants' first experiences. They have simultaneously developed transport anxiety (Pyer & Tucker, 2017) because of the numerous obstacles and negative attitudes they have encountered (and continue to encounter).

### *First experiences*

Taking a bus in a city for the first time is stressful for most people. For disabled Montrealers who use mobility aids, the stress is exacerbated by obstacles, negative attitudes and a fear of being out place. Similar to the métro, buses cause transport anxiety for most participants. Isabelle is a Montréal native. Growing up she lived in Rosemont with her parents, she did not have the opportunity to explore her surroundings by herself because she was dependent on her parents for her mobility. Isabelle used Transport adapté during her childhood, her adolescence and for most of her adult life. The first time she got on a bus was with her friends when she was a CÉGEP student. At that time, inaccessible buses were still quite common. Isabelle used her walker and was able to get up the stairs with the help of her friends. She remembers:

J'étais au cégep, donc ça fait environ 10 ans. J'étais en marchette pis je voulais foxer des cours. J'avais deux copines délinquantes qui m'encourageaient à foxer des cours. J'allais à l'école en marchette pis à la pause de 10 heures, on partait. Il y en avait une qui m'aidait à embarquer. Il y avait au moins six marches. Et l'autre prenait ma marchette.

Even though these little escapes have left her with good memories, they did not push Isabelle to try to ride the bus by herself in the years that followed. She tells me that she did not even know how to get on a bus with her wheelchair. Her use of buses is fairly new—she started two years ago. Nobody had taught her how the system works for a wheelchair user. She explains:

Avant, je ne les prenais pas parce que je ne savais pas même pas comment ça marchait. La première fois que j'ai pris un autobus, je ne savais même pas où fallait que j'arrête, comment reconnaître mon arrêt. Je ne comprenais rien. En plus, vu que tu es assise de dos, tu n'as aucune vision d'ensemble. Si tu ne connais pas ta ville, tu n'as aucune idée où arrêter. J'avoue que je n'ai aucun sens d'orientation donc ça n'aidait pas non plus.

Isabelle says that she got tired of the inefficiency of TA and has started taking the bus alone whenever weather permits. She quickly has gained confidence and notes advantages in comparison with her numerous experiences with TA. She says that she enjoys having more control of her schedule and not having to wait for long periods of time:

L'attente est moins envahissante. J'aime mieux attendre l'autobus qui passe à une heure précise que d'attendre durant 30 à 40 minutes le transport adapté sans avoir aucun pouvoir d'action et me faire répondre « ah, mais il va arriver dans 10 minutes » pour ensuite d'avoir rappeler car il n'est toujours pas arrivé. C'est épuisant.

Unlike Isabelle, Pierre arrived in Montréal in his early twenties. He stayed in an apartment located downtown for two years where he quickly discovered that he could wheel to most of his destinations. The accessibility of buses was an abstract reality to him. The information available on the STM's website was not clear and using the service seemed complicated. "C'était encore un peu cryptique," he sums up. When Pierre moved to Rosemont, wheeling was not as easy as when he lived downtown because the distances to travel were greater. This was when he started to use the bus regularly to get to meetings in the evening. He remembers being excited about this new freedom. He discovered a flexibility that he never had with TA:

[...] mes premiers amours d'autobus se sont faits avec la 24. J'ai été beaucoup impliqué dans le Forum social québécois en 2009. J'étais coordonnateur de la logistique. J'étais sorti tous les soirs quasiment pendant une année de temps. Je prenais la 24 pour aller à l'UQÀM ou au Cégep du Vieux-Montréal. Je l'ai utilisé massivement.

Isabelle and Pierre both identify control and spontaneity as the main reasons for riding the bus instead of using TA. Another commonality between their experiences is their initial lack of knowledge on how to get a bus. It was only by riding buses that they have developed their own knowledge and set of skills.

Marie-Josée was still living on the Université de Montréal campus when she tried to use a bus for the first time. She was accompanied by her orientation and mobility therapist, whom she was meeting regularly, and in this way she learned how to navigate the city and to develop her mobility skills. Not only did Marie-Josée have to learn how to negotiate the city from a wheelchair user's perspective but also from the perspective of a person with visual and hearing impairments. In their round trip, she and her therapist had two completely different experiences. She remembers:

La première fois, le chauffeur ne voulait pas m'embarquer pis on n'était pas aux heures de pointe. L'intervenante a dû pousser un peu. C'était [un bus avec] la rampe en arrière. [...] Pour le retour, le chauffeur a été super fin. Il a été impeccable, mais le premier était comme bourgonneux. Eille regarde, on n'est pas dans les heures de pointe! Force-toi, lève ton petit doigt. Tu pèses sur le piton! Les mauvaises attitudes des chauffeurs, c'est ça qui fait que je crains plus de prendre le transport de la ville. C'est l'attitude.

Marie-Josée has since moved to an apartment in Villeray and lives on the corner of two bus stops. However, she never rides the bus alone. When she does so, she travels with someone else because she finds riding buses by herself too stressful. There are too many risks and she does not feel safe. She explains that getting on the ramp is challenging, because some drivers do not think about the space needed for the ramp when they stop. Furthermore, the communication between the drivers and her is often a source of anxiety. She also finds it difficult to swipe her OPUS card. “J’ai beaucoup de difficulté avec ma carte OPUS. La machine est loin. Michael doit m’aider pour l’atteindre. Tout se passe vite,” she sighs. Marie-Josée says that she feels pressured to get on buses quickly. The series of gestures that are required to get on a bus are shaped not only by physical access and drivers’ attitudes, but also by a particular pace that bus riders are expected to follow. This points to a normalized way of boarding a bus. A disruption of this norm has the potential to create discomfort. Nancy Hansen and Chris Philo (2007) have argued that:

Disabled people are often treated as though their way of doing things is disruptive to the ‘normal’ speed, flow or circulation of people, commodities and capital because they ‘waste’ more time and space than they should, maybe reducing profit margins. Moving at a slow pace when boarding a train, bus or taxi or being slow in making a purchase acts as a hindrance to the ‘natural’ rate of commerce [...]. (pp. 498–499)

This is precisely what most concerned the STM before allowing wheelchair users in the late 1990s and why attitudes towards the boarding of these “different” users was measured and those using mobility aids were subject to the opinion of non-disabled users.

During a summer between two university years, Marie-Eve was awarded an internship at the Fédération des travailleurs et travailleuses du Québec (FTQ) near Crémazie métro station. After discussing the intership with her parents, she thought that it would be better for her to use the métro and bus system to travel there. However, things did not go as planned. On the second day of her summer internship, she hit a wall:

C’était ma deuxième journée de travail je pense. La première, je pense que ma mère était venue me porter ou quelque chose comme ça. La deuxième, j’étais arrivée tellement fatiguée d’avoir stressé, d’avoir marché pour l’autobus, d’avoir stressé dans l’autobus. C’était dans le temps où il y avait encore des marches dans certains bus. Je me souviens d’en avoir pris et toutes les marches dans le métro et tout ça tsé. Je suis arrivée dans le bureau et je me suis assise dans la salle de conférence et je me suis mise à brailleur. La secrétaire qui était en charge de moi a dit : “mais qu’est-ce qui se passe là?”. Elle capotait!

To get to the closest bus stop to her apartment, Marie-Eve had to cross a major intersection. While we were crossing that very same intersection, she explains how scary it was when she used to cross it on her two feet:

Pour débarquer de l'autobus, fallait traverser la rue Sherbrooke. Il y a comme des bosses, des petites vagues. Vu que je n'ai pas de genou, ma jambe elle accrochait dans les vagues. J'avais tellement peur de tomber dans le milieu de Sherbrooke. C'était l'une de mes mégas peurs. ([see video Veilleux-2](#))

On the third morning of her internship, Marie-Eve ran as fast as she could to catch her bus, which was about to pull away from the bus stop. She did catch up with it, but did not knock on the door to get on. The bus took off without her. “Je n'étais pas assez *outgoing* pour frapper dans la porte. Pour faire comme ‘non j'ai droit à ma place, ouvre tes portes’, donc je l'ai laissé passer. Je suis retournée chez nous. J'ai appelé ma mère en braille. Je brillais beaucoup dans ce temps-là,” she recalls.

Shortly after these difficult experiences, Marie-Eve started using TA on a regular basis. I ask her if she had thought that the problem was the lack of access on buses or if she blamed herself for not being able to commute to work by public transit. “Je pensais ‘c'est moi qui est le problème et c'est moi qui doit s'adapter’,” she recalls. At the time, Marie-Eve did not know that ableism existed and had difficulty to articulate her experiences from a critical perspective. She quickly registered for TA to be able to get around without compromising her mental and physical health. When she got her scooter a few years later, she did not try to get on a bus, because she did not trust herself enough to understand the procedure. Furthermore, she worried that she would not be allowed on board—some scooters are not authorized because of their dimensions. It was only when she acquired her electric wheelchair that she started using the buses regularly. At the same time, the STM put into service new buses with front-door ramps.

As much as she appreciates these new buses for their more reliable access, Marie-Eve notes that many drivers are now hostile when she tries to board buses via the rear-door ramps. Some drivers have even been aggressive towards her because they did not want to have to deploy the rear-door ramp for her and claimed that she should wait for the next front-door ramp bus.<sup>69</sup> As a

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<sup>69</sup> In the old STM app that provided bus schedules, buses with rear-door ramps, which had previously been labelled as wheelchair-accessible, were no longer labelled as such. Only buses with front-door ramps were indicated as being wheelchair-accessible by the STM. This application no longer exists. The STM now invites its clients to use the Transit app. In the first

result of these traumatic incidents, Marie-Eve now avoids these buses. She even changes her route, if necessary. She explains:

[...] c'est incroyable comment j'évite les bus avec rampes arrières. Je n'en prends plus. [...] Il y a un chauffeur particulièrement sur Sherbrooke le matin où deux fois de suite, il m'a vraiment engueulé comme si j'étais du poisson pourri. Il ne voulait pas me servir. [...] Quand je regarde les autobus, dès que je vois que ça va être un bus à rampe arrière, je change mon trajet ou j'attends plus longtemps pour que ce soit un bus avec une rampe avant.

Sandra, who lives in the neighbourhood of Notre-Dame-de-Grâce, also tells me that she does not take the bus as much as she used to when she started using the buses about 10 years ago. "Sometimes I take the bus, but sometimes it is difficult. It takes a lot of energy to take the bus. It was easier when I was younger," she explains. Marie-Eve and Sandra now use buses less often even though the fleet is becoming more accessible. This shows that the arrival of buses with front-door ramps, which represented an advance for disabled people's right to ride buses, has limited benefits for some people using mobility aids. Other problems remain, such as the negative attitudes of drivers, and buses with malfunctioning ramps. The fact that both Marie-Eve and Sandra now use the bus less frequently also demonstrates that transit habits are not fixed in time and are subjected to changes throughout a person's life course.

### *The particularities of winter*

The weather conditions are likely to worsen transport anxiety. Participants have unsurprisingly identified winter as the most difficult and stressful season to use buses. However, the literature about the (in)accessibility of buses during Canadian winter is scarce. In the only study available on the bus experiences by wheelchair users living in Québec, there is not much information related to winter (Boucher et al., 2015). The participants claimed that they did not ride buses during the cold season. They indicated that the snow removal is done poorly and that snow prevents them from accessing the buses. The researchers also met with bus drivers. Regarding the presence of wheelchair users during winter, one bus driver stated that they should not be allowed on board because they are a burden: "Ils devraient malheureusement se contenter du STAC [Quebec City's adapted transit] et ne pas venir embourber le système sur une certaine période. Ils devraient vraiment déterminer, de telle date à telle date, « désolé, mais il n'y en a plus

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version of the app, buses with rear-door ramps were identified as non-accessible. The STM recognized that this information was not accurate. Buses with rear-door ramps are now identified with the pictogram of a wheelchair user and a question mark.

de fauteuils roulants ».” (Boucher, 2015, p. 54) Another study has explored the winter experiences of young wheelchair users aged 15-22 living in an urban area in Ontario (Lindsay & Yantzi, 2014). Most users were concerned about their safety when using buses because ramps were often broken due to the cold and snow and ice accumulation (p. 2198). These accessibility problems had the effect of limiting their capacity to participate in social and recreational activities during many months every year. Montréal participants expressed similar concerns in winter.

During and after snowstorms, the Ville de Montréal is supposed to clear bus stops in priority. However, the snow removal varies considerably from one bus stop to the next. The differences are even greater from one borough to another. Furthermore, the area that is cleared generally only gives access to the front door. The access to buses with rear-door ramp is therefore not considered. Broken ramps are also more common due to the combination of cold, snow, ice, rocks and salt. Nabila claimed that riding the buses during winter is simply not an option. It is too dangerous.

The interactions with bus drivers are most likely to be tense in winter. As I already have mentioned, the STM has enforced a rule for many years that suspends service to wheelchair users after snowstorms. Wheelchair users were not authorized to board until every borough of the city had completed most of their snow removal operations. It could take as long as a week before the suspension was lifted. The rule created some confusion for some drivers. Some drivers thought (or falsely claimed) that the service was suspended for wheelchair users throughout winter. Even though this rule no longer applies, boarding buses during winter can still be difficult. In the end, drivers have the power to decide whether or not the ramp can be deployed.

Caroline was confronted with an unequal power dynamic on a cold December day when she was with Anne-Frédérique, her four years old daughter. A bus driver refused to let them on board, claiming that the bus stop was inaccessible due to snow. Caroline argued that all he needed to do was to move a bit forward to deploy the ramp, but he refused, arguing that he would block a shopping mall entrance. “Le chauffeur était malfaisant. Il ne voulait pas avancer son autobus de cinq pieds pour que la rampe tombe à la bonne place. Nous sommes capables de trouver toutes des solutions et ils ne nous écoutent pas,” she explains. This experience shocked Caroline to the core because it put her young daughter in a precarious situation. Anne-Frédérique suffered from minor frostbite. As a disabled mother with a chronic health issue and very little

support, Caroline is constantly battling to provide good care for her daughter. She could not let this incident pass without saying anything. She shared her experience on Facebook and received media attention (TVA Nouvelles, 2015b). It was through a media report about this bus incident that I first heard about her.

### *Ableist attitudes, design and regulations*

Ramp malfunctions are a major obstacle for disabled people using mobility aids. The faulty design of the rear-door ramp is well known. In recent years, new concerns have been raised by disabled riders regarding the buses with front-door ramps. Despite these recurrent issues, the verification of the ramp prior to departure is not mandatory. The Société de l'assurance automobile du Québec (SAAQ) requires the STM to inspect its ramps every 20,000 kilometres, or every six months. In 2014, the STM decided to verify front-door ramps more often. Since then, these ramps are now checked every four to six weeks.<sup>70</sup> It is interesting to note that section 55 of the *Règlement sur les normes de sécurité des véhicules routiers* states that “all buses carrying people with disabilities must have a functional ramp.” However, the verification of the ramp is not on the daily mandatory circle check developed by the SAAQ. For example, the driver has the obligation to make sure the entrance and exit steps and the doors are in working order and danger-free. However, the draft regulation initially included section 55 in the mandatory circle check (Québec, 2013, p. 77). When I contacted the SAAQ and the Ministère des Transports, de la Mobilité durable et de l'Électrification des transports about the absence of the ramp verification on the circle check, I was first told that section 55 concerns solely the *Règlement sur les véhicules routiers adapté au transport des personnes handicapées* (personal communication, November 24, 2016). They have claimed that the latter *Règlement* does not apply to regular public buses equipped with an access ramp but only to Transport adapté vehicles such as minibuses and adapted taxis. Therefore, under the legislation currently in force in Québec, public buses are not considered vehicles carrying disabled people even though they have accessibility features that are supposed to guarantee access to this clientele. In other words, ramps are seen as non-essential components of buses.

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<sup>70</sup> In comparison, following numerous complaints from disabled bus riders, the ramps of the Toronto Transit Commission (TTC) buses are checked every day before leaving the garages, a practice that was put into place in 2013. The TTC indicates that “if [the ramp] will not deploy as intended, the bus does not go out into service until it is repaired” (TTC, 2013).

I spoke with a representative of the Ministère des Transports, de la Mobilité durable et de l'Électrification des transports, who suggested that this was probably due to the fact that, according to the legislation, Québec transit agencies are still not required to operate wheelchair-accessible buses (personal communication, November 28, 2016). In fact, section 67 of the *Act to secure handicapped persons in the exercise of their rights with a view to achieving social, school and workplace integration*, indicates that public transit agencies must submit a “development program for the purpose of providing, within a reasonable period, public transportation for handicapped persons within the territory served by it” for approval by the Ministère des transports. The Ministère has the power to accept or refuse a development plan. Even though these plans should improve the accessibility of public transit services, there is no specific obligation requiring public transit agencies to operate wheelchair-accessible buses. The Ministère simultaneously argues that public transit agencies should provide access to disabled people and refuses to regulate accessibility features on buses claiming that there is no such legal obligation. I argue that this shows how the Act is inefficient and how a law meant to secure rights for disabled people is used to justify and maintain ableist practices, such as excluding bus ramp verification from the daily mandatory circle check.

Many participants also identify the interior configuration of the buses as a major problem. Louise cannot get on the buses with her scooter. She once tried, but it didn't work because the space was too narrow. ([see video Blouin-3](#)) Even if she had been able to get on, she would have run into another problem: each bus has only one space reserved for clients using a mobility aid, which means that Louise cannot ride the bus with her partner, Christian.<sup>71</sup> This is an issue that Pierre has been familiar with since he moved to Montréal. His brother Michel also uses a wheelchair, which means that the two brothers are not able to get on the same bus. This transit headache became even more serious when he started to date Marie-Eve, also a wheelchair user. This restriction affects them every time they go out without booking TA. Because they cannot get on the same bus, they often have to use two different routes to reach the same destination. Often that means that one or both of them will wheel instead of taking the bus. The couple have shared the reserved space on a few occasions when the driver has allowed it.

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<sup>71</sup> Since 2017, new buses have two reserved spaces for mobility aid users.

Caroline explains that to go downtown she needs to take two different buses. Sometimes her trip is interrupted because there is already another wheelchair user on the bus she needs to use. She says:

[...] quand tu arrives à Honoré-Beaugrand pour pogner la 185, s'il y a un autre fauteuil roulant ben tu as manqué ta shot ! [...] C'est drôle, par exemple, les poussettes, trois ou quatre poussettes peuvent bien s'adapter eux, mais nous on ne peut pas? Pourtant, j'ai déjà embarqué avec quelqu'un en fauteuil roulant et le chauffeur n'a rien dit.

In explaining the problem, Caroline raises an important issue: Why is there a limit on the number of wheelchair users on board and not on the number of strollers? I have had the opportunity to travel in over a dozen large cities in North America and Europe in the past decade. Among these cities, two had buses with only one space for wheelchair users: Montréal and London, UK. The issue has been extensively documented by the London disability rights organization Transport for All. A group of British researchers have written on the impacts of the London bus design, which can only accommodate one wheelchair user at a time. The research focused specifically on disabled teenagers and highlighted the consequences on their social lives. The authors argue:

The inability of these disabled young Londoners to travel together, despite being physically and financially able to travel separately, illustrates our argument that mobility capabilities can exist at the group level as well as the individual level. We believe that the possibility of such group-level capabilities may have been somewhat neglected, both outside and within the mobilities literature. (Goodman et al., 2014)

In Montréal, the situation is different. Disability organizations representing disabled riders have supported and validated the bus configuration. In 2009, while conducting interviews for my master's thesis, I asked Marie Turcotte, the STM board's representative for Transport adapté users at the time, why the buses only had one wheelchair-accessible space each. She replied that the need for two spaces did not exist yet (Parent, 2010). I must admit that I was shocked by her answer, since I had been affected by this limitation for several years already and I knew that many wheelchair users had family members, lovers and friends who also used wheelchairs.

In 2011, I filed a complaint against the STM for discrimination in its métro, bus and TA services. One of my demands concerned the lack of accessible spaces on buses. The STM responded by arguing that nobody had ever complained about being denied access to a bus because the only accessible space was already occupied and that the design with a single space for wheelchair users had been decided in collaboration with the Table de concertation sur le transport des personnes handicapées de Montréal (Table) administrated by RUTA. The Table and

the STM claimed that adding a second space would cause prejudice to other clientele needing to sit at the front of the bus such as people with reduced mobility, elderly and pregnant women and compromise the fluidity and security of all users (Commission des droits de la personne, 2015, p. 19). They argued the additional space would make it impossible to have a reserved seat for these clients and that they could not only consider the needs of wheelchair users.

However, these justifications do not hold water as other transit agencies have managed to design buses with two wheelchair-accessible spaces and accessibility features accommodating a diversity of people. The chosen design is not based on lack of space inside the bus but rather on ableist perspectives on disabled peoples' mobility and a disregard for their access to the city. It assumes that wheelchair users either travel alone or with people who do not use wheelchairs. The design limiting the number of wheelchair users to one on Montréal and London buses is a good example of how space plays an important role in the construction of disability, as has been argued by many disability studies scholars and activists (Chouinard, 1999; Young, 2012). Rob Kitchin claims that "spaces are organised to keep disabled people 'in their place' and 'written' to convey to disabled people that they are 'out of place'." (p. 343) In addition to the lack of wheelchair-accessible spaces, some participants also pointed out two other design issues. The absence of an automated stop announcement system compromises Luc's and Isabelle's mobility.<sup>72</sup> Blind and visually impaired people have been waiting a long time for this missing accessibility feature. Isabelle is not visually impaired but because she uses a wheelchair, she has to sit facing the rear of the bus to conform to a STM safety regulation. "J'aimerais beaucoup qu'un jour il y ait un panneau qui affiche les différents noms de rues parce que dès qu'il fait noir ou dès que je suis fatiguée ou dès qu'il y a beaucoup de monde je ne vois plus nécessairement où est ce que je suis rendue," she explains. She has argued that she cannot rely on bus drivers' help to get off where she wants as some of them are not thrilled by her presence on board to say the least.

As mentioned previously, bus drivers' attitudes regularly have a negative impact on disabled people's experiences on buses. Interactions with drivers and other passengers are particularly inevitable for mobility aids users. Drivers must activate the ramp to enable people to get on and off the bus. This additional step is not part of the standard procedure performed by drivers hundreds of times every day, which is to stop the bus and open the door. When I want to

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<sup>72</sup> All buses are now equipped with an automated stop announcement system. While it is a significant improvement, some users have told me that the volume is sometimes too low. Furthermore, the screen is at the front of the bus, while wheelchair users face the back of the bus.

get on a bus, I usually have to make my presence felt and ask for the ramp to be lowered. While most drivers generally react quickly—a notable improvement since I started using the buses in 2002—some are still surprised by my request. I have even had drivers ignore my request and leave without me. Unfortunately, I have not been able to find any text-based sources about bus drivers’ perspectives on their interactions with disabled people. In its *Plan de développement d’accessibilité universelle 2016–2020*, the STM has recognized that even though current training programs for bus drivers integrate modules on universal access, “l’expérience client vécue par la clientèle ayant des limitations fonctionnelles demeure inégale.” (Société de transport de Montréal, 2017, p. 68) One of the objectives of the Plan is to develop training for new drivers that specifically addresses universal accessibility (p. 70). The study conducted with Quebec City (Boucher et al., 2015) bus drivers may provide some insights but it should be considered with caution, since the Quebec City bus system is quite different that of Montréal.<sup>73</sup>

One group of drivers who were interviewed claimed that wheelchair users were slowing them down. To eliminate this problem, some drivers suggested confining “slower clients” [those with physical disabilities] to TA (p. 53). They explained that they did not understand why people using mobility aids wanted to use regular buses:

Pourquoi est-ce qu’ils veulent tellement s’en venir dans un régulier où ils savent qu’ils vont être brassés, pas respectés ou se faire soupirer dessus ou çà ou ça? Pourquoi se donner toute cette peine-là? Oui, je le sais bien, pour se faire reconnaître comme partie intégrante, intégrale et normale, mais à un certain moment donné, si tu ne réponds plus aux exigences de la normalité, pourquoi tu ne profites pas du système qui est déjà adapté pour les gens qui sont comme toi maintenant et essayer de l’améliorer pour qu’il soit meilleur? (pp. 53–54)

The other group of drivers interviewed argued that they are not given enough time to deal with different factors such as traffic, weather conditions and customer service (p. 53). Under these circumstances, deploying the ramp often implies running behind schedule. This perspective is particularly interesting because it points to both systemic issues (the need to be on time) and some of the political and economical dimensions of Quebec City bus drivers’ reluctance to welcome mobility aid users on their vehicles. To understand the interactions between the drivers and the passengers, we must take into consideration the context in which these interactions take place.

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<sup>73</sup> The Réseau de transport de la Capitale operated its first wheelchair-accessible buses in 2012. In 2018, only 7 bus lines out of 103 are accessible to wheelchair users. Mobility scooter users are not allowed on RTC buses (Réseau de transport de la Capitale, n.d.). Montréal has a large bus fleet and a longer history of operating wheelchair-accessible buses.

Riding a public bus also involves daily interactions with other passengers. Passengers have to negotiate a confined space that is often overcrowded during rush hour. Most of the time, these interactions are non-verbal and require very little communication; they are almost automatic. However, for passengers with mobility aids, these interactions are generally more complex. The way that buses with front-door ramps are designed, it only takes one person standing at the front of the bus to block the way for a wheelchair user. To make matters worse, Montréal's bus system stands out among other North American bus systems I have used because of the way bus drivers rarely intervene to help wheelchair users position themselves in the reserved space; it is not part of their tasks. In other cities that I have visited, the driver leaves their seat, accompanies the wheelchair user to the space and, if necessary, asks seated passengers to vacate their seats, since the reserved space contains regular seats that lift to make room for a wheelchair user. In some cases, the wheelchair user is asked whether or not they want their wheelchair secured.

In Montréal, users have to wheel through fellow passengers (the reserved space is in the middle of the bus) and ask seated passengers to vacate their seats for them. I have used buses for over 14 years and making my way to the wheelchair-accessible space still feels like a perilous endeavour. Furthermore, I still regularly have to explain to seated passengers that I need the space. The Quebec City bus drivers explained that most passengers get impatient when a wheelchair user gets on board. "Il y a de l'impatience quand on déploie la rampe et ce n'est pas seulement quelques personnes, c'est généralisé. C'est comme s'ils trouvent qu'ils n'ont pas leur place là. Ils ne sont pas les bienvenus," said a group of drivers (p. 59). They have argued that passengers want to get to their destination as fast as possible and that anything that slows them down is perceived as irritating. From the stories that participants shared with me, in addition to my own experiences, it seems like Montrealers are more patient even though some attitude problems persist. Many participants have talked about the difficulty of navigating the interior of the buses and dealing with the negative or uninformed attitudes of other passengers, but they also spoke about the positive impacts of travelling with other people.

Five years after Laurence stopped using the bus, she got on one with her co-worker who is a wheelchair user. She recalls that she did not like the way other passengers looked at them. "Dans l'autobus, je n'ai pas aimé le regard des gens sur ma collègue et moi. Quand tu le prends souvent peut-être que tu es immunisée, mais je trouve que je n'ai pas ce regard là quand je

marche dehors,” she observes. I ask Laurence to be more precise about those looks. Were they filled with pity? Laurence replies that passengers seemed to wonder why they were on the bus with them. She talked about the danger of labelling disabled people as “irregular” users of a “regular” transit system, making an analogy with the debate around the inclusion of disabled students in regular classrooms. She explains:

Ils me regardaient pas méchamment, pas de pitié non plus, mais bizarre. Qu’est-ce que ça fait là? Comme si on n’était pas des êtres humains. [...]. Je vais t’expliquer ça par une analogie. En ce moment, dans le débat sur les coupures en éducation, il y a beaucoup de gens qui parlent de classes régulières et de classes non régulières. Pour moi c’est une catastrophe. Ça ne devrait pas exister. C’est la même chose dans cette situation là. On ne devrait pas nous regarder comme si on était des “non réguliers” dans un transport « régulier ».

In a study conducted with disabled women using wheelchairs in London, Mariela Gaete-Reyes (2015) found that they often have to deal with “prejudices, barriers, discrimination and exclusions.” (p. 352) “The ‘dys-appearance’ of the bodies of women wheelchair users and their construction as non-citizens occur in their embodied everyday experiences of place, during their intersubjective encounters with non-disabled people,” she writes. (p. 360) Nabila has been overtly asked by other passengers what she was doing on a regular bus on a couple of occasions. “Les lignes 90 et le 17, ce n’est pas la grande joie. La plupart du temps les rampes ne fonctionnent pas. L’intervalle entre les bus est de 20 minutes. La réaction des gens aussi. Ils se demandent ce qu’on fait là. ‘Vous n’avez pas de transport adapté?’,” she tells me while we are wheeling on the bumpy sidewalks that she often chooses to wheel to avoid having to take a bus. Nabila feels like these comments send a clear message: she is not welcomed. In Rob Kitchin’s words (1998), these passengers have told her that she is out of place.

Isabelle recalls that when she started using the buses by herself, she felt uncomfortable. Other passengers would stare at her. “Au début, j’étais un peu gênée parce que quand tu embarques tu déranges le monde. C’est gênant. Le monde me regardait,” she remembers. Kitchin claims that “the majority of us experience guilt or apprehension when we know we are somewhere we should not be, like hiding in your parent’s bedroom or sneaking into the boss’s office.” (p. 350) However, Isabelle explains that, after some time, the way people looked at her did not matter anymore. She has discovered the benefits of being on a bus with other people. She argues that it has helped her to better understand the

diversity of Montréal's population and to feel more positive about her own body image and her life. She confides:

Il y a toutes sortes de monde et ça m'a encore plus ouvert à la réalité de qui sont les montréalais, qui fréquentent mon coin, qui fréquentent le centre-ville. Il y a vraiment toute une gamme de personnes. C'est drôle, mais plus je fréquente de personnes, plus j'ai un regard positif envers moi-même. Je ne suis pas si différente que ça. Mais quand on est isolée, on se voit plus différente. Dans notre imaginaire, on a des personnages de télé qui sont tout le temps beaux, que leur vie est parfaite. Mais quand tu es avec le vrai monde, tu n'es pas si différente que ça.

This perspective shows that beyond the practical benefit of being able to get around the city, riding the bus can have an impact on disabled peoples' perceptions of themselves and of others. It also suggests that riding TA can be lonely because interactions with fellow passengers are rare.

Even though the STM bus fleet is becoming more accessible to mobility aid users, there is no study available that measures the use of buses by this specific clientele. In a 2014 interview with CBC News in Montréal, Marvin Rotrand, the STM's Vice-President at the time, claimed that the STM only registers about 5,000 to 6,000 rides per year made by wheelchair users (CBC News, 2014). This equals approximately 13.7 to 16.4 trips a day, which is about six to eight round trips per day. The accuracy of these numbers is highly questionable, since most vehicles do not track the number of riders who use wheelchairs.<sup>74</sup> There are people like Isabelle and Marie-Josée, who recently have discovered the flexibility that riding buses can offer and they try to take them as often as they can. There are also people like Nabila and Marie-Eve, who have been using the buses for a few years but are now avoiding them as much as they can because of all the bad experiences they have endured. There are also people like France, who does not use Montréal buses because of all the horrific stories she has heard from her friends and the few bad experiences she herself has had. There are also people like France, who does not use Montréal buses because of all the horrific stories she has heard from her friends and the few bad experiences she herself has had.

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<sup>74</sup> The STM will eventually get more accurate statistics as all buses will be equipped with a system that monitors various bus components, including the ramp.



**Figure 14:** During the wheeling interview, Isabelle gets on a bus. The ramp is located at the rear of the vehicle. I follow her even though there is a limit of one wheelchair user per bus.

Participants' experiences with buses tell stories in which ableism, mobility, legislation, space and power intersect. A bus is a space where the presence of mobility aid users still challenges specific rules and norms. Nearly two decades after the introduction of the first wheelchair-accessible buses in the STM bus fleet, ableist attitudes, design and regulations continue to jeopardize mobility aid users' capacity to get on board easily and safely. Given the poor accessibility of the métro and the bus system, Transport adapté plays a particularly important role in the mobility of many disabled Montrealers.

### ***Transport adapté***

*August 2002.*

*I just moved to Montréal from one of the smallest villages in Québec. This is my first day of class at CÉGEP, and I am so nervous. I will soon become a real city girl.*

*Finally.*

*My college is located in the heart of the city, a city I have already (and innocently) fallen in love with. I have chosen the coolest CÉGEP, so I can rub elbows with the coolest people.*

*I am 17 years old.*

*I have to take a special bus to get to school.*

*I don't want to take it.*

*I have never taken a special bus before. In my hometown, I would travel on the same school bus as my non-disabled peers.*

*I don't want to be identified as "handicapée."*

*People often tell me they don't even see my disability.*

*That's a compliment.*

*But here I am, on that special bus for the “handicapés”.*  
*It feels weird to be on this bus.*  
*It doesn't feel good. It doesn't feel right.*  
*I see a crowd of students crossing Ontario Street to get to the main entrance of the CÉGEP.*  
*They look like an ant colony.*  
*I am aware that they are all coming from the nearby métro station. One of the 65 métro stations I can't access.*  
*The métro has 65 stations.*  
*My bus stops a few meters away from the main entrance. I am getting off at a different entrance.*  
*I am not part of the ant colony.*  
*I wish I were.*  
*I don't feel like I'm 17.*

—November 4, 2009

In the early 1970s, Jacques and Jean-Marc Forest, two brothers using wheelchairs who lived in Montréal, founded the first wheelchair-accessible transit service in Québec (Parent, 2010). At that time, the Québec state did not assume any responsibility regarding the transport of disabled people. The Forest's brothers had to find the funding necessary to create the service by themselves. In 1973, they invested their own personal savings to create Minibus Forest. At its inception, the door-to-door service was only available in downtown Montréal. The service was rapidly extended to other sectors in the east of Montréal, but it was still unable to meet the demand. Murielle Larivière, a disabled activist in the 1970s, remembered Minibus Forest's first years of operation when I met her for an interview for my master's thesis. She says:

Ils ont démontré ainsi à quel point les besoins de déplacement des personnes notamment en fauteuil roulant étaient criants. Faute de moyens financiers, le service ne répondait qu'à une toute petite partie de la clientèle. Les administrateurs avaient dû établir des priorités autant pour le type de client que pour les raisons du déplacement. La clientèle prioritaire était les travailleurs et les étudiants seulement. Même pour la clientèle prioritaire, on ne pouvait pas répondre à l'ensemble des besoins. (personal communication, December 17, 2009)

In 1976, the Forest brothers received their first government grant, which served to absorb a deficit of \$51,540 (Prix Gilles-Coutu 2002 décerné aux frères Forest, 2002). Two years later, the National Assembly of Québec unanimously adopted the *Act to secure handicapped persons in the exercise of their rights*. Section 67 defined the obligation of public transit organizations to provide transportation for disabled people. The Ministère des Transports would cover three quarters of the costs. In 1980, the Montréal public transit commission submitted a plan to the Ministère des Transports that proposed the creation a public paratransit system. The plan was approved, and the Forest brothers' company activities were integrated into the new public paratransit system. In addition to the métro and bus network, the STM formerly known as the

Commission de transport de la communauté urbaine de Montréal) became responsible for the operation of what has been named Transport adapté (TA). However, this new division had little in common with the métro and the bus network.

Transport adapté had its own rules and practices, such as an mandatory admission process to be accepted as a registered client,<sup>75</sup> limited opening hours, restricted services during and after snowy days and the obligation to book trips in advance. Despite these restrictions, the STM and the Office des personnes handicapées du Québec have argued that Transport adapté has the potential to offer the same services and opportunities as the métro and the buses (Commission de transport de la communauté urbaine de Montréal, 1985; Office des personnes handicapées du Québec, 1984).

In 1985, the STM announced that all the transportation needs of disabled people living on Montréal Island would be met by 1987 (Commission de transport de la communauté urbaine de Montréal, 1985). The belief that Transport adapté could be an equivalent to the métro and the bus system was based on an ableist perspective on disabled people's mobility (Parent, 2010). It is important to note that according to disability advocate Christian Dufour, the Forest brothers believed that Transport adapté could not replace regular public transit. "Ils voulaient adapter le transport public," remembered Dufour (Fougeyrollas, Boucher & Grenier, 2018, p. 150). In 2009, Marie Turcotte claimed:

C'est sûr que le transport adapté même s'il est très bien organisé, ça va toujours demeurer un service qui doit être planifié et structuré. Tu dois réserver à l'avance. Tu pourras jamais, à mon avis, avoir la même spontanéité comme client du réseau du transport adapté que quelqu'un qui utilise le réseau régulier (personal communication, November 12, 2009).

In the United States, disabled people started to fight for accessible public transit in the 1970s arguing that to "limit disabled persons to a demand-response paratransit system is to segregate them, a violation of civil rights" (Pfeiffer, 1990, p. 160). However, in Montréal, métro and the bus accessibility has not been on the agenda of the disability rights movement. For instance, the Regroupement des usagers du transport adapté (RUTA), a disability rights

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<sup>75</sup> In order to be a TA user, disabled people must apply and go through an admission process. To be eligible, a person needs to meet specific criteria that are defined by the Ministère des Transports. Admission criteria have changed through Québec's TA history and are likely to change in the future. Mike Oliver (1996) argues that the state's determination of who is considered disabled is highly influenced by political economy.

organization founded after the creation of Transport adapté in Montréal, advocated solely for better Transport adapté services (Parent, 2010). The organization did not identify the lack of access to public transit as a form of segregation. Quickly, Transport adapté imposed itself as the only appropriate means of public transportation for many disabled people, such as those unable to use stairs or walk long distances.<sup>76</sup> According to the Institut de la Statistique du Québec, only 7% of the disabled population had used an adapted transport service at least one time in the past 12 months in 2006 (Institut de la Statistique du Québec, 2010, p. 183). The use of adapted transportation is higher among disabled people who have “severe impairment” (p. 184). All people I have interviewed fall into that category according to this medical definition and categorization of disability.

Over the years, Transport adapté has experienced many changes, such as a major increase in the number of contracts given to taxi companies and the implementation of the online reservation system. In 2017, the STM Transport adapté delivered 4 million trips and served more than 31,000 clients, a record in its history (Société de transport de Montréal, 2018a). The ridership has boomed over the last decade, with an average annual increase of 6.5% (*Ibid.*). While the demand for Transport adapté is growing, as is the number of clients who are completely dependent on this mode of transportation,<sup>77</sup> the Ministère des Transports’ funding has remained

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<sup>76</sup> In my master’s thesis, I explained how the creation of Transport adapté has divided disabled people into two categories: those who could ride the métro if some changes were made and those who could not ride it because their disability is deemed too severe. I wrote: “This idea relates to the medical model of disability, which puts blame on individuals for their exclusion in arguing that the problem is located within the person (Pfeiffer, 2001, p. 30). The Transport adapté system required every potential Transport adapté user to go through the process of a medical evaluation in order to be recognized as disabled enough to use the Transport adapté system. The Montréal public transit commission defined some disabled people as being “partially handicapped” (Commission de Transport de la Communauté Urbaine de Montréal, 1985, p. 87), which makes them potential candidates for using the regular public transit. For example, some environmental changes were proposed in order to make the subway more accessible for people with visual impairments, as it was argued that those changes were a question of social equity, and also as a way of reducing paratransit expenses qualified as avoidable (p.88). Disabled people who cannot use stairs, however, were labelled as being “too handicapped to use regular public transit.” (Parent 2010)

<sup>77</sup> One thing most Transport adapté’s users have in common is that they are in a generally precarious financial situation. In 2011, 80% of Transport adapté customers living in Québec had an annual income below \$20,000, 9% higher than the last available statistics from 2004 (Ministère du Transport du Québec, 2014, p. 12). In the same period of time, the number of captive users increased from 4% to 11% (p. 14). Captive users are users who never use one of the following six modes of transportation: personal vehicle, vehicle owned by a friend or family

static for many years (Ferraris, 2016). In Montréal, provincial disengagement has forced the STM to invest more money in Transport adapté to sustain the increase in demand (Société de transport de Montréal, 2018a). In 2016, the STM reduced the opening hours of the reservation centre by 30 minutes. The transit agency claimed that these cuts were necessary to sustain the growth of the demand (RUTA, 2016). In September 2016, several users reported having to wait for more than 50 minutes before reaching the line to book a trip (Tellier, 2016). Similar situations have since happened on numerous occasions in the evening but also during the day (Brière, 2018; Lefebvre, 2018).

All participants had something to say about TA, whether they were current users or not. A number of them talked about their general feeling towards TA, while others shared many stories offering perspective on how their relationship with TA has changed over time (and space, in the case of Pierre and Marie-Josée). In this section, I explore the reasons why people use or do not use Transport adapté, as well as some of the repercussions of TA on the everyday life of two participants: Marie-Josée and Nabila. In doing so, I challenge the idea that Transport adapté is the most appropriate means of transportation for all disabled people, especially for people using wheelchairs, and that TA users are a homogeneous group of people. I argue that TA simultaneously enables and prevents its users' from exercising their right to the city (Lefebvre, 1968), depending on the context in which they find themselves. While participants' stories about the métro and the buses mostly evoke physical barriers as the major source of their experiences of exclusion, stories about TA are more about a system built on practices that continually marginalize its users.

### *To ride or not to ride TA*

Transport adapté was the public transportation mode that most of the participants were familiar with, which reflects its importance in the disability community. All participants were eligible for Transport adapté, and 11 of them are regular users. Three non-users, Geneviève, France and Kéven, are car owners. Kéven explains that even though he registered for TA a few months ago, he has never used it. Since he moved into his new apartment, he has access to indoor

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member, (regular) public transit, taxi, volunteer transport or any form of transportation other than Transport adapté. The Ministère des Transports report reveals that the customers who have impaired physical mobility or who use a wheelchair is the most captive.

parking, a great improvement over when he first moved to Montréal. His new workplace also has an indoor parking garage. It is expensive, but necessary. Kéven acknowledges that if he did not have easy access to indoor parking, he would have to resign himself to taking TA. France started using TA in the 1990s after her accident. She was a client for eight years before getting her own vehicle. She has very negative memories associated with TA. “Je fais de l’urticaire quand on me parle du TA,” she admits. She continues:

Je n’ai pas de beaux mots à dire sur mon expérience de TA. Vraiment ça m’a fait perdre du temps. Ça m’a frustrée pis aussi, tsé, toute la perte de spontanéité. Tu es dans un endroit pis tu as du fun. Pis c’est là ton transport. Il vient. Tu te sens comme un petit enfant là. Tu te sens vraiment comme si ta maman venait te chercher dans un party pis elle te disait « on s’en va » pis tu n’as rien à dire. Je garde des souvenirs très négatifs de mon expérience.

Christian, who only uses TA as a last resort, explains why he avoids this mode of transportation as much as possible. “Comme beaucoup d’autres personnes ayant des incapacités, je ne suis pas un fervent du Transport adapté. Je te dirais que la principale raison c’est essentiellement parce que je ne trouve pas cela pratique (réservation à l’avance, horaire bâtarde, long déplacement, attente, etc.),” he wrote in the text he gave me prior to the wheeling interview. Among the regular users, only Laurence exclusively uses TA among STM transit services.

Laurence, like Louise and Luc, is what is called, in TA jargon, a transferable user. This means that she does not require wheelchair-accessible taxis. Having access to both regular and adapted taxis means that Laurence, Louise and Luc can generally book a trip on the same day, since more vehicles are available to them. This is not an option for participants using non-folding mobility aids (motorized wheelchair and scooter users), who are identified as non-transferable. These users must make a reservation at least a day before their trip. In short, there are inequalities among TA users regarding the availability of the service based on how they move.

Most participants started using TA after moving to Montréal or after becoming disabled in their adult life. Isabelle, Marie-Josée and Pierre used it when they were children to get to school. Jacynthe, Marie-Josée and Pierre experienced TA in smaller towns and explained how different it was from Montréal. Jacynthe explains that in her hometown, she had to book her trips before noon a day in advance: “C’était hyper contraignant!”. She was looking forward to moving to Montréal, where she was told she could get a ride with only four hours’ notice. However, she was quickly disappointed when she arrived. She recalls:

En arrivant à Montréal, je les ai appelés et leur ai dit que j'étais inscrite au Saguenay. Mais ils m'ont dit que ça fonctionnait pas comme ça. Il y avait un délai d'un mois et demi avant de pouvoir avoir un transport. Donc, j'ai dû me déplacer par mes propres moyens pendant tout le mois de septembre. Se taper la côte pour monter jusqu'à Sherbrooke, c'était vraiment ardu. J'arrivais et j'étais super crevée.

Pierre, a Drummondville native, remembers that the TA made more sense because the trips were conducted by the TA manager himself. He explains:

En région, c'était le monsieur qui était directeur du transport qui faisait les routes. Il faisait son chemin à la main et il le faisait pour que, si tu allais chercher une ou deux personnes, ce soit sur le chemin. Je n'ai jamais fait des détours qui n'ont pas de sens ou des choses comme ça avant d'arriver à Montréal.

Pierre argues that using a transportation service different from his non-disabled friends did not bother him much. What mattered to him was to reach his destination and then carry on his activities with his numerous friends. Marie-Josée has had a much different experience. She has bitter memories about her experiences in St-Jean-sur-Richelieu. "J'haïssais le minibus scolaire adapté. Je devais quitter 30 minutes avant la fin des cours au secondaire. Ça m'a toujours fait chier," she says. Marie-Josée had to fight with her mother in order to stop using TA and board the regular school bus. She wanted to ride the school bus to be with "les autres." She started using the bus in Secondaire 3. "Je sentais que je faisais partie de tout le monde, de la « normalité ». Plus incluse... Je cherche les bons mots," she remembers emotionally. This shows how space plays a role in one's identity and sense of place. Riding the adapted minibus not only forced Marie-Josée to leave school before the end of the classes but also made her feel different from her peers. She remembers that being disabled was extremely difficult to embrace as a teenager. Peter Freund (2001) argues that "one can argue that disabling features of socio-material environments produce 'a vivid but unwanted' consciousness of one's impaired body. Anybody that cannot comfortably use and/or 'find a home' in spaces will not only feel alienated from that space, but from his or her body as well." (p. 698) Valorie Crooks and Vera Chouinard (2006) explain that "identities are understood as being forged through changing relations to significant places of life and people within them." (p. 346) For Marie-Josée, the decision to stop using the adapted minibus was a strategy she used to feel better about herself as a disabled teenager.

Participants gave one or two main reasons that led them to become TA users in Montréal: to save energy and to feel safer and/or to simply get to the places they would not be able to go due to the numerous barriers in the métro and bus system. This speaks to the importance of TA in

their everyday lives—without TA, some activities, such as commuting every morning, would be impossible. Louise, Marie-Eve and Laurence talk about the impacts that trying to navigate an inaccessible transit system has on their bodies. Using TA is a strategy they use to mitigate pain, physical exhaustion and stress. Their experiences show how bodies matter and should not be ignored, as has been advocated by many disabled feminist scholars (Chouinard, 1999; Kafer 2013; Wendell, 1996). It also echoes Christine Miserandino’s spoon theory (2003), which argues that people with disabilities or chronic illness have a reduced amount of energy to perform everyday life and mundane activities. Therefore, they must plan their day and make sure they have the spoons—which are metaphorical units of energy measurement—they need.

Louise became a part-time TA user when she got a job at Université de Montréal. She was living in the east of Montréal and claimed that the commute between her home and her workplace would have involved too much walking to get from one bus to another. She would have been exhausted. Marie-Eve had an interesting first encounter with the TA provided by the STM. In her early twenties, she was a new student at McGill University. Even though both of her parents lived on the Montréal Island, she decided to live on McGill campus to avoid having to commute everyday. TA trips of no less than 50 minutes were incompatible with her chronic illness. McGill had its own adapted transportation system on campus, dedicated only to disabled students, which worked perfectly for Marie-Eve’s needs at the time. However, living on campus was not economical, and she was struggling to make ends meet. Marie-Eve advocated to get the financial aid available to students who live too far from their parents to stay with them, claiming that she did not have access to proper transportation between her parents’ homes and McGill University. The STM even wrote a letter supporting her claim, stating that they could not guarantee trips under 90 minutes long. She finally got the financial aid and stayed on or around campus a few years.

When she moved out to her first apartment in Plateau Mont-Royal, where we chose to meet to start the wheeling interview, she unsurprisingly did not think she would get around by TA. She tried to use the métro and the bus system but quickly hit a wall. It would not work for her. She started using TA on a regular basis. Her first memories of TA are of the moments spent waiting for it. “Je me souviens d’avoir attendu le transport en avant de la FTQ. [rires] Je me souviens d’avoir attendu devant la FTQ car c’est juste sur le bord de l’autoroute. Il y avait énormément de poussière. Je me souviens des tourbillons de poussière,” she recalls. Other than

that, she says that her first TA experiences have been uneventful. She started having problems during the school year, when taxis were regularly loaded to their full capacity. She did not have any space for the leg she can't bend. The STM did not want to book two seats for her even though she needed them. Although that matter was eventually resolved, Marie-Eve has faced several other problems over the years. TA quickly became a necessary evil for accomplishing her daily activities. When she got a motorized wheelchair, her dependency towards TA slightly decreased—she was able to wheel to many places. However, she continued to use TA for many trips, despite all the problems she has encountered, because it still saves her energy, or in other words, spoons, that she cannot afford to waste. She explains:

Je prends le transport [TA] parce que rouler le matin de bonne heure je trouve ça difficile. Je le fais des fois quand j'oublie de réserver mon transport. [...] Ça me demande un certain effort conduire mon fauteuil. La piste cyclable, les trous, toute la concentration que ça demande de gérer le trafic et tout.

Laurence's decision to use TA likewise was motivated by concerns about her body capacities and personal safety. She came to that decision after being a métro and bus rider for many years. As explained earlier, Laurence frequently was denied a reserved seat for disabled people by fellow passengers, who did not acknowledge her disability or just did not have the courtesy to do so. This made her commute extremely tiring. Furthermore, since her disability impairs her sense of orientation, it took her many spoons not to get lost while getting around the city by métro and bus.

Taking TA has been extremely positive for Laurence, as it has changed her relationship with the city. She finally is able to go to a greater number of places and feels much safer and less stressed. "Je me sens plus en sécurité parce que c'est du porte à porte. Avant, j'avais le stress 'Ok, je sors du métro. Je m'en vais où? Qu'est-ce que je fais?' Ce stress là, je ne l'ai plus," she explains. TA has changed how Laurence plans her everyday life. She remembers learning how to organize her life 24 hours in advance. The hardest thing, she says, was to get her entourage to understand that they also needed to adapt to her new reality and let her know in advance when they wanted to make plans with her. "Malheureusement, j'ai des amis que j'ai perdu de vue parce qu'ils ne sont pas capables de s'organiser 24 heures d'avance pour différentes raisons. Moi, je ne peux pas à une heure d'avis venir te voir. C'est pas possible," she claims. This shows how the organization of time and space can impact disabled peoples' social lives as argued by disabled feminist Susan Wendell (1996, p. 38). Laurence has told me that while she lost friends,

she also made new ones in the disability community. She argued that she was surprised to realize that having disabled friends was great as there are many things that do not need to be explained over and over again.

Additionally, participants' use of TA varies according to the weather conditions and their destinations. Nabila explains that during the winter, she relies solely on TA, which means that it can take up to an hour to go somewhere as opposed to the summer, when it takes her much less time if she wheels. Furthermore, there are days when she can't go out at all because TA only accepts bookings for medical, school and work purposes due to predictions of difficult road conditions.<sup>78</sup> Winter has a similar effect on Isabelle's transit habits. To get to her bus stops, she always takes the same routes, as she has poor orientation skills. If she has to modify her route due a poorly shovelled curbscut, she will get lost. The cold is also a major issue, as she has no resistance to cold. Regardless of weather conditions, many destinations are out of reach, with the few accessible transit options and participants' varying wheelchair mobility. At the time of the interview, Pierre had a full-time job in the West Island. His workplace was located 32 kilometers from his home in Rosemont. To get there, he took four buses, and a trip with no ramp incidents took at least two hours. Considering the poor reliability of the bus ramps and the adventure that each trip could represent, TA was his only option to get to work every day of the week.

### *Repercussions on the everyday*

The explosion of the demand for TA in Québec over the last 10 years can erroneously lead to the conclusion that TA users are making more trips than ever before, and therefore are more mobile. In reality, statistics show the opposite. The number of TA users may have increased, but the number of trips they make has not. Across the province, the annual average of trips was 75.71 per TA user in 2013 (Ministère du Transport du Québec, 2013, p. 13). This was a decrease of 3.20% over 2012. In 2002, the STM estimated that the average wheelchair user aged between 21 and sixty-five rides paratransit 66 times a year.<sup>79</sup> Comparatively, a "usager sans déficience" used regular transit 660 times a year (Comité sur l'Accessibilité du Métro de Montréal, 2002, p.18). A survey conducted by the *Ministère des Transports* in 2011 indicated that the number of trips taken by the users is inferior to the number of trips that they would have needed to take (Ministère du Transport du Québec, 2014, p. 29). In the case of TA, disabled

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<sup>78</sup> These service interruptions have been criticized by disability activists in the past few years (Parent, 2015; Parent, 2013; Parent, 2011a; RAPLIQ, 2014; TVA Nouvelles, 2015a).

<sup>79</sup> I have been unable to find more recent data.

people may not be facing architectural barriers to access the vehicles, but they do face practices that restrict their mobility options. These practices jeopardize their right to the city by isolating them in a segregated transit system.

As I have mentioned before, in recent years, disabled people have been active on social media telling their own TA stories. On the Facebook group *Transport mésadapté*, which I co-founded with Marie-Eve Veilleux, such stories are posted by a variety of members on a regular basis. “*Transport mésadapté* has become a new space of disability activism, where members address important critiques to public transit organisations, the STM in particular, and to the mainstream Montréal disability rights movement,” Marie-Eve Veilleux and I write (2017, p. 89). While I was writing this portion of my dissertation, a video was posted on the *Transport mésadapté* page that showed Mikael Theimer, an able-bodied man, waiting for TA with his friend Michel Pépin, a TA user. This TA would bring them to Michel’s apartment. In the video, shot by Mikael on his cellphone, he explains that they had been waiting for at least an hour only to find out that the driver who was supposed to pick them up wrote them off as absent. Because of the rain and the cold, they were waiting inside a building. Mikael said the driver took off without making his presence known to them. This delay meant that Michel would miss his lunch, as his attendant had to leave his home to see another client. Mikael understandably was outraged as he was telling their story, while Michel appeared calmer in background. Mikael explained that Michel was still in good spirits because he is used to that kind of situation. On *Transport mésadapté*, many people commented on the video, echoing their familiarity with the story. It is not uncommon for TA users to wait for more than 30 minutes only to find out that the driver has left without them.

Despite these issues, the STM TA service has consistently received high satisfaction rates over the years. Each year, the transit agency publishes the results of their telephone survey on clientele satisfaction. The latest results available, from 2017, indicate a level of customer satisfaction with *Transport adapté* services of 95% (STM, 2018). To be surveyed, a client needed to have used *Transport adapté* at least twice during the past month. The data does not indicate the number of participants who have taken *Transport adapté* on a regular basis (i.e., users who used it at least 10 times a week). The high level of STM TA client satisfaction differs from the results obtained by the Ministère des Transports, which conducted its own survey among *Transport adapté* users across Québec in 2011. Only 35% of the comments were positive. The majority of

the comments pointed to problems such as delays, lack of service, poor customer service and safety (MTQ, 2014, p. 36). Of course, this survey does not make any distinction from one region to another, which makes it hard to know the proportion of comments formulated by Montréal users. However, these findings seem to better reflect the experiences of the Transport adapté users who I have met for my research and who use Transport adapté much more often than twice a month.

Through the wheeling interviews, I have learned that even though people have had many bad TA stories, telling them is not that easy. There are many stories forgotten in the sea of bad experiences. There are also the stories that have more significance for participants, as they have shaped their relationship with TA and even with the city to some extent. The latter are obviously what I was looking for. When I asked participants to share a significant TA story, most paused, laughed and replied that they could not think of one off the top of their heads. “Je pourrais quasiment faire un roman avec ça tellement que j’ai eu des aventures. Là, je ne sais pas, mais tsé, ça ne me vient pas de même là,” says Marie-Josée. It is at moments like this that my friendship with many of the participants revealed itself as particularly useful.

On a few occasions, I would remember stories that they had previously shared with me. “Je me souviens d’une fois que tu attendais le transport à l’Université de Montréal,” I told Marie-Josée. I didn’t even get to the end of my sentence before she interrupted me and started telling the story I had in mind. Marie-Josée was living in student housing on the Université de Montréal campus. During the day, she used the adapted transportation service operated by the university to go to her classes. However, at night, she had to rely on TA, because the university service stopped running at 5:00 pm. On one particular winter evening, Marie-Josée had a similar experience to that of Mikael and Michel’s. The TA driver reported to the STM that she was absent and left without her, even though she was there waiting for her ride back home. On that night, STM told her that they would send another TA to pick her up. She waited quite a few minutes, with no TA in sight. Meanwhile, a security officer told her that she would need to wait outside because he had to lock the doors of the university building for the night. As she had no idea when the second TA vehicle would show up and she was feeling troubled by what was happening, Marie-Josée panicked. It was cold outside, and the thought of being alone in the cold without any knowledge of whether or not she would make it home bewildered her. The university security officer ended up offering to leave her mobility scooter in a locked classroom and drive

her home. She accepted and got home around midnight. This experience was a turning point for Marie-Josée, who could not wrap her head around the fact that TA had let her down like this in the middle of winter:

J'étais crevée, mais tellement en maudit. Je ne pouvais pas concevoir que l'on me laisse dehors de même. Ça a été bien marquant. J'ai porté plainte, mais ça pris un mois et demi pour me faire dire que « ah, il ne savait pas trop où c'était le pavillon ». C'est toujours l'excuse facile pour les chauffeurs. On est comme rien. On est comme de la marde apparemment.

After this experience, she restricted her outings to a bare minimum and noticed that her anxiety increased considerably. “J'avais comme pas tellement le choix [de continuer à prendre le TA]. C'était mon seul moyen de transport. [...] J'étais beaucoup beaucoup stressée. C'était le stress constamment. Tout le temps,” she remembers. Marie-Josée's story illustrates the dilemma in which many TA users find themselves. They have no other choice but to continue to use a mode of transportation they no longer trust. Rob Imrie (2000) argues that “disabled people are forced to live in different spheres even when in public space (e.g., using paratransit or sitting in the back of the theatre)” (as cited in Freund, 2001, p. 698). Marie-Josée also explains that many TA drivers ignore her hearing impairment or assume she is non-verbal because of it.

In addition to these uncertainties, some TA rules affect some people more than others. Nabila talked about two rules in particular, which impact her family life. These two rules are specific to TA and do not apply to the métro and bus system. The first rule stipulates that users can be accompanied by no more than one person who is older than 14 years old. The second one concerns luggage and shopping bags. In the TA user guide, it is indicated that luggage and shopping bags are accepted only if the user can carry them by themselves, do not take up additional space in the vehicle and are securely stored or held. The STM warns that drivers can refuse to take riders if they have items they cannot carry themselves.

The rule about travel companions was one of Nabila's main concerns when we met. She was extremely worried that she would not be allowed to ride TA with her two daughters in the near future. As I mentioned previously, this rule already had prevented Nabila from getting around the city with her daughters and her husband. In two years, her youngest daughter will be 14 years old. She explains:

[dans deux ans] je n'aurai plus d'enfants. Les enfants que j'ai seront considérés comme des accompagnateurs donc j'aurai, non seulement à choisir entre mon mari et mes filles, mais je

devrai choisir aussi entre mes filles. Je ne pense pas que je vais vivre une plus grande frustration que ça. Ça me fait peur que ce jour arrive.

When Nabila complained about this issue to RUTA, she was told the rule was fair and had the objective of dedicating the scarce resources to disabled people first, not their family. Nabila felt invalidated in her role as a mother. As she was telling me the story, I could not believe it. I stepped out of my role of researcher and proposed to help her to contest this ableist and sexist rule. We wrote a letter and we sent it to the Ministère des Transports, the STM and RUTA. This letter got the attention of Radio-Canada and Nabila's story was featured on the TV show *La Fracture* in February 2016 (Radio-Canada, 2016a). Despite these actions, the rule has not been modified yet.

The second rule on luggage and shopping bags complicates one of Nabila's responsibilities as a stay-at-home mother. Last year, a TA driver refused to let her get on board while she was coming back from the grocery store with her daughters. She remembers:

J'avais fait mes achats au Maxi avec mes deux filles. J'avais mes sacs accrochés après mon fauteuil. Ma fille avait son sac à dos d'école et un sac de nourriture dans ses mains. Le chauffeur ne voulait pas nous laisser monter. Il a dit: « vous avez pas le droit d'amener votre marchandise ». Il m'a laissé tomber. Il était 9h du soir et il faisait froid. Il a appelé un inspecteur. Je lui ai dit: « vous n'allez pas me laisser à 9h du soir et deux enfants et tous mes sacs! » Mais il ne voulait pas. J'ai demandé qu'un inspecteur vienne sur place. L'inspecteur l'a autorisé à partir et il est parti. L'inspecteur est ensuite venu et m'a dit que le chauffeur de transport adapté avait le droit de me refuser. Il m'a proposé de ramener mes filles dans son véhicule qui évidemment n'était pas accessible. J'ai hésité avant de les laisser partir avec lui. Moi je suis partie en roulant. J'avais un trajet de 45 minutes à parcourir. Pendant tout ce temps, je me suis demandée: « Est-ce que j'ai bien fait de laisser mes filles avec un inconnu? Est-ce que j'aurais dû les garder avec moi? J'ai passé 45 minutes à me demander si j'avais décidé la bonne chose.

Nabila confides that this event hurt her more because it affected her children. “Si j'étais seule, si je me retrouvais seule dans des situations pareilles, ça me ferait moins mal. Mais, les vivre avec elles...,” she says. This story touches upon different components of Nabila's life and identity: her family cannot afford a car, which forces them to carry shopping bags on public transit; she does not live close to a grocery store and has to take transit or wheel a long distance to get to one; she has a family of four to feed, which means that she has more shopping bags than someone who lives alone or has a smaller family; she is a woman; she is the mother of two teens who are female; and she is easily identified as a Muslim because she wears a hijab.

Nabila explains how powerless and unsafe she felt on that evening. She wonders if her religion could have played a role in the drivers' hostile attitude since he had no reasonable motive to deny her access. "Je ne sais jamais si c'est mon handicap ou ma religion le problème. [...] Si je n'avais pas le foulard, est-ce que ce serait différent? On commence à se poser 36000 questions. Pourquoi? Pourquoi il agit comme ça?", she argues. As Nabila tells me her story, I keep thinking that if I found myself in a similar situation, I am not sure that I would be treated in the same way, because I am white and I don't wear a hijab. Our discussion about transportation leads us to talk about employment. Nabila told me that she has not yet been able to get a job even though she graduated from university in Algeria. Again, she never knows what role is played by employers' negative prejudices based on disability, gender, race or religion. She also explains that even if she could get a job, she is not sure if she could keep it and continue to do everything she needs to do as a mother considering that commuting to work with TA would take up too much time and energy. She is also afraid of arriving late to work regularly because of TA's infamous delays. Nabila's worries are rooted in what is expected from a productive person in today's society. Susan Wendell (1996) argues that:

when the pace of life in society speeds up, expectations of 'normal' performance and 'high level' functioning increases. For example, the more the life in society is conducted on the assumption of quick travel, the more disabling are those physical conditions that affect movement and travel. (p. 38)

We continue to wheel and talk and from one story to another, Nabila confides that she feels trapped and guilty towards her family, and more particularly towards her daughters. Nabila's stories illustrated how TA rules do not take into consideration the diversity of the disability community and the level of mobility a citizen is supposed to be able to perform. It also assumes individuals, not people in relation to each other.

France and Marie-Eve both remember experiencing situations when they were treated differently because they were women. There are two particularities that distinguish TA from regular buses. The first distinction is that TA users are regularly alone with the drivers in the vehicles. This creates proximity between users and drivers that rarely exists on the buses. Secondly, an overwhelming majority of TA drivers are men. When she started using TA in her twenties, Marie-Eve said that some drivers would comment on her physical appearance. "J'avais pas mal plus de commentaires déplacés. Des commentaires comme « ah tu as des beaux yeux! » ou bien juste aussi des tentatives de conversations," she remembers. On one occasion, she felt

that a driver had his hands too close to her body when he bucked her seatbelt. She did not say a word. She was not able to tell him to stop.

Marie-Eve has noticed that sexual harassment is not something she has to deal with anymore. She suggests that she might be less of a target because she is now older. I ask her if she has stopped smiling and being nice to the drivers and she nods in agreement. “Ouais, c’est ça. J’ai un air bête automatique qui dit « je n’ai pas envie de vous parler »,” she adds. She also became more aware of how she may be treated differently as a woman since witnessing how her boyfriend Pierre, who is also a TA user, is treated by drivers. “Quand on prend un TA ensemble, certains chauffeurs parlent à Pierre, mais ne me parlent pas à moi. On a déjà remarqué que des chauffeurs l’appellent Monsieur Lemay, alors que moi, ils m’appellent Marie,” she observes. In a later conversation on Facebook Messenger, Marie-Eve said “un chauffeur m’a déjà appelé Madame Lemay même si je n’étais pas avec Pierre.” France does not recall being inappropriately touched or having her body commented on by drivers. However, she remembers that when she used to ride TA to go to CÉGEP, she needed help to zip her winter coat to go outside to catch her TA ride. One day, a TA supervisor contacted her to tell her that drivers would no longer be able to help her. He claimed that this was to prevent any confusion about sexual touching. France could not believe it. This really put her off. She also remembers the regular unease of drivers when buckling her seatbelt. “Les femmes ont des seins. Ben oui. Les femmes handicapées ont des seins. Nous ne sommes pas des martiens,” she says ironically. Marie-Eve and France’s accounts reveal a portion of the sexual politics of riding TA. These have been historically overlooked. Disabled women activists and scholars, however, have shown for a long time how disabled women are treated differently from disabled men and their non-disabled sisters and experience higher rates of sexual violence and infantilization (Barile, 2006; Chouinard, 1999; DAWN-RAFH Canada; 2013).

In many different ways, participants’ experiences with TA show how this transit system requires its users to conform to a series of rules and practices that do not exist in the métro and bus systems. The system that is supposed to meet disabled people’s “special needs,” in fact, requires its users to be particularly disciplined. For example, users must be ready to go at pick-up time or they might miss their ride. There is no room for flexibility (i.e., needing to go to the bathroom while waiting for TA is out of question). However, the STM requires users to wait 30 minutes before reporting a late pick-up and regularly show up late. “Il y a un double standard. Si

je suis pas là, il quitte, ce qui ruine ma journée. Si lui est en retard, il n’y a aucune conséquence. C’est hyper injuste,” sighs Marie-Eve. Marie-Josée always makes sure to be ready before pick-up time, even if this means she has to cut short something she is doing, because she is afraid to miss her ride.

One strategy many participants use to reduce their stress involves limiting their number of TA trips. This reality is still undocumented; it would almost be impossible to capture or record the number of trips people wished they could have taken. Here Michel Foucault’s work on power and discipline (1975) offers an interesting perspective on the regulatory effects of TA on its users. Foucault argues that schools and hospitals are disciplinary institutions as much as prisons. They define, classify, control and regulate people. In order to function, TA defines who is eligible to TA according to their medical diagnosis. It classifies users according to these same diagnoses or types of mobility aids used (i.e., there are different codes for people with intellectual disabilities, people with physical disabilities, wheelchair users who can transfer from their manual wheelchairs to the car seat, wheelchair users who use power wheelchairs, etc). It controls and regulates TA users’ mobility by enforcing different rules and practices (i.e., a user can only travel with one person aged over 14 years old, or the suspension of services when difficult road conditions are foreseen). This affects how TA users behave and negotiate the limitations of the system.

### ***Conclusion***

In this chapter, I have demonstrated that most participants ride the métro, the bus and TA to various degrees, and that the mode they use depends on numerous factors. Participants navigate three different systems—each with its own set of barriers—that are still not designed to connect. For example, people who use the STM’s services either use TA or the “regular” métro and bus network. The STM does not yet offer options for those who would like to use the métro or the bus in addition to completing a portion of their trip by TA. Since 2015, Nabila, Marie-Josée, Marie-Eve and Pierre have been using the métro on an occasional basis. However, these moments remain rare because the participants do not live close to an accessible station, and possible destinations are also limited. The participants’ transit habits, as well as their strategies to resist to the numerous obstacles they encounter, are continuously evolving. Their use of public transit is on the move. They showed clearly that they were not passive users but active agents of change challenging the ableism embedded in the STM’s transit systems. Much can be learned from their

experiences. A better understanding of ableism is necessary—there needs to be more than just changes in the infrastructure in order to make the network accessible and welcoming for disabled riders; there must be some recognition of the inequalities disabled riders have experienced and are still experiencing.

Participants' stories also demonstrate that the poor accessibility of the métro and bus system does not impact all disabled people in the same way. The impact on their everyday lives also changes over the course of their lives. The differences they embody matter. This echoes the words of Canadian disabled geographer Vera Chouinard (2009) who argues “disabled citizens' capacities to exercise legal rights are compromised by their peripheral places within law, society and space.” (p. 224) For example, the privilege of owning a car to make up for the inaccessibility of public transit, ut it is out of reach for many.<sup>80</sup> While space and physical obstacles play a central role in the transit experiences of disabled people, I argue that temporality should not be a neglected factor. For instance, weather conditions, which can be extreme during Montréal winters, radically change the public transit system and people's experiences. The attitudes of STM staff and fellow passengers are also major concerns for those wishing to use the métro and the bus system.

Put together, participants' stories tell a larger narrative about a scarcity of transit choices for disabled Montrealers and the severe limitations to how mobile they would like (and need) to be in the city.<sup>81</sup> Tovi Fenster (2005) claims that “the more choice people have the stronger their sense of belonging becomes.” (p. 227) Geneviève explained how she sometimes feels like she does not know her city because she cannot ride the métro:

Il y a plein de bouts de Montréal que je ne connais pas parce que je ne me déplace pas tant que ça. On se déplace en auto et ce n'est vraiment pas la même chose. [...] Tu ne crées pas tant de liens. [...] Quand les étudiants étrangers à l'université me demandent “c'est où le métro?” Tsé, je ne suis même pas sûre de savoir il est où. Tu es mieux de regarder sur Google. Je ne peux pas bien t'orienter. Je ne sais pas il est où. ([see video Vanier-3](#))

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<sup>80</sup> Car owners with disabilities generally have more freedom of movement than their peers who use paratransit. However, their capacity to get around the city with ease is significantly limited during winter. Finding accessible parking can also be difficult in some parts of the city. Reserved parking spaces are also frequently taken by non-disabled drivers who have no reason to use these spaces (Allard, 2018).

<sup>81</sup> It should also be noted that getting access to a wheelchair-accessible taxi in Montréal is still extremely difficult. This is why participants, who mostly use a motorized mobility aid, did not talk about taxis as a transportation option. In my experience, taxis, like TA, need to be booked in advance.

This relationship between mobility and sense of belonging will be explored in greater detail in the next and final chapter.

## Chapter 6

### Belonging in Montréal Disability Communities and in the City

*En 2009, un an après mon entrée dans le monde des Critical Disability Studies, j'ai écrit un article intitulé « Is this city my city? ». J'étais de retour à Montréal pour l'été après avoir passé un an à Toronto. Je sentais le besoin de trouver une réponse à ma propre question. En quittant Toronto, j'ai laissé derrière moi la spontanéité, un réseau de transport en commun plus accueillant qu'hostile et un cercle d'ami-es allumé-es sur les questions du handicap. En revenant à Montréal, j'ai retrouvé plusieurs de mes privilèges associés à ma langue et ma classe ainsi que mon réseau d'ami-es et ma famille. Pour la première fois de ma vie, j'ai remis en question mon appartenance à Montréal.*

*Près de 10 ans plus tard, la question « Is this city my city? » demeure pertinente. Toutefois, j'ai compris que même si la question est simple, je ne suis pas obligée de répondre par oui ou par non.*

—April 20, 2018

On living in Montréal in the mid-1990s as an Anglophone, Elspeth Probyn (1996) writes “It is difficult to consider living here without being touched by the constant appeals to belong” (p. 67). Issues of race and language are sensitive topics, as Probyn reminds. In 1995, Québec’s electors were asked to vote for a second time on national sovereignty. The “no” won with 50.58% of the vote. More than two decades later, I am pretty sure Probyn would make the same claim. Even though the issue of Québec sovereignty is no longer at the forefront of political debates, other issues relating to belonging are still highly politicized. Debates on the place of religion, race and language are still central in Québec and in Montréal. At first glance, it may seem that disability has nothing to do with the construction of a sense of belonging, as it has been completely excluded from those debates so far. However, my personal experience and my previous research on the history of the inaccessibility of the Montréal métro (Parent, 2010) has led me to think differently. I am convinced there is something to explore. My primary goal, when I started to think about my doctoral research project, was to understand disabled Montrealers’ sense of belonging. I wanted to see if they share similar thoughts as mine. Do they question their belonging in Montréal? That is where I intended to start. However, it quickly became clear that I needed to ask many other questions before tackling this delicate subject. Previous chapters have shown that ableism is embedded in the city. Every day, participants are confronted by ableist infrastructures and policies that constrain their choices and limit their sense of agency and their

movements, at the same time that it demands their full attention and often causes anguish and fatigue.

The notion of belonging is studied in various disciplines. In the fields of philosophy, sociology and psychology, everyone seems to agree: belonging is one of the conditions required to live a good life. “Human beings are fundamentally and pervasively motivated by a need to belong, that is, by a strong desire to form and maintain enduring interpersonal attachments,” write Roy F. Baumeister and Mark R. Leary (1995, p. 522). In his famous theory on the hierarchy of needs, psychologist Abraham Maslow (1943) ranked belonging third. Kenneth Pelletier (1994), a clinical professor of medicine, argues that a sense of belonging “appears to be a basic human need—as basic as food and shelter.” (pp. 137–138) In *Le Droit à la Ville* (1968), French Marxist philosopher and sociologist Henri Lefebvre articulated the concept of the right to the city: the inhabitants of a city have the right to use urban spaces, to participate in all decisions that contribute to the production of those spaces and to feel that they belong. In *The Practices of Everyday Life* (1984), philosopher Michel de Certeau describes belonging as a “sentiment, which is built-up and grows with time out of everyday life activities and use of spaces.” (as cited in Fenster, 2005, p. 222) De Certeau privileges walking as a means of building belonging in spaces. He explains that accumulated knowledge, memory and intimate corporal experiences are gained through walking practices (*Ibid.*).

The importance of the sense of belonging makes its way into the law. The *Americans with Disabilities Act* (ADA) defines belonging as a major life activity. It means that disabled Americans should have the “freedom to enjoy life among family, friends, coworkers and fellow citizens.” (Hubbard, 2004, p. 217) In other words, disabled citizens should be able to participate in society like non-disabled citizens. In Québec, the “À part entière” policy (2009) aims to increase the social participation of disabled people and its ultimate objective is to enable their full inclusion in society. Even though the sense of belonging is not clearly identified in the policy text, it is in the backdrop. Research on disabled people’s sense of belonging in different communities across Québec, however, is extremely limited. According to the *Modèle de développement humain et Processus de production du handicap* (Fougeyrollas, 2010), which is very well-established within Francophone research, disability rights organizations and governmental institutions in Québec, social participation is the total accomplishment of an individual’s life habits resulting from the interaction between personal factors and environmental

factors. Each life habit can therefore be measured with a scale ranging from “full social participation to a total disabling situation” (RIPPH, n.d.). According to this model, personal factors such as age, gender, race and disability belong (*appartiennent*) to individuals. This approach minimizes—and, in many instances, erases—the role played by power relations and systems of oppression, which are at the root of disabled people’s exclusion. It also seeks to quantify something that is difficult to measure and is constantly subject to change. For these reasons, this model appears to be inadequate to investigate the complexities of belonging. The stories gathered in this thesis clearly show that people’s everyday life experiences can hardly be put in boxes.

While emphasizing the importance of belonging, many scholars have also pointed out its subjectivity, its performative nature as well as its instability. Alyson L. Mahar, Virginie Cobigo and Heather Stuart (2012) define belonging as a “subjective feeling of value and respect derived from a reciprocal relationship to an external referent that is built on a foundation of shared experiences, beliefs or personal characteristics.” (p. 1026) Building on Judith Butler’s work on the performativity of gender, Vikki Bell (1999) claims:

one does not simply or ontologically “belong” to the world or to any group within it. Belonging is an achievement at several levels of abstraction. Butler’s work has been vastly influential in arguing that even the notion that one belongs to a sex or gender can be problematized, not merely because of cultural and historical variation, but because gender, to cut a long story short, is an effect performatively produced. (p. 3)

Emotions, space, symbols and discourses shape who belongs in a city. Emotions, for example, play a central role in people’s sense of belonging. As Probyn (1996) argues, a sense of belonging is “a profoundly affective manner of being” (p. 13); emotions are themselves shaped, as they are deeply political and embodied. Sara Ahmed (2013), one of the most well-known affect scholars, explains that emotions shape what bodies do in the present, or how they are move by the objects that they approach. For Probyn, one of the most fascinating aspects of belonging is that people long to belong. For her, belonging is about desire. “Briefly put, desire is productive; it is what oils the lines of the social; it produces the pleats and the folds which constitute the social surface we live. It is through and with desire that we figure relations of proximity to others and other forms of sociality.” (Probyn, 1996, p. 13) Sally Lindsay and Nicole Yantzi (2014) explain that places and environmental contexts shape a sense of belonging “because power and privilege operate through both physical and social barriers and facilitators” (p. 2196). Inspired by the work of urban policy scholar Brendan Gleeson (2001) and geographer Rob Kitchin (1998), Sally

Lindsay and Nicole Yantzi argue that “inaccessible environments reduce the capacity for individuals to engage in activities and participate as full citizens in everyday life; they also convey the message that people with disabilities do not belong” (*Ibid.*).

Probyn invites us to think about belonging as queer, and to pay attention to the “in betweenness of belonging” (p. 19). In research on women’s everyday urban experiences, Tovi Fenster (2005) argues that Lefebvre’s conceptualization of the right to the city “lacks sufficient attention to patriarchal power relations which are ethnic, cultural and gender-related and as such it doesn’t produce a practical standpoint” (p. 217). She claims that these power relations compromise women’s right to the city and therefore negatively affect their sense of belonging in the city.

Another aspect of belonging, explored by many researchers whose work has captured my attention, is that it is not static—it is always shifting and unstable. “The categorisation of people in typologies of belonging should not be static, as external events, change in life stage, identity change and social mobility will change meanings attached to place,” write Mia Arp Fallov, Anja Jørgensen and Lisbeth B. Knudsen (2013, p. 470). Nira Yuval-Davis (2006) argues that “even in its most stable ‘primordial’ forms, however, belonging is always a dynamic process, not a reified fixity, which is only a naturalized construction of a particular hegemonic form of power relations.” (p. 199)

Inspired by this rich literature, in this chapter, I explore two dimensions of belonging: belonging in Montréal disability communities and belonging in the city. My goal is not to determine who belongs and who doesn’t, or to measure participants’ sense of belonging, but to better understand how they “make sense of their lives” (Probyn, p. 5) and the “why, how, where, and with whom [they] may feel that [they] belong” (p. 35). I am interested in how ableist power relations, as well as participants’ different positionalities impact disabled people’s sense of belonging. Because of the very nature of my research project and the stories shared during the wheeling interviews, I am also exploring the relationship between participants’ sense of belonging and mobility. Fallov, Jørgensen and Knudsen (2013) claim that “to understand what characterises people’s rootedness in places, we have to take into account their routes to and within places and the meanings and practices involved in both.” (p. 471) Simply put, they argue that “mobility resources result in different scales of belonging.” (p. 483) In the context of this

research, I aim to find out, for example, if owning a car and being free from the limits imposed by Transport adapté results in a stronger sense of belonging in the city.

### ***Belonging in the disability communities***

*After making a few trips in the large cities in the United States, I came to realize that nearly every time I ran into another wheelchair user on a sidewalk, that person would acknowledge my presence either by a simple eye contact, a smile, a wave or a hello. I loved that. The little moments made me feel like a part of a community. In Montréal, wheelchair users generally do not acknowledge each other's presence. I would even say that we often actively avoid each other's eye contact. The vast majority of my attempts to connect with another passer-by using a wheelchair have failed so far. Sometimes I don't even try. But I long for this connection. For this solidarity. Without it, every battle feels a little harder.*

—March 4, 2018

Am I the only one who longs for this connection? Do the participants desire to belong to disability communities? And more importantly, do they identify as disabled in the first place? These are the difficult questions I am trying to answer. Unsurprisingly, most participants did not share my longing for connection with other wheelchair users in public spaces. They had more nuanced perspectives on it. As Sandra explains:

Sometimes I will acknowledge them. I don't know why. I feel like just because the other person is disabled, it doesn't necessarily mean that we have something in common. Yet at other times, I do. I don't know why. I dislike when someone asks "Oh, do you know so and so, they are in a wheelchair as well." We're supposed to know every disabled person.

Kéven mentions that he reacts differently each time. He says:

Ça dépend de mon humeur. Des fois, il y a un échange de regards, mais je ne sais pas si c'est de la complicité ou juste un hasard de hauteur. Dans un environnement certain, ça peut influencer. Par exemple, à un arrêt de bus.

Of course, I am not arguing that disability belonging must always involve a connection or an acknowledgement between disabled people in public. However, I think this kind of recognition or acknowledgement is a good starting point for a conversation about disability belongings.

Sandra's and Kéven's quotes suggest that belonging to disability communities is far from being simple. But first of all, I should be clear about what I mean by disability communities. In fact, there is no such thing as a universal definition of a disability community. Virginie Cobigo,

Lynn Martin and Rawad Mcheimech (2016) have developed a notion of community based on peer-reviewed literature and a collaboration with four persons with intellectual and developmental disabilities: “A community is a group of people that interact and support each other, and are bounded by shared experiences or characteristics, a sense of belonging, and often by their physical proximity.” John C. Walsh and Steven High (1999) suggest that a more complex and dynamic definition of community is needed for historical research. “Three elements are fundamental to understanding the historical significance of community: community as imagined reality, community as social interaction, and community as a process,” they argue (p. 255).

Scholars and activists working in the United States and the United Kingdom have argued that disabled people are part of multiple communities and there is no such thing as a singular disability community (Taylor, 2017). Disability communities can take various forms according to various identity markers such as medical diagnosis, age, gender and sexual orientation. In his text “Disability Communities (Plural),” Andrew D. Pulrang (2017), a disabled activist and writer based in the United States, argues that another way to identify disability communities is by looking at their different approaches and perspectives on disability. He defines five sub-groups: the activists, the culturalists, the bootstrappers, the assimilators and the cure questers. Pulrang claims that one person can belong to more than one community at once and that this belonging can also shift during a lifetime.

Research shows that disabled people’s sense of belonging must be grounded in their specific contexts. For example, Paul Milner and Berni Kelly (2009) interviewed 28 disabled people with motor impairments in New Zealand who indicated a stronger sense of belonging to disability communities than to mainstream spaces. Isabelle Ville, Monique Crost and Jean-François Ravaud (2003) studied the sense of belonging to disability communities among tetraplegic people with spinal cord injuries in France. Their results claim that 56% of the participants recognized the existence of a community of disabled people and 34% of the participants said they belonged to that community. In her article “When Transport Becomes a Destination: Deaf Spaces and Networks on the Mumbai Suburban Trains,” Annelies Kusters (2017) investigates the Mumbai Deaf community by observing and interviewing Deaf people travelling in train compartments reserved for disabled people. The author explains that “deaf spaces in the trains are places where deaf people sign and engage in deaf sociality, relax and time out, learn and exchange knowledge, and negotiate the diversity of deaf travellers in enabling and

oppressing ways.” (p. 191) These spaces are used to maintain a sense of belonging in the Mumbai Deaf community. Norma J. Mejias, Carol J. Gill and Carmit-Noa Shpigelman (2014) conducted interviews with nine members of a well-established empowerment support group for young disabled women based in the United States. They discovered that through their participation in the support group, these young disabled women developed a sense of belonging to the disability community that was accompanied by a sense of disability pride. In the United States, the passage of the *Americans with Disabilities Act* (ADA) in 1990 is considered as a turning point for disability communities (Brown, 2015; Davis, 2016; Engel & Munger, 2003). In research based on the life histories of disabled Americans, David M. Engel and Frank W. Munger (2003) found that disability rights awareness and disability identity are deeply connected in the lives of disabled Americans. Annual celebrations of the passage of the ADA also testify to this. Most disabled people are proud of the ADA and many of them are ready to fight for it: U.S. Congress passed a bill in February 2018 to weaken the ADA (Corbett, 2018; DeBonis, 2018; Ray & Leveille, 2017).

Ravi Malhotra and Morgan Rowe (2013) argue that the situation is different in Canada where there is no federal disability law, but there is legislation in various provinces. Contrary to U.S. disability communities, Canadian disability communities do not share a similar point of reference that can help to foster a sense of belonging to disability communities. Most disability issues are a provincial responsibility.<sup>82</sup> In Québec, the adoption of the first disability law in 1978 and its revision in 2004 brought many disability rights groups together. However, unlike the ADA, this legislation is generally unknown to disabled people who are not actively involved in the movement, nor is it something people take pride in or use in their everyday lives to fight for their rights. Throughout the wheeling interviews, none of the participants mentioned this law.

The linguistic and cultural differences between Québec and the rest of Canada also shape disability communities and disability belonging. The interactions between Canadian and Québec disability communities are quite limited. As an accessibility consultant working for different federal institutions—such as Elections Canada and the Canadian Museum for Human Rights—I have experienced and felt the gaps between these communities. Accessibility consultants from other Canadian provinces generally share the same cultural and political references, while French-speaking consultants from Québec share different references that are often not relatable to

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<sup>82</sup> For example, the federal government cannot force the Québec government to make the Montréal métro accessible. However, it can allocate funding to make it accessible. This is what happened in 2016 (Société de transport de Montréal, 2016).

consultants from the rest of Canada. These gaps widen when they get lost in the simultaneous translation on which most Anglophones and Francophones rely. During breaks and lunch, English-speaking and French-speaking consultants who are not bilingual, which is generally the case with the majority of these individuals, rarely mingle. Moreover, consultants from Québec generally pay less attention than their Canadian colleagues to disability issues at the federal level. Their priorities are located at the provincial level and what is happening in Ottawa seems far from the everyday life of the people they represent. To my knowledge, there is no research specifically on disabled people's sense of belonging in disability communities in Québec and Montréal. As explained in Chapter 3, the literature on Québec's disability communities has focused on the "milieu associatif de la défense des droits des personnes handicapées." Even though the history of the movement is certainly helpful for understanding how some disabled people got together and fought for their rights, I argue that more perspectives are needed to better understand the complexities of belonging to disability communities.

I use the term "disability communities" instead of "the disability community" to acknowledge the diversity of disabled people and perspectives on disability issues in Montréal. This diversity is rarely recognized. I will not attempt to define disability communities in Montréal or to find out which communities each participant belongs to. My interest here is to better understand the obstacles participants faced on the road of belonging to disability communities, how their perspectives on disability have shifted and what belonging to disability communities means to them.

### *The first step: Identifying as disabled*

Identifying as disabled is the first step towards developing a sense of belonging to disability communities. Even though this may seem self-evident for people with visible disabilities, research shows that identifying as disabled does not come naturally for most disabled people, regardless of whether or not they have visible or invisible disabilities. In her piece "Becoming Disabled," feminist disability studies scholar Rosemarie Garland-Thomson (2016) writes:

Not long ago, a good friend of mine said something revealing to me: "I don't think of you as disabled," she confessed. I knew exactly what she meant; I didn't think of myself as disabled until a few decades ago, either, even though my two arms have been pretty significantly asymmetrical and different from most everybody else's my whole life. My friend's comment was meant as a compliment, but followed a familiar logic—one that African-Americans have noted when their well-meaning white friends have tried to erase

the complications of racial identity by saying, “I don’t think of you as black,” or when a man compliments a woman by saying that he thinks of her as “just one of the guys.”

Garland-Thomson’s story resonates with mine. Prior to being introduced to Critical disability studies and anti-ableist disability communities, I used to believe that I should be happy when people tell me that don’t see my disability. Not seeing my disability meant that my disability changed nothing to the person that I was. It meant that disability was not part of who I was.

Many critical disability scholars have written about how disabled people are taught and conditioned to reject disability as a part of their identity (Garland-Thomson, 1996; Linton, 2007). The most prevalent response to disability in Western cultures is to overcome it (Titchkosky, 2007). In the media, “an incredibly powerful tool in shaping the way we think about disability,” (Young, 2012) disabled people are often portrayed as courageous people overcoming their disability (Haller, Dinca-Panaitescu, Rioux, Laing, Vostermans and Hearn, 2012; Rojas, 2016; Young, 2012). Renee Martin (2015) uses the term “Super Crip” to describe this media representation. She writes:

A Super Crip doesn’t succumb to pain or limitations, they simply soldier along and sometimes even go above and beyond to give the appearance that the ableist structure of the world isn’t hard to negotiate every day. It’s always the Super Crip that you see in the special interest pieces on the six o’clock news, putting a so-called brave face on disability.

When disability is made visible, it is to show how the hardship of disability must be overcome—generally with a good attitude.

French disabled activist Elisa Rojas (2016) criticizes the use of phrases such as “malgré le handicap” in mainstream French media. She writes:

En utilisant cette expression, beaucoup d’entre vous imaginent sans doute sortir des sentiers battus. Après tout, ce qui est placé avant ou après « malgré le handicap », ne vient-il pas utilement démontrer que tout est possible aux personnes concernées, voire suggérer habilement les difficultés qu’elles peuvent rencontrer, mais aussi surmonter? Que nenni. La tournure vient simplement souligner et confirmer, sans le questionner, que votre postulat initial demeure invariablement le suivant: il est communément admis et non contestable que « par essence » le handicap empêche de réaliser tout cela et n’est pas compatible avec une existence ordinaire.

Portraying disabled people as *overcoming* disability in these ways separates them from their disabled identity and sends a clear message: disability is a bad thing. Garland-Thomson (2016) claims “the one thing most people do know about being disabled is that they don’t want to be that.” Fiona Kumari Campbell (2008) argues that disabled people are submerged by negative

ontologies of disability and have very few role models who propose non-hegemonic perspectives on what it means to be disabled. In Chapter 3, I explained that some participants were reluctant to get their first wheelchair. They did not want to want to be identified as disabled or at least not more disabled than others already perceived them. They navigated the bumpy road of internalized ableism by denying, or at least minimizing, their disability.

According to Campbell, internalized ableism, or disabled self-hatred, has two main impacts on disabled people: it distances them from each other and pressures them to match or even surpass ableist norms. In her poem titled *Internalized Ableism*, feminist and disabled artist and activist Maria R. Palacios (2017) writes:

Internalized ableism is  
believing the lies we have been told about our bodies,  
believing that nobody will love us or want us,  
believing we are damaged  
and broken  
because others have said we are.  
Internalized ableism is  
negating ourselves the right to say no,  
denying ourselves the right to say yes  
or saying yes when we should say no,  
or saying no when we should say yes  
because we've been made afraid to trust  
ourselves.  
[...]  
Internalized ableism is  
Not wanting to be friends  
with other disabled people, reminding ourselves again  
that we're not one of them, and believing that "those people"  
do have problems, but they're not our problems

In their research with young disabled women, Mejias, Gill and Shpigelman (2014) observe that these women have experienced different forms of oppression that have devalued their bodies and sexuality. They have encountered multiple obstacles either in their environments or in the implementation of exclusionary policies. As they write, "These forms of oppression had been internalized and cumulatively prevented the women from developing a positive self-concept and strong sense of belonging toward those around them." (p. 217) Deborah Marks (1999) argues that this kind of internalized oppression is extremely powerful and hard to challenge. She writes:

Once oppression has been internalized, little force is needed to keep us submissive. We harbour inside ourselves the pain and the memories, the fears and the confusions, the

negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives. (p. 1)

Tom Shakespeare (2006) gives additional reasons why disabled people may not identify as disabled. He observes:

most people have multiple affiliations: they may be more likely to associate and self-define in terms of sexuality, ethnicity, religion or gender than their impairment. In other words, they may feel they have more in common with other gay people or Muslim people than with others who share their impairment but nothing else. (p. 186)

Shakespeare adds that many disabled people are the only disabled person in all spheres of their life: it is harder for disabled people to relate to other disabled people if they never have the opportunity to develop relationships with them. Many participants talk about their struggle to identify as disabled while growing up almost exclusively surrounded by non-disabled people. In her mid-twenties, prior to working for the Association des étudiants ayant des incapacités au post-secondaires (AQEIPS), Laurence did not have any relationships with other disabled people. Somewhat embarrassed, she states:

C'est drôle à dire là pis je suis pas fière là, mais je vivais, j'étudiais. Je vivais dans un milieu très normalisé. [...] J'avais jamais eu d'amis en situation de handicap pis c'est pas par méchanceté ou quoi que ce soit. C'est juste que ça a jamais été un besoin de côtoyer ces personnes.

Louise, who went to a school specialized for disabled children until the age of 16, says that she had many non-disabled friends outside school. She recalls that she never noticed significant differences between herself and her non-disabled peers as a child. She is not sure when exactly she started to identify as a disabled person. However, she offers the following insight on how this changed as she entered into her teen years:

C'est beaucoup à l'adolescence. À l'époque où mes amies ont commencé à avoir des amoureux. [...] Mes amies non handicapées sont toutes parties parce qu'elles avaient des copains. C'est peut-être à ce moment-là. J'étais pas comme tout le monde.

It is interesting to observe that even though Louise spent most of her elementary and high school years surrounded by other disabled children, this experience did not help her to identify as disabled.

Some participants remember not wanting to meet and be associated with other disabled people when they were younger. As a child, Marie-Josée expressed a strong reluctance to meet other disabled people, short-statured people in particular. "J'étais très rebelle et je ne me voyais

pas handicapée. Selon ma mère, je voulais rien savoir des personnes de petite taille,” she explains. She still went to an activity organized by the Association québécoise des personnes de petite taille (AQPPT) when she was 10 years old but she did not like the experience. France admits that during the first years following her accident she did not want to be seen with other people using wheelchairs: “J’avais honte. Aujourd’hui là, je regarde ça puis je me dis ‘mon dieu que j’étais superficielle. J’étais handicapée et je jugeais les handicapés’.” I respond that I used to have the same attitude even though I had been disabled since birth. I confess:

J’avais pas de modèle pis moi aussi j’avais ces idées là. [...] Tsé, je n’avais pas d’amis handicapés. À l’université, il y avait le bureau pour les étudiants handicapés où j’allais car il y avait des ordinateurs et des casiers disponibles en tout temps pis je parlais à personne.

In her twenties, Marie-Eve was told that she would be better off with a boyfriend who was also a wheelchair user. That suggestion upset her:

Je n’avais jamais côtoyé des personnes handicapées à part ma meilleure amie que je ne considérais pas comme handicapée même si elle utilisait un fauteuil roulant. [...] Dans ma tête, je n’allais pas avoir un chum handicapé parce que ça ne faisait pas partie de mon réseau.

Marie-Eve’s testimony shows disabled people may not only reject disability identity for themselves but also for other disabled people close to them.

The concept of passing is useful to understand the stories of internalized ableism and the distance that many participants express with disability communities and disability identity. Passing was first associated with black or multiracial Americans being perceived as white (Ginsberg, 1996). Since then, the term “passing” has been used and experienced by members of other minority groups including disabled people (Bednarska, 2006; Brune & Wilson, 2013; Samuels, 2003). Jeffrey A. Brune and Daniel J. Wilson (2013) insist on the complexity of “disability passing” and argue that “it is hard to understand disability and identity in modern America without examining issues of passing.” (p. 1) I would argue that the same is true in Québec and Canada. Brune and Wilson define disability passing as:

the way people conceal social markers of impairment to avoid the stigma of disability and pass as “normal”. However, it also applies to other ways people manage their identities, which can include exaggerating a condition to get some type of benefit or care. Going further, disability passing encompasses the ways that others impose, intentionally or not, a specific disability or non-disability on a person. (p. 1)

Passing can be chosen, imposed by others or even unconscious (Chally, 2010; Chainey, 2014). Even though passing as non-disabled may seem particularly challenging for people with visible disabilities, such as people who use wheelchairs, many visibly disabled people employ that strategy on a regular basis or for specific occasions. “For individuals with such disabilities, passing often meant passing in plain sight. In other words, they had to develop strategies that suggested to others that the individual was not, after all, really disabled,” explain Brune and Wilson (pp. 5–6). However, it should be noted that the success or failure of every attempt to pass relies mostly on other people’s perceptions.

Kimberlyn Leary (1999) raises one of the paradoxes of passing: “It represents a form of self-protection that nevertheless usually disables, and sometimes destroys, the self it means to safeguard.” (p. 85) Even though the ability to pass is not something that is discussed in the Québec disability rights movement, there is certainly an emphasis on disabled people’s abilities, which puts a particular kind of pressure on disabled people. Often, the message of the inclusion discourse is that disabled people are just as able as non-disabled people. There is an impulse to erase disability, as much as possible, from one’s identity and to be a productive citizen. Of course, some disabled people can achieve this more easily than others.

Another reason why disabled people may tend to refrain from identifying as disabled is that once they do, claiming other identities gets harder. James Overboe (2009), a disability and queer scholar, argues that “the category of disability overshadows all other categories that are indexed (such as sex, gender, race, sexual orientation, age).” (p.83) This separates disabled people from the complexities of their identities.

### *The second step: Finding communities*

Because I conducted wheeling interviews with people I have met through my activism in the Montréal disability rights movement, each participant was involved in that movement at some point in their lives. At these particular moments, something about their perspectives on disability changed as well. When and how these turning points occurred, however, varied from one participant to another.

Nabila remembers that she was as young as seven years old when she first realized that she could be discriminated against because of her disability. “On m’a refusé d’intégrer l’école à Alger. Déjà à sept ans, j’ai compris que je pouvais être refusée par la société, mais je n’avais pas

de terme. J'avais pas de terme pour cette situation," she recalls. No other participant described such a memory in their childhood. The obstacles they faced were simply part of their everyday lives. For example, Isabelle argues that she had been aware of accessibility for as long as she could remember. However, she used to think that nothing could be done and she simply had to deal with it. "I guess I always knew that I was different but as a kid you don't really understand to what extent," Sandra says. Most participants' first clear memory of disability discrimination occurred in their young adult life. For Kéven, it happened when he was studying at Université de Sherbrooke in his early twenties. "Je pense que d'être expulsé d'un bus à Sherbrooke a été assez frappant," he remembers.

In most cases, participants explained that their understanding of disability changed not when they first confronted disability discrimination but when they got to meet other disabled people either through their work or their involvement in well-established or emerging disability organizations. When France discovered integrated dance, it quickly became clear that she would need to meet other disabled people to pursue her professional goals. She needed other disabled dancers on stage with her. She states:

Il a fallu que je rencontre d'autres personnes. On dirait qu'au départ tu as honte de ton milieu. Mais après ça, tu te rends compte que d'être en contact avec des personnes handicapées, c'est super enrichissant parce qu'elles te donnent des trucs. Elles te partagent leur vécu. Souvent, tu vis les mêmes angoisses, les mêmes interrogations donc je trouve ça super important. Aujourd'hui, je me fais un devoir. Mes cours sont super inclusifs. Fait que c'est ça, je me fais un devoir d'accepter le plus de monde possible.

Through her dance practice, she discovered and contributed to the development of a disability community that is now part of her life. It was almost by chance that Laurence got a job at the Association québécoise des étudiants ayant des incapacités au post-secondaire (AQEIPS). Through her new job, she developed friendships with some of her disabled co-workers who became her first disabled friends. She confides:

Je réalise que c'est mieux. J'ai encore des ami-es pas en situation de handicap, mais c'est tellement mieux de côtoyer des personnes en situation de handicap. Je me sens moins toute seule. Je me sens moins, comment je pourrais dire ça... Je me sens plus comprise. Tsé, les gens autour de moi ont toujours fait un effort puis ils ont toujours été très compréhensifs. Mais avoir des ami-es en situation de handicap, comme toi, ça fait en sorte qu'ils comprennent naturellement. Tu sens pas qu'ils comprennent, mais que dans le fond, ils comprennent pas vraiment. Je sais pas si tu comprends ce que je veux dire...

“Oui, oui, oui,” I reply nodding my head. Making disabled friends who understand her more easily changed Laurence’s life. It echoes the words of Molly McCully Brown in her op-ed co-written with her friend Susannah Nevison entitled “Explaining Our Bodies, Finding Ourselves.” She writes about her friendship with Susannah, another disabled woman, and about how they understand each other in a way that is impossible to achieve with her non-disabled friends:

When I make my life legible to an able-bodied world, all the nuance, all those contradictions, which aren’t really contradictions, get sucked out of it, somehow. [...] And it hits me all at once that none of this is in translation, none of this is *explaining*. *Legs are the worst*, I say, *I hate them*. And I know she knows I mean it, but that I also mean: *I love them* and *I’m grateful* and *I’m glad you’re here*. I also mean *I’m tired*. And I also mean *thank God*. (Brown & Nevison, 2017)

I ask Laurence if she was uncomfortable when she first met her disabled co-workers, since they were the first disabled people with whom she had established a relationship. She answers:

Oui, il y avait un espèce de malaise au départ. J’étais pas consciente de tous les problèmes que les personnes en situation de handicap vivaient, honnêtement. J’en avais tellement peu côtoyées que ça m’a comme frappé. Au début, quand je travaillais là, je posais des questions à ma collègue qui étaient niaiseuses, mais honnêtement, je ne le savais pas. [...] Je pense qu’il ne faut pas nier les étapes par lesquelles on a besoin de passer. [...] Je pense pas que tu puisses vivre dans un milieu normalisé, comme j’ai vécu, sans avoir quelques prejudices, tsé, même si c’est pas méchant.

When I question Louise about the moment when she started to identify as a disabled woman, she exclaims “Ah mon dieu! C’est une bonne question ça!”. Louise explains that this journey began when she met Maria Barile<sup>83</sup> at a gathering organized by an informal disabled women’s group in Quebec City where she lived at the time. She remembers this moment:

J’ai commencé à réfléchir plus à ma condition de femme handicapée puis quand je suis revenue à Montréal, Maria a repris contact avec moi. Elle m’a embarquée sur le CA d’Action femmes (AFHM). Ça, c’est quand j’ai commencé à m’identifier, je te dirais.

Louise left the board of AFHM in 2004 to focus on other projects. It was during her second mandate as a board member in 2011, that she started to identify as a disabled woman instead of disabled person. She argues that through her involvement in the feminist organization she came to understand key issues: “Je te dirais que c’est un long processus et que c’est Maria qui a réveillé ça.” Isabelle claims that it was through her implication with AFHM and her discovery of

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<sup>83</sup> Maria Barile was a well-known disabled feminist in disabled women’s communities in Québec and Canada. She died in 2013 at the age of 59.

feminism that something shifted. “À partir de là, j’étais plus militante. J’étais dans l’idéologie de revendiquer,” she proudly asserts. Isabelle immediately specifies “C’est sûr que je suis très douce. Je suis moins du genre à me *pitcher* contre les murs et aller bloquer toutes les portes. Je suis moins de ce genre là.” Through her academic work as a doctoral student on the violence experienced by disabled women, she found a way to advocate that fits with her personality. Both Louise and Isabelle argue that through AFHM they found a community that matches their values as disabled women.

Marie-Eve and Pierre have different stories to share. They both claim that even though they have been involved in disability rights organizations as young adults, their understanding of disability as a political issue came much later and happened outside of the mainstream disability rights movement. Pierre explains that despite his keen interest in human rights, that he did not have much knowledge on disability discrimination and other concepts related to critical disability studies. “Jamais, j’avais été sensibilisé pis informé. Ça ne faisait pas partie de moi. [...] C’est comme si on en ignorait l’existence,” he reflects. I add that there was nothing in our high school history classes on the history of disabled people in Québec. “Ah non, c’est sûr! Ben pas compliqué, il ne s’est rien passé au Québec! Ben à moins que tu me dises le contraire. Ben pour moi, il ne s’est pas passé grand-chose là,” Pierre states. I reply that many things have happened in Québec and I gave him the example of the protest against the inaccessibility of the métro in 1988. Pierre argues that our history classes did not cover the second half of the twentieth century in much detail: “Tsé la révolution tranquille, l’arrivée de René Lévesque, le référendum pis voilà! [...] On n’a jamais vraiment eu d’histoire sociale. [...] Les gays et lesbiennes... Tsé, j’ai aucune espèce d’idée de l’héritage du mouvement LGBT au Québec.” Pierre raises an important point discussed previously in this thesis: the literature on the history of disability communities in Montréal and in Québec is scarce and nearly impossible to access for most people. In that context, developing a sense of belonging to communities that history has ignored seems nearly impossible. Pierre remembers that when he was involved in a disability organization in his hometown of Drummondville, he did what he thought was the right thing to do. He did not have a history to ground his values and to anchor his objectives. “C’était beaucoup moins revendicateur, c’était un militantisme *soft* un peu à la Ex Aequo. Après ça, je suis arrivé ici puis je t’ai connue,” he adds. ([see video Lemay-1](#)) In the light of the critical disability knowledge he has gained in the last couple of years on the margins of the “milieu associatif,” he argues that he would certainly have done many things differently. “Ma pensée a évoluée avec tout ça,” he admits.

Like Pierre, Marie-Eve asserts that her initial involvement in a disability rights organization did not contribute much to changing her perspective on disability:

J'aidais les employés à organiser des trucs à l'AQEIPS, mais je sais pas à quel point j'y croyais. [...] Je ne pense pas que j'avais les notions et les outils pour mettre des mots là-dessus. Je défendais une cause pis des acquis, mais sans vraiment avoir les convictions qui viennent avec tsé. ([see video Veilleux-1](#))

“C'est à quel moment que ça a changé?”, I ask Marie-Eve, even though I already have an idea of what her answer would be. “Quand je t'ai connue,” she laughs. “Ok, ok, plus impersonnel... Quand j'ai connu le RAPLIQ,”<sup>84</sup> she specifies. She remembers that she had participated in an action organized by RAPLIQ for accessible terraces, in addition to taking part in the Journée de l'Accessibilité on Mont-Royal Avenue and Masson Street (RAPLIQ, 2010a). “Et ensuite tu m'as ajoutée sur Facebook,” she recaps, laughing again. She explains that learning about the social model of disability and different anti-ableist discourses radically changed her understanding of disability. She states:

J'ai besoin d'avoir une raison logique pour croire à des trucs. J'ai besoin que ça soit logique sinon je doute tout le temps tsé. J'ai besoin de preuves. Je ne sais pas si je suis trop scientifique, mais j'ai besoin de preuves. Pour moi, ça m'a donné comme cette espèce d'assise théorique [...] pour vraiment arrêter de penser que c'est moi qui a un problème. ([see video Veilleux-1](#))

Marie-Eve became more critical towards the “milieu associatif” because she did not feel that they had a critical perspective on disability issues. Aside from her involvement with RAPLIQ until 2014, Marie-Eve did not feel a strong connection with these mainstream disability organizations. She did not feel like a part of this community even though she would take part in some events from time to time. Marie-Eve argues that she now feels closer to online disability communities that are engaged in the fight against ableism. Many of these communities are English-speaking and have roots in the United States. Marie-Eve is not the only participant who has shown a lack of interest in and disconnection from Montréal disability rights organizations. Amongst the eight participants under the age of 35 at the time of the interviews, six are not part of a mainstream disability rights organization. This echoes Didier Gysler and Benoit Racette's study (2015), as mentioned in Chapter 3, on the low representation of young disabled people in the Montréal's disability rights movement.

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<sup>84</sup> I am one of RAPLIQ's co-founders. I was the RAPLIQ vice-president between 2009, when the organization was founded, and 2014.

Some participants have indicated that disability advocacy, which is at the heart of Montréal disability communities, is exhausting. As seen in Chapter 4, the *Construction Code* and Québec's disability legislation contain numerous flaws, which force disabled people to file human rights complaints and get involved in disability advocacy. Nabila states that she should complain more often when she encounters discrimination and obstacles. However, she simply does not have the time and energy to do it. She explains:

Ça prend de l'énergie. Ça prend du temps parce qu'on peut passer une journée à rédiger une plainte. Il ne faut pas tomber dans le piège de la diffamation. Il faut raconter les faits tels qu'ils étaient, se rappeler des mots. Des fois, le jour où l'évènement s'est passé, on n'est pas prêts pour écrire la plainte. Il faut l'écrire deux ou trois jours après. [...] On vit la frustration deux fois. Au moment où ça se passe et au moment de la rédiger. Il m'est déjà arrivé plusieurs fois de pleurer, et je dis bien pleurer, c'est-à-dire des larmes versées, quand je parle d'un problème que j'ai vécu. Donc ça, c'est pas facile. Pis, on doit subir l'enquête. On doit subir d'autres confrontations. On doit subir tout ça. C'est l'énergie qui nous manque. L'énergie gaspillée pour rien.

Geneviève explains that she regularly feels torn between pointing out obstacles and demanding better access and not saying anything to avoid dismissive answers that will ruin her day. She adds:

Ça dépend de l'humeur. Des fois tu dis « Ah, il faut changer le monde. Il faut leur dire ». [...] J'ai aussi autre chose à faire dans ma journée. J'aimerais ça profiter de la vie. Être encore contente dans une heure tsé. Parce que souvent on a des réponses frustrantes. Des gens qui disent « Ah, mais ça arrive jamais. Ah, les autres ils s'arrangent eux. »

France also admits that she tries to avoid inaccessible places and obstacles most of the time. “À un moment donné, j'ai envie d'être positive dans ma tête,” she admits before telling me that she could not be an activist “like me.” All these negative feelings towards the burden of being an advocate on a daily basis can certainly complicate the sense of belonging that disabled people feel for Montréal disability communities.

Marie-Josée's and Nabila's testimonies powerfully demonstrate that obstacles on the road to disability belonging are not limited to internalized ableism—an absence of other disabled people in people's networks and a scarcity of resources to think critically about disability are equally important. Both women also mention the discrimination they face in disability and Deaf communities. Once again, the concept of intersectionality (Crenshaw, 1991) helps to comprehend how different systems of oppression intersect and complicate what it means to belong to disability communities. At the very end of the wheeling interview, Nabila and I stop on a quiet

sidewalk in the Town of Mont-Royal to talk face-to-face and slowly dismantle the filming equipment. We reflect on the interview and we both tell each other how much we had appreciated our afternoon together. We are about to wrap up when she reveals, “Je vais te faire une confidence, mais que tu peux publier. Je veux partager quelque chose avec toi,” she insists. She confides:

Récemment, j’ai intégré le CA du RAPLIQ pour défendre justement l’AU [accessibilité universelle]. Donc, je suis sensée me battre et combattre pour ça, mais au fond de moi je me dis « et si jamais un jour, je rencontrais une personne qui me dit: pourquoi tu te bats alors que c’est pas ton pays? C’est pas ta ville! Va te battre chez toi au lieu de nous enquiquiner avec ces problèmes! » Et crois-moi, depuis que je suis au CA et que je dois défendre les mêmes causes [...] et le faire à haute voix, je crains ce moment-là. On me voit avec un foulard. Ça veut dire ce que ça veut dire. Je viens d’ailleurs. Je ne fais pas partie de cette société. Et je crains le pire.

Nabila laughs, not because what she is sharing was funny, but because she is overwhelmed by the Islamophobia she faces in her everyday life and she knows that I am an ally. Her confidence touches me but her experience does not surprise me. Through my involvement in the Montréal disability rights movement, I have witnessed various manifestations of racism and Islamophobia, in particular. Nabila adds, “C’est comme si parce que je suis étrangère, je n’ai pas le droit de défendre mes droits.” I ask her if she has had to deal with racist comments since joining the RAPLIQ board. “Non. C’est juste une crainte. C’est juste une crainte parce que tout ce qu’on a vécu avec cette histoire de Charte,<sup>85</sup> on craint le pire. Sincèrement, on craint le pire,” she explains with sorrow.

Marie-Josée has talked about the obstacles and discrimination she faces in different disability and Deaf communities. As a young adult, she started returning to activities that are organized by the Association québécoise des personnes de petite taille (AQPPT). Contrary to her first experience when she was 10, she is now interested in meeting other short-statured people. She has started to get involved in the organization. However, she says that she quickly became disenchanted because other members, who were all hearing, never took her hearing impairment into consideration. Their audist attitudes have prevented her from participating and feeling like she belongs to this community. For many years, she has ceased all involvement with AQPPT. She has attended some activities and has tried to get involved but is often disappointed. In

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<sup>85</sup> Charter of Quebec Values (French: Charte de la laïcité or Charte des valeurs québécoises).

parallel, as a new resident of La Maison des Sourds,<sup>86</sup> she has tried to connect with her Deaf neighbours and be part of this community. However, she has been met with discriminatory attitudes towards her physical disability. Many of her Deaf neighbours infantilize and pity her. She argues that they are not used to interacting with physically disabled people and, in particular, short-statured people. Despite her longing for a sense of belonging with Deaf and disabled people, Marie-Josée finds herself in-between two communities. She faces audism in the disability community and ableism in the Deaf community. Sandra also highlights a communication barrier that limits her involvement in disability communities. As mentioned in Chapter 2, Sandra notes that many disability organisations operate solely in French, making them inaccessible to her as an Anglophone.

Participants' stories clearly show that there are several obstacles on the way to identifying as disabled and belonging to disability communities in the context of Montréal. One of the main observations is that participants do not have access to the stories that are told by disabled people, particularly stories that challenge disability stereotypes and hegemonic discourses on disabled people's lives. Building on the work of Francesca Polletta (1998) on the role of narratives in mobilizing students across the United States during the 1960s, Ravi Malhotra and Morgan Rowe (2013) argue that subversive stories contribute to the emergence of collective identities. Fiona Kumari Campbell (2008) claims that "[u]nlike other minority groups, disabled people have had fewer opportunities to develop a collective consciousness, identity or culture, let alone interrogate cultures of ableism." Rosemarie Garland-Thomson (2016) argues that most non-disabled people do not see disabled people as a group with a "shared social identity and a political status". Marie-Josée's and Nabila's testimonies in particular bring attention to the fact that disabled people's access to belonging is differential, even in communities where they should, in theory, be more than welcomed. "Becoming disabled" (Garland-Thomson, 2016) and finding disability communities are experiences that are therefore not equally accessible to all disabled people and are highly subjective. The paths taken to get there vary greatly as do participants' perspectives on disability. This underscores the profoundly situational context of belonging. While some participants explain that it is through meeting other disabled people in a disability rights organization that has shifted their perspective on disability, giving them a community of people

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<sup>86</sup> The Maison des Sourds was inaugurated in 2012. All residents are either Deaf, hard-of-hearing or Deaf-blind.

with similar concerns and values, others claim to have had this experience outside the mainstream disability rights movement.

*Disability pride: An ingredient to cultivate a sense of belonging*

Several authors argue that identifying as disabled and belonging to disability communities contribute to the development of disability pride (Brown, 2015; Garland-Thomson, 2016; Linton, 1998). Psychologists Kathleen R. Bogart, Emily M. Lund and Adena Rottenstein (2017) claim that disability pride protects disabled people's self-esteem against stigma. Many cities across the United States host annual disability pride celebrations. In Canada, Toronto will host its seventh edition in 2017. Disabled writer and radical justice activist Lydia X. Z. Brown (2014) writes:

The concept of disability pride, which has existed for decades in an organized fashion, is revolutionary in its biting response to the paternalism and discursive constructions of disability popular in our society. The idea that people with deformities, people with visible physical disabilities, and people with neurological or mental disabilities are capable not merely of accepting themselves but of publicly proclaiming their pride in being disabled is anathema to a society in which deviation and divergence from neurological and physical typicality is labeled pathology and defect. (Brown, 2014, pp. 42–43)

On the subject of disability culture and disability pride, disability ethicist and psychologist Carol Gill states:

A disability culture movement can foster disability pride. It promotes pride in us; it allows us to project a positive image to the public. We renew each other and our strength through shared experiences and rituals. If we express our culture in some unified way, we're signaling; we're communicating what our values, goals, and identity are. Through our culture we can recruit people. When we present a strong image, it motivates people to want to belong. They want to be part of something that powerful. (Johnson, 1987, p. 4)

There are numerous manifestations of disability pride on social media. A tweet from queer, disabled and Latina/x YouTuber, activist and artist Annie Segarra (@annieelainey) captures the impact that disability community and disability pride can have in disabled people's lives: "When I started losing abilities & quality of health thanks to #EDS<sup>87</sup>, disabled community, #cripplepunk, & #disabilitypride were there to catch me." (annieelainey, 2018) Following the death of world-renowned scientist Stephen Hawking, disabled people reacted to the ableist media coverage that claimed Hawking was finally free from his disability and that all disabled people desire to no longer be disabled. Many people used the hashtag #Ilovedmydisability to explain why they are

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<sup>87</sup> EDS stands for Ehlers-Danlos syndrome.

proud of who they are, and that disability is part of their identity even though being disabled can be difficult at times due to chronic pain, persistent stigma, and systemic discrimination. In Québec, I was only able to find one tweet critiquing the idea that Hawking was finally liberated from his disabled body. Kéven Breton (@kevenbreton) wrote:

#StephenHawking ne croyait pas en Dieu et encore moins aux miracles chrétiens. Il était un scientifique, un scientifique en fauteuil roulant. Maladroit de lui « rendre hommage » ainsi, en l'imaginant se débarrasser d'une partie de son identité grâce à une intervention divine. (kevenbreton, 2018)

Even though Breton's tweet is not necessarily a bold statement on disability pride, it must be understood as a critique of the discourse on disability in Québec.

During the wheeling interviews, discussions on disability identity and belonging to disability communities did not lead to explicit discussions on disability pride. Many factors can explain this situation. Garland-Thomson argues that “always overdetermined metaphoric uses of disability efface and distort the lived experience of people with disabilities, evacuating the political significances of our lives and mitigating the influence of disability culture.” (2005, p. 1565) In this context, telling stories that go against mainstream narratives and embrace disability pride is extremely difficult. Furthermore, as a community insider and a disabled woman myself, I know that the concepts of disability pride and disability culture are not developed in Québec. I have never heard even the idea of “fierté handicapée” in my mother tongue. A few months after the interviews, I had an exchange with Jacynthe on Facebook Messenger about disability language and identity. She told me that, unlike me, she does not like to be identified as “personne handicapée” and much prefers “personne à mobilité réduite” and “personne en situation de handicap.” She admitted: “À un moment donné, ça va peut-être changer. Genre, quand la société va arrêter de m'envoyer comme message que je vauz rien. Mais j'ai ben de la misère. J'admire les gens à l'aise avec l'étiquette et l'identité, même la fierté. Je suis vraiment loin de ça. ☹.” I replied that I have learned to be proud, not in Montréal, but mostly through my involvement in Anglophone disability communities online and outside of Québec.

Of course, this does not mean that disability pride does not exist in Montréal. The seeds of disability pride are certainly there. For example, I think about Caroline who proudly introduced me to the apartment building where she lives by asserting “Tu vas trouver ça vraiment génial! C'est une place qui est ben accessible pour les personnes en fauteuil roulant parce qu'on est tout une gang d'handicapés!” As I mentioned in Chapter 3, online disability activism also holds great

promise. Virtual platforms offer spaces for new ways of doing disability activism and fostering a sense of belonging among disabled Montrealers. I will now continue this exploration of belonging by turning my attention to participants' sense of belonging in the city. Were they facing similar struggles to belong in Montréal?

### ***Belonging in the city***

*Au cours des dernières années, j'ai eu la chance de visiter de nombreuses villes au Canada, aux États-Unis et en Europe. À quelques exceptions près, ces villes étaient plus accessibles que Montréal en termes d'aménagements urbains, commerces et transports en commun.*

*Au cours des dernières années, à chaque fois que l'avion dans lequel je suis assise s'apprête à poser les roues sur la piste de l'aéroport à Dorval, deux émotions m'envahissent. D'abord, le bonheur de revenir à la maison et de voir la ville vue du ciel. Montréal est tellement belle.*

*Et ensuite, le goût amer de retrouver la ville où le capacitisme a la vie trop facile.*

—February 20, 2018

I am starting this exploration of participants' sense of belonging in the city with a concept initially developed by Henri Lefebvre: the right to participate. It is a right to be included in the decision-making processes that are at the heart of the production of urban space (Lefebvre, 1968). For Lefebvre, the right to participate is central to the right to the city. "Here belonging is about being involved in decision-making, it is about the territorialization and appropriation of space by being involved in designing it," writes Tovi Fenster (2005, p. 228). For example, participating in a public consultation on an important urban planning issue is one way for an individual to exercise their right to participate. However, as argued by Fenster, this right is not equally accessible to everyone—power relations shape it. Building on Iris Marion Young's work (1998), she explains:

Reality shows that in many cases where "the public" is involved, women, blacks or other people of colour, working-class people and poor people tend to participate less and have their interests represented less than white, middle-class professionals and men (Young, 1998). This is so, argues Young (1998), when participatory democratic structures define citizenship in universalistic and unified terms. They then tend to reproduce existing group oppression, what Young calls: 'the paradox of democracy' by which social powers make some people more powerful citizens than others (Young, 1998). (Fenster, 2005, pp. 226–227)

This is also true for disabled people who are still in the margins of decision-making

spheres. Article 29 of the *United Nations Convention on the Rights of Persons with Disabilities* stipulates that disabled people should be able to fully participate in political and public life. In its first report under the Convention, the Government of Canada simply has indicated that disabled people aged 18 years or older have “the right to vote in elections and the right to run for public office, on equal basis with others” (2014, p. 14) and that “Elections Canada is implementing measures to reduce or eliminate barriers when voting.” (*Ibid.*) This is a narrow, restricted understanding of political and public life and of citizenship.

Unfortunately, disabled people’s participation in political and public life is not well documented in Québec. Even though Québec’s policy *À part entière* aims to foster the social participation of disabled people, I have not been able to find any substantial information on their involvement in political, public or cultural life.<sup>88</sup> Research conducted among 143 disabled Montrealers between the ages of 18 and 35 found that two out of three youths would like to be more involved in social and political life (Gysler and Racette, 2015, p. 34). Considering the scarcity of data on this key issue, participants’ testimonies about their experiences in decision-making processes are particularly valuable.

Since 2002, the Ville de Montréal has been working in close collaboration and partnership with a few Montréal disability rights organizations reunited in the Comité des partenaires en accessibilité universelle (Ville de Montréal, n.d.). These organizations have been identified as “partenaires ville”. As explained in Chapter 3, this advocacy approach has been the only method validated within the movement. In order to participate in the city’s consultations on accessibility and disability, you must represent one of these organizations. A similar approach is used at the Société de transport de Montréal (STM). In 2012, the STM created a committee composed of

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<sup>88</sup> I contacted the Office des personnes handicapées du Québec in the hope of finding more information. I was informed that there was indeed a lack of data on the participation of disabled people in political and public life in Québec. They sent me a report written in 2007 entitled *La participation sociale des personnes handicapées au Québec: la vie communautaire*. There is a short section on the “exercice de certains droits politiques” (p. 51). The report indicates that disabled people are more likely to speak in public than their non-disabled counterparts. However, it also states that they are less likely to sign petitions or boycott a product. I must admit that I do not consider these findings to be relevant for my research for different reasons. These findings do not consider the obstacles disabled people may encounter when participating in political and public life even though these obstacles are important (i.e., inaccessible meeting places, lack of transportation, sign language interpreters not being available, a lack of consultation documents in alternative formats). Furthermore, I do not consider petitions and boycotts as significant parts of decision-making processes on urban issues.

representatives of more or less the same organizations. This committee is the STM's only community partner on issues related to accessibility. I have not been able to find anything about the STM's accessibility consultations that is open to the public. In addition to solely including members of a limited number of disability organisations—exclusively French-speaking organizations, I should add—these partnerships rarely make public the information about the work they do.<sup>89</sup> Furthermore, without an online presence and a more open process for getting involved, these committees are simply out of reach to the majority of disabled Montrealers. Even though Marie-Eve is highly interested and involved in disability and urban issues, she tells me that she is not aware of most of these consultations: “Elles ne sont généralement pas ouvertes au public et il est très difficile de savoir ce qui se passe. Pourtant, j’aimerais être consultée et prendre part à ces discussions.” According to Pierre Majeau, who has been a very active activist in the 1980s, unlike the period when disability organizations used to make a great deal of noise by organizing protests and occupying government offices, it is now difficult to know what disability rights leaders are doing to be heard by politicians and government officials. He explains:

La question que je me pose, je vais être très honnête avec vous: est-ce que ça se fait encore? Et qu'est-ce que ça fait? Je sais qu'il y a des gens qui travaillent là, mais qu'est-ce qu'ils font? Est-ce qu'ils préparent des mémoires? Ils font du lobbying à l'intérieur, probablement, mais je ne suis pas capable de répondre à ça. [...] Mais ça dépend de la vision des leaders des mouvements aussi. Si tu ne veux pas trop de mobilisation... Tu veux plus une sorte de petit groupe de lobbying qui fait ses petites affaires par en-dessous, tu vas t'orienter vers un groupe de lobbying qui fait des représentations de l'intérieur, mais qui prend très rarement des positions publiques? (Fougeyrollas, Boucher & Grenier, 2018, p. 166)

Pierre (Lemay) would like to be involved with the Regroupement des usagers du transport adapté et accessible de Montréal (RUTA), one organization working in partnership with the STM, because inaccessible public transit has a major impact on his everyday life. To this day, Pierre's involvement with RUTA has not been possible. Pierre explains why:

Je leur ai demandé s'ils pouvaient tenir leur assemblée générale annuelle le soir ou un jour de fin de semaine. Ils m'ont dit que ce n'était pas possible. À chaque année, c'est comme ça. De plus, leurs réunions de travail ont lieu les jours de semaine. Je ne peux donc pas joindre leur CA car je travaille les jours de semaine.

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<sup>89</sup> For example, I only recently learned about the existence of the Comité consultatif en accessibilité universelle at the Ville de Montréal through my new role at the Société de transport de Montréal. The committee works on issues related to urban planning and transportation. Just the mere existence of this committee is not information that is made available to the public.

The accessibility of non-disability-specific public consultations is also an issue. The Ville de Montréal and its boroughs regularly consult Montrealers on various issues. The philosophy behind this is to bring politics closer to people's everyday life and to create a "ville à l'échelle humaine" (Gehl, 2012). One recurrent issue is the lack of information about the accessibility of these consultations. Will the location be wheelchair-accessible? Will there be sign language interpreters? Is the consultation documentation accessible to people using screen readers? These are questions left unanswered far too often.

In July 2017, Promenade Masson, which is a non-profit organization of business owners on Masson Street, launched a public consultation on a new urban design for this popular commercial avenue of Rosemont–La Petite-Patrie. The organizers invited citizens to come and see three proposals so that they would be able to vote on their favourite one. However, there was no accessibility information about the location where the proposals were being presented. Marie-Eve, who resides a block away from Masson Street, reached out to the organizers. They did not tell her whether the location was accessible and they told her she could vote online (Promenade Masson, 2017). During a conversation on Gmail chat, she shared her disappointment with me:

J'ai vraiment été déçue. On habite le quartier depuis un an. On va souvent sur Masson. On prend part aux activités du coin. On a exactement le même profil que les gens qui veulent participer à la vie de la Promenade Masson, mais on ne nous inclut pas dans la consultation. La première rencontre pour proposer des idées s'est faite dans le sous-sol de la librairie, que je présume comme étant inaccessible. [...] Comment est-ce que les personnes handicapées peuvent être incluses dans la planification si on les exclut des consultations et de la planification. On s'en lave les mains en disant qu'elles peuvent voter, mais c'est pas assez!<sup>90</sup>

This was far from being the first time Marie-Eve encountered inaccessible public consultations or activities whose aim was to promote local democracy and civic participation.

In other instances, even though disabled people are not explicitly left out of the consultations, the questions are designed in a way that overlooks disability and accessibility issues. This opens the door for the erasure of disabled people's perspectives. For example, in March 2018, the Conseil jeunesse de Montréal, which advises Montréal's mayor and executive committee on issues relating to youths, invited people between the ages of 17 to 30 to fill out an online survey about their mobility needs. The goal was to make recommendations to the city. Even though disabled youths who had access to the Internet and the ability to fill out the survey

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<sup>90</sup> We had this conversation on July 25, 2017.

could participate, none of the questions specifically sought their input. There was no way for respondents to indicate if they were disabled. Furthermore, Transport adapté was not included in the long list of modes of transportation, and there were no questions on accessibility issues.<sup>91</sup>

The marginalization of disabled people in political and public life cannot be separated from the fact that they are poorly represented among elected officials and in Québec's media and popular culture. Among the 103 people who were elected during the Montréal 2017 municipal elections, only one self-identified as disabled (Ville de Montréal, 2017c). To date, there is no programme to support disabled candidates in campaigning. The recruitment of disabled candidates is still not on the agenda of most political parties. It is also interesting to note that, since its foundation in 1978, the Office des personnes handicapées du Québec, the government's office for disability issues, has never been led by a disabled person. This situation has never caused a public outcry and continues to be largely accepted. In media and popular culture, ableist representations and an absence of disabled people are striking (Breton, 2015b; Breton, 2016a; Breton, 2016b; El Kouri, 2016; Louw, 2016; Parent, 2012b; Parent & Veilleux, 2015; Pomerleau, 2015; Pratka, 2016; Rouleau, 2016).

As I mentioned in the introduction, when Montréal celebrated its 375<sup>th</sup> anniversary, the contributions of disabled people to the city's history were nowhere to be found. Disabled Montrealers were also absent from the promotional campaign produced for the festivities. One video in particular, which featured Québec artists, attracted media attention. The video only included white able-bodied people. "Con, stupide," commented Denis Coderre, the mayor of Montréal at that time (Normandin, 2017). Due to the critiques of numerous artists, journalists and politicians, the organizers of the 375<sup>th</sup> anniversary had no other choice but to apologize and make a new video, which included people of colour the second time around. The erasure of disabled people, however, stayed under the radar and was perpetuated in the second video as well. Québec's television dramas are not doing any better. The rare disabled characters are usually

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<sup>91</sup> I contacted the Conseil jeunesse de Montréal to let them know about this situation. They apologized and promised to remedy the situation in the future. They asked me if I had statistics on the mobility of young Montrealers with disabilities, as they could not find any. In my role of Transport adapté representative on the Société de transport de Montréal's board, I got the latest statistics on Transport adapté's users and found out that there was no data specifically on disabled youth.

played by non-disabled actors. Furthermore, the storylines around these characters are not about the injustices they live but about the burden they represent for their families.<sup>92</sup>

I would argue that one of the reasons why ableism in Québec's media and popular culture generally goes unchallenged is because there is still no disabled journalist in the mainstream media or a public figure familiar with ableism. Aware of the need for more diversity within its own ranks, in March 2018 *La Presse*, one of the largest Québec's newspapers, launched a scholarship to support new journalists from marginalized communities. The call for applications reads: "Notre salle de rédaction doit englober une multitude de cultures, de groupes ethnoculturels et linguistiques, de genres, d'orientations sexuelles, de groupes d'âge et de religions." (La Presse, 2018. Disabled people are not identified as a marginalized group to be included in representing Québec's diversity. This is something I have seen countless times. Jacynthe perfectly summarizes the absence of disabled people in the discourses on diversity in Québec's media and culture: "Le handicap c'est dans l'angle mort de la diversité au Québec." Kéven notes a difference between Anglophone and Francophone media coverage on disability issues: "For some reason, the French-language media in Québec seem to see accessibility as a charity issue, whereas in the English-speaking world, especially in the United States, it's seen as a human rights issue." (Pratka, 2016) Considering all of the obstacles faced by disabled Montrealers throughout the city as well as their marginalization from political, public and media spheres, it is not an exaggeration to claim that their right to participate in decision-making processes is highly compromised.

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<sup>92</sup> During the winter of 2018, I watched three popular drama shows on Radio-Canada. *District 31*, *Hubert et Fanny* and *Ruptures* all shared a common feature: they had one disabled character that promoted ableist storylines. Non-disabled actors played these characters. Two of them had completely silent roles and were bed-ridden. Two of them lived in institutions, and that was portrayed as being normal. One of them died. One of them was seeking to die through medical euthanasia. All of them were burdens on their families. In *District 31*, the disabled character was the reason why his non-disabled brother was single. Taking care of his disabled brother, who lived in an institution, apparently prevented the non-disabled character from having a partner. In *Hubert et Fanny*, the disabled character caused the divorce of his parents and compromised the childhood of his brother. His brother even chose to get a vasectomy to make sure he would never have a disabled child. This storyline is ridiculous: the character's disability was cerebral palsy, which is a non-genetic condition. In *Ruptures*, the disabled character, a married woman in her forties with a degenerative disease, could not sexually satisfy her husband. Even though he cheated on his wife, he was portrayed as a good man because he was caring for her.

### *Te sens-tu Montréalaise?*

When Louise moved to Montréal as a young adult, she was afraid to go to certain places and do certain things, such as riding the métro. She argues that her fear came from the fact that she did not know anyone in the city. She reflects:

Être toute seule dans une ville, ça marche pas. Fait que ça grossit tes peurs. Mais maintenant, je connais des gens. Il y a du monde dans ma vie. Je suis beaucoup mieux à Montréal. Fait que j'ai moins peur. Je relie ça au fait d'être dans des bonnes ou moins bonnes conditions de vie.

“Te sens-tu Montréalaise maintenant?”, I ask her. “Oui, je pense oui. Je trouve que ma vie est à Montréal maintenant,” she answers. “C’est beaucoup Christian. C’est un vrai Montréalais. Il m’a beaucoup fait connaître la ville,” she specifies. When I ask the same question to Geneviève, I get a much different answer. Geneviève confides that when she travels internationally, she is proud to tell people that she comes from Montréal notably because it is the largest French-speaking city in the Americas. Her statement, however, is quickly followed by a “sauf que.” As mentioned in the previous chapter, Geneviève draws a relationship between the mode of transportation she uses, the places she goes and her sense of belonging to and in Montréal. She explains that because she mostly gets around by car, due to the inaccessibility of the métro, she is unfamiliar with many parts of the city and often feels disconnected from it:

Tu traverses vite pis tu crées pas de liens quand tu rentres pas dans les places. Tu t’en vas à une place pis c’est ça. Il y a plein de places que je suis jamais allée, que je suis jamais rentrée, que je sais pas c’est où parce que je rentres. ([see video Vanier-3](#))

Geneviève argues that even though she has lived in Montréal for a long time, she cannot really recommend restaurants to people visiting Montréal. “Je sors pas si souvent là. Je peux t’en suggérer deux ou trois, mais ça veut pas dire que ce sont les meilleurs. Ce sont ceux où je peux rentrer. [...] Tsé, il y a des places cool branchées où je vais pas parce c’est pas accessible,” she admits. She explains that she has paid more for a house located in Rosemont–La Petite-Patrie, a lively neighbourhood with a lot of services, but has ended up not being able to use most of them. Geneviève has tried to find solutions to get around her neighbourhood more easily. “Je me disais, je sais pas je profite pas assez d’être dehors pis me promener. [...] On devrait peut-être plus le faire pis peut-être qu’on serait plus heureux de vivre ici,” she says. She has bought a manual hand-cycle that she can attach to her wheelchair to navigate uneven sidewalks. However, as our stroll together clearly demonstrates, the task of manoeuvring around obstacles is still extremely difficult and physically exhausting.

Since our wheeling interview was recorded, Geneviève has given birth to a baby girl. Going for walks as a new mom, she is finding, is nearly impossible. She borrowed my motorized hand-cycle to try it with her daughter. Even though she found that it worked well, she initially decided not to buy one because of the expensive price.<sup>93</sup> A few months later, she bought one—being able to get around her neighbourhood with her daughter is not a luxury but a necessity. Geneviève also talks about other frustrations that she has experienced since buying a house in Rosemont–La Petite-Patrie. The City has refused to lower the sidewalk in front of her house to give her access to her car and denied her request to build a ramp on her property, claiming that the ramp would not conform to accessibility regulations. Because the city has denied her request, she cannot get in her house through the front door.

She has noted that suburbs similar to where her parents live would be more accessible. “C’est plus neuf les trottoirs. Tu as ton terrain. Tu t’arranges avec ton terrain. [...] Tu mets ton auto comme tu veux,” she argues. Her parents, who see her struggling with these multiple obstacles, think that she should move to the suburbs to make her life easier. However, Geneviève explains that she is not interested in living in the suburbs. I asked her if she could consider leaving Montréal for another city outside of Québec. She says that she had thought about it and could easily imagine herself living in the European cities she had visited but she chose to stay in Montréal because she is close with her family. “Il y a des places où ça pourrait être plus accessible, plus facile,” she says as she remembers how much she enjoyed being able to get around certain European cities by wheeling and using public transit. When she was living in Prague for an internship, people would often apologize for lack of access and help her navigate steps and stairs. It was a strange feeling for her: she was able to access some of Prague’s metro stations, while the Montréal métro was still fully inaccessible at that time. “Ils se sentent comme en retard,” she explains about Prague’s inhabitants, their apologies and their willingness to assist her.

In Montréal, her experiences are completely different. The lack of access is normalized, and many people prefer to make up excuses for it:

À un moment donné, faut qu’on arrête de se trouver des raisons de ne pas le faire. Faut qu’on se dise que oui c’est à faire pis qu’on avoue qu’on est pas parfaits, que ça pourrait être mieux. Qu’on prenne action. J’ai l’impression souvent que les gens disent que si tu es en fauteuil, c’est normal que tu ne puisses pas aller quelque part. ([see video Vanier-2](#))

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<sup>93</sup> The new model costs \$2,395 USD.

“Montréal n’est pas une terre d’accueil sympathique,” she sums up. It is interesting to note that Geneviève uses the concept of “terre d’accueil,” which is generally reserved for discussions about immigration, even though she was born and raised in the region of Montréal.

Geneviève’s testimony is powerful: it highlights some of the complexities of belonging in an ableist city for a disabled person and how belonging is influenced by one’s own multiple, conflicting positionalities. First, as a French-speaking Montrealer, she clearly expresses her pride in being able to say that she comes from a Francophone city when she visits other countries. However, she also points to the paradox of feeling like a stranger in the city she calls home and at the same time feeling proud of it when travelling overseas. Furthermore, she clearly insists on the importance of being able to “walk” a neighbourhood to feel like a part of it. Not being able to do so has had negative impacts on her mental health, and these feelings of disconnection have real impacts in her everyday life. Geneviève explains that the inaccessibility of the neighbourhood and the immediate environment around her house has led her to question her choice of residence as she admits to feeling trapped at home at times. In other words, her borough’s ableist planning practices not only affect her ability to get around her neighbourhood but also her ability to get in and out of her own home.<sup>94</sup> This echoes Tovi Fenster’s (2005) critique of the right to the city developed by Henri Lefebvre (1968)—public and private spaces, like the home, should not be thought of separately: “the right to use public spaces and the right to participate in decision-making must begin at the home scale.” (Fenster, 2005, p. 220) She writes:

By isolating the discussion on the right to the city from the right to the home Lefebvre creates a rather neutral ‘public’ domain which is sterilized from any power relations and by that has no relevance to the realities of many women in cities. (p. 221)

Like Geneviève, France has travelled extensively. When she visits cities that are more accessible than Montréal, coming back home is hard. “Quand je reviens de voyage, je suis vraiment frustrée,” she says without hesitation. France recounts her experience during a trip to Athens: “Je parle même pas la langue pis les gens ils venaient me voir pis ils me montraient les

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<sup>94</sup> Having access to affordable and accessible housing as well as appropriate home support services are among the biggest issues faced by disabled Montrealers (Caron, 2018; Robichaud, 2017). These issues did not come up much throughout the interviews. This can be explained by the location of the interviews (outdoors), the short duration of the interviews, my interests in urban mobility and accessibility in the city, and the privileges that many of the participants and I shared in terms of financial means and abilities.

pancartes où étaient les ascenseurs pour me diriger.” The frustrations she experiences every time she comes back to Montréal quickly lessen as she gets back to her everyday activities:

J’essaie de me concentrer sur les endroits où je peux aller et non frustrer sur les endroits où je ne peux pas aller parce que c’est pas accessible. Parce qu’à un moment donné, j’ai envie d’être positive dans ma tête.

For France, mobility means not using public transit due to its poor accessibility and the risks of being stranded at a bus stop and getting around the city either by using her car or wheeling with her wheelchair.

Marie-Eve confides that she feels like a sense of belonging to Montréal is out of reach. She argues that she simply cannot belong to the city in the same way that other non-disabled Montrealers do, because there are too many places she cannot go and because she does not see herself represented in the city’s images and institutions. “Je pense qu’on y pense pas trop. On est résilients à la place,” she says about disabled people’s sense of belonging to Montréal. In August 2016, Marie-Eve took a trip to Seattle with her boyfriend and his family. She told me how much she enjoyed being able to get around easily by using public transit and having access to most restaurants and stores. During a conversation on Facebook Messenger, I asked her if coming back to Montréal was hard. She replied:

Autant j’ai de la colère à chaque fois que je vois une place inaccessible... Je me vois vraiment pas ailleurs qu’à Montréal et j’étais hyper contente de revenir pareil. Parce que revenir, c’est reprendre ma routine, dormir dans mon lit, manger de la bouffe que j’aime et fréquenter les endroits accessibles que je fréquente... Je me suis pas imaginée plus heureuse à Seattle.<sup>95</sup>

Marie-Eve’s testimony shows that it is possible to feel at home in a city where you do not feel like you belong.

Marie-Eve’s boyfriend, Pierre, has a different perspective to share. It is important to remember that they both use motorized wheelchairs to get around and spend most of their time outside work together. Pierre remembers how much he loved visiting Montréal when he was a child. “Montréal ça toujours été festif! Tsé, la grande sortie!”, he says. Somehow, he always knew he wanted to move to Montréal. He explains:

J’ai toujours su que j’étais quelqu’un d’action pis j’aimais ça quand ça bouge. Je veux faire des choses pis tout le kit. Je veux voir des spectacles. Faire çï, faire ça. Écoute, dès tout

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<sup>95</sup> We had this conversation on August 24, 2017.

jeune, c'est la première chose que je t'aurais dite. « Quand je vais être grand, je veux vivre à Montréal. » Fait que c'est clair que je ne sortirais pu, tsé. [...] Je suis vraiment un montréalais. J'ai vraiment adopté Montréal bien avant que j'y arrive, tsé.

I ask Pierre if he could talk about a moment in particular when he felt deeply connected to the city. He responds:

Juste aujourd'hui, il me semble que de faire ça, c'est génial. Écoute, se promener en ville. Tu passes dans des commerces. Tu t'en vas dans un bout de piste cyclable, un bout de commerces, un bout dans un marché. Je trouve ça fantastique. Super le fun. Moi j'adore ça. Il me semble... Qu'est-ce que tu veux demander de plus? Non? Malgré tous les obstacles qu'on a eus depuis qu'on est partis, pis tout ça, moi je me sens quand même bien dans ma bulle, tsé. Je me sens partie prenante pis tout ça.

Pierre's deep attachment to Montréal makes me ponder my own relationship to the city. I wish I could claim without hesitation that I belong in and to Montréal and that I love this city unconditionally like him. As I have explained in Chapter 2, Pierre and I have a lot in common. We are only one year apart in age, we come from the same region, we now live in the same borough, we have never been in a difficult financial situation, we have great networks of support from our parents and friends, we have used power wheelchairs for many years, we have completed post-secondary studies without facing many difficulties, and we need home support services to live independently. And yet, our sense of belonging in Montréal is different.

My relationship to Montréal is much more complicated and conflicted than Pierre's. Why is that? When I asked him about his first bad experiences with Montréal buses, he replies:

Écoute, je suis obligé de te dire que moi je suis quelqu'un de très résilient pis de très... Je ne m'en fais pas avec grand-chose. Je ne m'en fais pas avec la vie pis tout ça. Fait que c'est comme... Je suis fâché sur le coup. [We were at an intersection and he asked me which way we were going. We negotiated a curb cut in bad shape and then resumed our conversation.] Fait que je suis quelqu'un de méga résilient pis de méga comme « ah, tout le monde fait de son mieux, tout le monde est gentil, tout le monde veut notre bien bla-bla-bla ». Je suis comme mal placé pour ce genre de questions là parce que pour moi si ça a mal été, je passe à autre chose tsé. Fait que j'ai pas tant de souvenirs que ça. ([see video Lemay-2](#))

Is Pierre's sense of belonging in Montréal less conflicted than mine simply because he is a more resilient and positive person than I am? Maybe. However, thinking about the context in which we moved to Montréal, our professional lives and the gendered dimensions of our urban experiences offers other perspectives on why we feel differently about our city.

I was 17 when I arrived in Montréal. Pierre completed his CÉGEP and undergraduate degrees in Drummondville and Sherbrooke and therefore was a bit older than me when he moved to the city. Needless to say, we were not at the same place in our young adult lives. Using Transport adapté for the first time in my life and encountering numerous obstacles was quite traumatic for me. Transport adapté became an obstacle between me and the Montrealer I wanted to be. “Ça a été les pires moments de ma vie,” I tell Pierre. He explains that his experience was much more positive. Having known the limited services offered by adapted transportation in Drummondville and Sherbrooke, he was pleased to discover that Transport adapté in Montréal was less restrictive. He was finally able to book a ride pretty much anytime he needed. “Ça m’ouvrait plus de portes,” he says. It should be noted that by the time Pierre had moved to Montréal, booking a Transport adapté ride had become much easier. He did not experience a time when you could wait on the phone for more than an hour and then be told that there was no ride available for the next day. That was my experience of Transport adapté during my first years in the city.

Furthermore, our professional lives are quite different. What he studied and what he does for work now are not related to disability. My studies and my work are all about disability issues. I have developed a critical understanding on disability issues. Contrary to Pierre, I have had opportunities to travel to numerous cities that are much more accessible than Montréal. Moreover, as a disabled woman I have faced obstacles and discrimination that Pierre has not experienced. In Chapter 4, I wrote about how Marie-Eve and I are afraid to use the bike path along the railroad tracks in Rosemont–La Petite-Patrie at night, while Pierre said he would not hesitate to use it before admitting he had never feared for his safety in Montréal. In Chapter 5, Marie-Eve has explained that some Transport adapté drivers show more respect to Pierre, her boyfriend, than to her. All of these things obviously have affected my personal life and my sense of belonging in Montréal.

In contrast with our discussions of belonging in Montreal as a whole, many participants have talked more openly about their attachment to their neighbourhoods. Geneviève insists on her desire to move without constraint within her neighbourhood. Even though the obstacles in her neighbourhood and in the city in general are pretty much the same, the ones close to her home affect her more. I argue that this suggests that mobility on a very local scale plays a major role in the construction of participants’ sense of belonging. This echoes Fallov, Jørgensen and

Knudsen's (2013) arguments on the relationship between the potential for mobility and the sense of belonging. They write that "mobility, immobility and the potential for movement form an important dimension of local belonging. Our everyday performance of mobility practices shapes the meanings and qualities attached to place and how we experience our localities." (p. 472)

Marie-Josée chose to move to Montréal in her early twenties to continue her studies at Université de Montréal and because she saw more opportunities in the city than in her hometown in the country. "Vivre à la campagne, tu es dépendante à 100% de tes parents. Moi je ne peux pas conduire à cause de ma vision pis à la campagne, il n'y a rien à faire à part de rester dans la maison et écouter la télévision, internet. C'est pas vraiment un style de vie que je voulais avoir," she confides. ([see video Blais-3](#)) She lived on the university campus during the first years in Montréal and spent much of her time between her room and classrooms. She recalls being afraid to explore her surroundings by herself due to the numerous obstacles she knew that she would face. Therefore, she did not get to know her neighbourhood. It is only when she moved to her apartment in Villeray that she started to identify as a Montrealer. She became familiar with some places near her apartment, such as Tim Hortons, where she likes to go and grab an iced coffee when weather permits. She also feels confident enough to go for short strolls in her neighbourhood now. These are things she would have never done when she was living on the university campus.

Laurence, who lives upstairs from her mother, confide that she would like to move to another apartment one day to be more independent. However, she says that she would probably stay in her neighbourhood for mobility reasons. "Je n'ai pas le sens de l'orientation. Pour moi, vivre dans ce quartier ici, c'est rassurant parce que je sais tout, tsé. Dans un autre quartier, il faudrait que je me réhabitue. Les distances. Des choses comme ça," she says. She adds that she has a preference for residential areas with various local services. "Je ne pourrais pas vivre dans le centre-ville dans le fond," she observes.

When Isabelle speaks about why she intends to stay in her neighbourhood to raise her future children, she mentions all the accessible places she could get to from her apartment, such as the kindergarten and the elementary school. "J'ai le goût de rester ici. J'ai tout ce qu'il me faut ici," she says. Sandra states that what she appreciates the most about her neighbourhood is that it is very quiet and that she's part of a great English-speaking community. She says that she does not need to leave her area regularly as she can find anything she needs close by. This is a major

advantage for her, since getting around the city is often harrowing with Transport adapté and regular buses. In a nutshell, these four testimonies have one thing in common: being able to get around the neighbourhood on foot, for Laurence, and on wheels, for Marie-Josée, Isabelle and Sandra—in addition to being able to access different familiar services—is central to their sense of belonging in and to their neighbourhood.

Nabila is the only participant who was born outside of Canada and wears a visibly religious symbol. Nabila is, without a doubt, the participant who hesitates the least when I question her about her sense of belonging in Montréal. This can probably be explained by the fact that her right to belong has been challenged by others several times and on multiple levels, especially since the debates around the *Charte des valeurs* proposed by the Parti québécois in 2013. Unlike the other participants, Nabila is often asked where she is from and made to feel like she can never be québécoise because of her origins and her religion. Nabila's emotions regarding her sense of belonging are bubbling up at the surface. Nira Yuval-Davis (2006) argues:

Of course not all belonging/s are as important to people in the same way and to the same extent. Emotions, like perceptions, shift in different times and situations and are more or less reflective. As a rule, the emotional components of people's constructions of themselves and their identities become more central the more threatened and less secure they feel. (p. 202)

As mentioned in previous chapters, Nabila has faced countless obstacles since her immigration to Montréal with her husband and their two young daughters. This experience has left her profoundly disappointed as it directly impacts daily life with her family. After we have been talking about various heartbreaking moments, I ask Nabila if she feels like a Montrealer. She laughs and says:

Si ça ne venait que de moi, je dirais « oui, je me sens tout à fait Montréalaise ». Mais quand je vois le comportement des gens, les formes de discrimination qu'ils font envers moi par rapport à ma religion, donc je me dis que non, je serai jamais, même si je sens que je suis Montréalaise, je serai jamais Montréalaise. [...] Aux yeux des autres. ([see video Nouara-2](#))

I then ask her if she feels Canadian or québécoise. “C'est pareil. Sincèrement, je me sens toujours étrangère,” confides Nabila. She explains that, even though she feels like a stranger, it is extremely important for her to consider Canada as her country because she wants to contribute actively to the community. “Si je pense que c'est pas mon pays, ça veut dire que je serais une mauvaise citoyenne. Si je suis venue ici, c'est pour contribuer déjà en tant qu'être humain pour

l'égalité et surtout pour respecter la citoyenneté que j'ai acquise en venant ici," she argues. She claims that her country is where she lives.

Even though, I did not find any research on how disabled Quebeckers' sense of belonging is affected by their origins or religion, I came upon a study from the Office des personnes handicapées du Québec on racialized disabled Quebeckers and their social participation in society (Lamothe, 2015). The report indicates that compared to white disabled Quebeckers, fewer disabled racialized Quebeckers claim to be happy. Only 78% of disabled racialized Quebeckers report being happy while 91% of white disabled participants say they are happy (p. 25). The proportion of people who identify as being unhappy is also higher among racialized disabled Quebeckers compared to white disabled Quebeckers (15% versus 6%) (*Ibid.*) Despite these significant differences, the issues faced by racialized disabled people are rarely on the agenda of Montréal disability rights organizations.

#### *Encounters with others and disability microaggressions*

Much has been written on the relationship between walking, interactions between (non-disabled) strangers and a sense of belonging. Rebecca Solnit (2001) argues:

Walking is only the beginning of citizenship, but through it the citizen knows his or her city and fellow citizens and truly inhabits the city rather than a small privatized part thereof. Walking the streets is what links up reading the map with living one's life, the personal microcosm with the public macrocosm; it makes sense of the maze all around. (p.176)

In addition to insisting on the importance of having access to everything the city has to offer, some participants have talked about how encounters with others impact their sense of belonging to the city. This is a dimension of disabled people's urban experience that is rarely on the radar as most advocacy energies and policies focused on the accessibility of the built environment but pay little attention to what is actually happening when disabled and non-disabled people interact in the public space. "As urbanites see others and are seen by others, they develop and display identities, indicating similarities and differences through fashion and spatial practices, as well as claiming the right to be included in a diverse crowd," write Anastasia Loukaitou-Sideris and Renia Ehrenfeucht (Binken, 2012, p. 638). The desire to visit the same places as other citizens and to share the same spaces is quite obvious in Geneviève's testimony. Other participants express similar thoughts and explain that it is through banal and uneventful encounters with other pedestrians that they feel connected with the city.

While wheeling on a crowded Mont-Royal Avenue with Louise on a beautiful day at the end of the summer, I ask her if she would normally choose to wheel on that sidewalk. I am expecting her to reply that she would prefer quieter sidewalks like I do when I want to get from point A to point B. However, to my great surprise, she says that she would choose the busy sidewalk. “Même s’il y a beaucoup de monde?”, I insist. She replies affirmatively again. Still surprised by her answer, I ask her why. “Pour voir du monde. Les commerces. J’aime ça sentir ce qui se passe,” she explains. ([see video Blouin-2](#)) Kéven insists on the importance of being able to ride the métro to foster a sense of belonging in the city. “J’ai une vision de Montréal très romantique. Ça inclut nécessairement le métro. [...] C’est un symbole super fort,” he tells me while we are riding the métro. Furthermore, métro rides make him feel like he is part of the city, something he does not feel when he drives his car. He appreciates being able to mix with other commuters.

Unfortunately, navigating spaces with other pedestrians or commuters can also come with its share of difficult encounters for disabled people. Encounters with other pedestrians always presents the risk of being confronted by ableist attitudes. In Chapter 4, I have written about street harassment that is experienced by disabled women. I am interested in bringing to the fore a critical discussion of these forms of disability microaggression. In 1969, psychiatrist Chester Pierce argued that counselors should recognize that their practices may be filled with racial microaggressions. Derald Wing Sue et al. (2007) have explained that racial microaggressions are “brief and commonplace daily verbal, behavioral, or environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative racial slights and insults toward people of color.” (p. 271) Disability microaggressions operate in the same way. “The distorted assumptions and beliefs that fuel negative attitudes and behaviors toward PWDs<sup>96</sup> still exist, but they operate in a much more subtle, secretive, and covert manner, often outside the level of awareness of well-intentioned perpetrators,” writes Derald Wing Sue (2010, p. 244). I have not been able to find statistics or even any document about this phenomenon in the context of Québec or Montréal. Daniel Solórzano (1997) argues that racial microaggressions are, by their subtle nature, difficult to document. During the wheeling interviews, participants have shared some of the disability microaggressions that they have encountered. On a few occasions, we even have experienced some together as we moved through the city. It is important to note that they did not use the term microaggression to describe those situations, as it is still not a concept used

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<sup>96</sup> People with disabilities.

in everyday language. Nevertheless, the bus driver who does not wait, the passengers who do not move, the students who take pictures, the bureaucrat who does not allow a ramp to be built are all forms of both individual and systemic microaggressions. These systemic microaggressions are built into our processes, our environments, and are, in some instances, the default way that becomes normalized.

Even though most of his experiences in the métro are positive, Kéven has sometimes had to deal with ableist comments from other passengers. A few days before the wheeling interview, he was waiting to get on a métro train at rush hour when a woman approached him and told him, “Il y a trop monde dans le métro. Vous ne devriez pas le prendre tout de suite même si vous êtes handicapé. Il n’y a pas de place pour vous.” Kéven tells me that he is usually friendly with people who make questionable comments to him, but on that specific day he was not in a good mood. “J’avais vraiment eu une mauvaise journée. Je l’ai juste regardé et j’ai dit ‘ok’. Je ne l’ai pas écouté pis je suis embarqué dans le métro pareil,” he says.

For Isabelle, negative encounters with pedestrians happen on a regular basis. While we are having a discussion about other women’s fear of homeless people, she speaks about the homeless people who are generally very nice and polite with her. She argues that the attitudes of non-homeless people are much worse. “Les trois quart du monde que je côtoie dans la rue vont juste m’ignorer et me regarder comme si j’étais une étrange,” she sighs. Isabelle’s statement makes me think of a quote from an op-ed letter co-written by Molly McCully Brown and Susannah Nevison. “My body requires explanation in public spaces because public spaces aren’t made for people who look like me,” writes Nevison (2017).

Furthermore, in the everyday interactions that disabled people face, pity and infantilization are not rare microaggressions. This kind of condescension has happened at least three times during the wheeling interviews. As Laurence and I are moving towards a park bench, we ran into a small group of nuns who looked at us as though we needed compassion. Once we are far enough away from them, Laurence sighs, “La pitié aussi ça m’énervé.” She specifies that when it comes from elderly religious persons, it bothers her less. I ask her if she was regularly pitied when navigating public spaces; she replies that it hardly happens anymore. “Qu’est-ce qui a fait que ça a changé?”, I ask her. “Je me mets moins dans des situations où les gens peuvent avoir pitié,” she says. She explains that she has stopped riding the métro, which was the place where she would meet the most people and be confronted with pity or infantilization. While we

are crossing a street downtown, a man, probably in his seventies, spots us. Visibly amused to see us, he takes his left hand out of his jacket pocket and waves at us when we pass by him, as one would wave at young children. This kind of encounter is not unusual for me. Perfectly aware that my short stature seems to give some people the right to infantilize me, I ask Marie-Eve, who is of average height, if she encounters similar attitudes. She replies that she is rarely infantilized. “Moi j’ai plus des sourires de pitié. [...] Il y a ben du monde qui prie pour moi aussi,” she says. Whenever this kind of interaction has happened, she has tried not to care, but it still has left her with a bitter taste. She says that what bothers her the most is that many of the people who pity her would never agree to pay higher taxes to make the city more accessible and eliminate the obstacles she encounters in her everyday life. Marie-Josée also complains about other people’s attitudes towards her. On a regular basis, she is treated as if she is not an adult. Because of that, she is always on guard when she is in public.

Lynsie Harris (2017) conducted research among university students with disabilities about their experiences of disability microaggressions. Harris found out that microaggressions have an impact on the students’ “willingness to participate and their sense of belonging in the classroom” (p. iii). Being *present* in the classroom is not enough to belong. The stories that are shared by wheeling interview participants about their encounters with fellow pedestrians highlight some of the microaggressions that disabled people may experience as they navigate the city. One of the strategies they employ to protect themselves is to try to avoid interactions. Even though the wheeling interviews did not extensively explore the difficulties one must endure to have meaningful and safe interactions with people in public spaces, it is important to acknowledge these challenges and consider that they affect negatively some participants’ sense of belonging in the city.

*Why was it so hard to talk about belonging?*

As I indicated in the introduction of this chapter, talking with participants about belonging in the city has turned out to be more complicated than I had anticipated. I must admit that it initially felt like a failure, as though I had planned to go somewhere but never made it to my destination because I took the wrong exit. Why did this happen? Was it my limited experience in oral history interviews? Was it my interviewing method?

The fact that I have chosen to conduct only one interview with each participant definitively imposed time constraints. Each interview lasted between 90 minutes to two hours. In

most cases, that was just enough time to talk about some of the obstacles that participants face in the city. Silences and pauses are more frequent during a wheeling interview than during a traditional interview. The conversation can also easily take various directions according to the space we wheel through. However, the influence of time and space on our capacity to talk about a sense of belonging in the city is only a part of the explanation. The difficulty of talking about belonging goes beyond these temporal and spatial constraints and tells an important story in itself. I argue that three other factors complicate the discussions I was initially hoping to have with the participants. First, the sense of belonging is a highly emotional topic; second, the language available to talk about ableism in French is very limited and third, most participants have benefited from various privileges, including those of class. In other words, talking about one's sense of belonging in a city is not exactly a walk in the park.

I already have explained that a sense of belonging is complicated and deeply emotional. These emotions are political. Ironically, a sense of belonging is not an easily accessible topic for discussion. In fact, it is quite challenging to tackle it, even for myself. I am fully aware that I am better at sharing my emotions on paper than out loud. Since childhood, my smile has been a passport to move through ableist spaces and interact with non-disabled people. I have used it countless times to ease non-disabled people's discomfort. I am able to pretend that things are good when they are not. As a woman, I also have been taught that expressing some emotions such as anger put me at risk to be further marginalized and to not be taken seriously (Gervais, 2018). As a disabled woman, this risk is multiplied. Reflecting on the fact that the participants and I were able to talk about the obstacles we faced without showing much emotion made me think about what prevented us from connecting with our feelings.

Here again, I am reminded of Maria R. Palacios' poem (2017) on internalized ableism. She writes:

Internalized ableism is  
the thick extra layer of skin we grow  
in order to not get wounded  
by the voices that say we're imperfect, and worthless  
and undesirable.

I know that I have grown this thick extra layer of skin. I suspect that most of the participants I have interviewed have as well. They may also have been conditioned to tell their stories in a particular way to fit within ableist narratives of disabled people experiences. "In narrating their

lives, interviewees draw on ‘pre-existing storylines and ways of telling stories’,” argues Steven High (2015, p. 18), citing Luisa Passerini (1987). Furthermore, I must acknowledge that having the wheeling interviews take place in public spaces may have created an obstacle that kept some people from sharing personal and emotional stories. There were many moments during our conversations that were not quite confidential, as there were other people nearby.

I have struggled in getting participants to explore the links between obstacles, which were deeply embedded in their everyday life, and their sense of belonging in the city. Rosemary D. F. Bromley et al. (2007) write about what they called “disabled acceptance.” (p. 237) They state that “wheelchair users are seemingly prepared to put up with, rather than challenge, poor levels of accessibility and obstructions to their mobility.” (*Ibid.*) “Many wheelchair users, like myself, become used to living within their own often harsh day-to-day environment, and simply learn to adapt to, and work around, any access problems,” claims scholar Jane Andrews (2005, p. 207). Ableism can easily go unnoticed or at least unchallenged because it is inscribed in policies and architecture, which are still often thought of as being objective (Boys, 2017; Parent, 2010). I argue that ableism is even more likely to go unnoticed in a French-speaking context since the concept of ableism itself was still largely unknown at the time of my interviews. As explained in Chapter 2, the term “capacitisme,” a French equivalent of ableism, was not used in the Montréal community. “Capacitisme” was only mentioned once, by Isabelle, when referring to an article written by Dominique Masson (2013) who is one of the first Francophone scholars to use the term “capacitisme.”

Obviously, this observation does not mean that participants refrained from talking about ableism. As I have demonstrated throughout my thesis, the participants have shared many stories highlighting the prevalence of ableism in their everyday experiences in the city. However, the lack of a concept to identify ableism should not be minimised. James L. Cherney (2011) argues that we must be able to name and identify ableism because the power of language and discourse matters: “To fully address it we must name its presence, for cultural assumptions accepted uncritically adopt the mantle of ‘simple truth’ and become extremely difficult to rebut.” Cherney cites cultural theorist Stuart Hall (1996) who defines ideology as:

the mental frameworks—the languages, the concepts, categories, imagery of thought, and systems of representation—which different classes and social groups deploy in order to make sense of, define, figure out and render intelligible the way society works. (as cited in Cherney, 2011)

Nabila, for example, broaches the power of language to shape the world and social interactions when she speaks about the difficulty in naming the discrimination that she feels:

Dès que quelqu'un te refuse un service, le sentiment est là. Mais est-ce qu'on donne des termes à ces situations? Finalement non. Il est là, le problème. On ne donne pas des termes à des situations. On ignore ces termes là.

Pierre admits that before being introduced to the concept of ableism and meeting other disability activists, he was unable to tell when he was being discriminated against on the basis of his disability:

C'était juste comme tellement imbriqué dans la société. Je ne sais pas toi qu'est-ce que t'en penses? Tsé, quand tu lis pis que tu vois tout ça, tu dis « mais voyons donc, mes droits étaient bafoués énormément pis ça fait aucun sens que je tolère ça » pis etc, etc. Mais avant là, à cette époque là, c'était ça. ([see video Lemay-1](#))

Pierre also observes that at his workplace, Francophones and Anglophones treat him differently. “Les anglophones me respectent bien plus comme personne que les francophones,” he says. I ask him if he could elaborate on that. He explains:

Ils ont plus une conception que j'ai les mêmes droits que tout le monde pis que j'ai des droits. Tsé, les francophones, c'est la petite pensée judéo-chrétienne. On fait ben pitié pis les services doivent être là parce qu'on fait pitié. C'est la charité, etc. Tu comprends? Tu sens un peu ce que je veux dire là? Mais, en tout cas, regarde, ça, c'est ma petite perception. ([see video Lemay-1](#))

In other words, for Pierre, a culture of charity has been inculcated in Québec that promotes what disability rights activists have identified critically as promoting a dated “politics of pity” which does not challenge hierarchies of power, privilege or control.

As explained in Chapter 3, the Montréal disability rights movement has dedicated most of its energies in the last 15 years to having the concept of universal accessibility recognized in the city. This concept is certainly useful in the contexts of policy and urban planning. However, it pays little attention—if any—to the role that ableism plays in shaping these spaces in the past, the present and as a result, in the future. Furthermore, ableism continues to be depoliticized through stereotypical portrayals of disabled people in Québec's media and popular culture, as briefly explored in this chapter. Without a concept to name ableism in French and to identify ableism as a system of oppression as systemic as racism and sexism, talking about how disability-based discrimination could impact participants' sense of belonging in Montréal was quite complicated and delicate.

As I recognized in Chapter 2, participants' profiles in terms of origin, language and race are quite homogeneous. Nine of them were born and raised in Montréal and its suburbs, and four of them were from another region in Québec. Only Nabila had to go through the Canadian immigration system to become a citizen.<sup>97</sup> Sandra was the only participant who did not speak French on a daily basis. This means that the great majority of participants have never been asked “where are you from?” or felt excluded from the saying “les Québécois et les Québécoises.” Simply put, most of them had a set of predefined, systemic privileges based on language and birthright that contributed to a sense of at least partial belonging to Montréal. As I have explained in the introduction, in Québec, the mainstream discourse on who belongs and who does not is mainly articulated around issues of language, race and religion. Disability is not perceived as a factor that influences people's sense of belonging.

For this reason, I anticipate that asking white French-speaking participants whether or not they belong in Montréal might catch many of them off guard. I suspect that it is possibly the first time in their lives that they have faced such a question. It certainly is challenging to talk about something—in an interview, no less—you have never thought about before. Recognizing privilege is still something many people who benefit from such privileges are not willing to do. Much research has demonstrated that white people tend to deny the existence of white privilege or that they profit from it (Dolan, 2015; Solomona et al., 2006). White disabled people are no exception. Disabled women of colour have critiqued disability studies for being racist and failing to acknowledge ableism as a “socially constructed complex system of disempowerment which intersects with, and is just as pervasive as, other systems of oppression” (Miles, Nishida, Forber-Pratt, 2017). Dan Goodley (2014) argues that “modes of ableist cultural reproduction and disabling material conditions can never be divorced from hetero/sexism, racism, homophobia,

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<sup>97</sup> In Canada, disabled people and their families wishing to become citizens are frequently turned down (CBC News, 2016; Zaikowski, 2017). Under Canada's immigration act, newcomers should not cause excessive demand on the health and social services system. “Immigration Canada sets the limit for ‘excessive demand’ at \$6,655 a year, the apparent average annual health and social service spending per Canadian,” write journalists Andrew Russell and Brian Hill (2017). Many families with young disabled children have made the headlines in the past few years while denouncing this rule that bans them from becoming Canadians. In April 2018, the government of Justin Trudeau announced that the limit would be increased to \$20,000 and that 75% of the people who used to be denied citizenship should now be able to stay in Canada (Buzzetti, 2018). Despite this change, I would be among the 25% denied Canadian citizenship, because of the public support care services I receive to be able to live at home, outside of institutionalized settings.

colonialism, imperialism, patriarchy and capitalism.” (p. 35) To this day, there is still almost no discussion about privilege in the Montréal disability rights movement. Perhaps participants who experience some modicum of privilege based on language, gender, race or social class find it difficult to critique a system that favours them on different levels. Because of this, thinking about their own sense of belonging in the city may be a door they would rather not open. That being said, I am aware that it is a quite heavy door to open while you are fighting for basic rights, such as having access to public transportation and appropriate healthcare in order to live at home, outside of institutionalized settings.

### ***Conclusion***

This chapter exposes the complexities of participants’ sense of belonging in Montréal disability communities and in the city. I have highlighted how participants’ right to the city and their capacity to belong are highly compromised. Building on Fenster’s critique of Lefebvre’s conceptualization of the right to the city, I argue that ableist power relations and the different positionalities of the participants set “the boundaries of belonging” for disabled Montrealers. Overall, participants express a stronger desire to belong to the city than to belong to disability communities, and since communities are “imagined and clearly embedded in much broader systems of power,” (Walsh & High, 1999, p. 273) there is no simple explanation for this preference. Internalized ableism is certainly an important factor. It has made it difficult for participants to identify as disabled in the first place and to find communities where they feel like they belong. Some participants point out that they have never had access to the stories told by other disabled people to encourage their sense of belonging and their pride. For example, Marie-Eve has mentioned that she only has found those kinds of narratives through online disability communities who are outside of Montréal.

On the other hand, participants’ desire to belong to the city is unambiguous. All participants either claim that they feel like they belong in Montréal or that they wish that they felt that sense of belonging. Simultaneously, they have identified several obstacles that prevent them from fully participating in the decision-making processes shaping urban spaces. Furthermore, some participants explain that they encounter disability microaggressions in their everyday interactions with fellow pedestrians, and they do not see themselves represented in political, public and media spheres. Considering all of the obstacles and the discriminations experienced by the participants, it is legitimate to wonder why most of them still feel like they belong in

Montréal.

It should not be overlooked that Montréal is renowned for its exceptional quality of life. Participants are conscious of everything Montréal has to offer, even though they cannot access the many places and services that give Montréal its enviable reputation. Who would not want to belong to such a dynamic city? Moreover, I must emphasize the difficulties I have experienced throughout the wheeling interviews in getting the participants to talk about their sense of belonging in the city. The fact that most of the participants benefit from various forms of privilege is no doubt part of this uneasiness. Additionally, the lack of language to talk about ableism in French is a recurrent obstacle. It is only when Marie-Eve was introduced to the social model of disability that she realized that the exclusions she experiences on a daily basis are not right.

The participant who had the most to say about belonging was Nabila, who had experienced discrimination on various fronts and whose belonging has been overtly questioned by others since she arrived in Canada over a decade ago. Belonging is not equally accessible to all disabled Montrealers. My conversation with Nabila makes me realize that sharing the stories of disabled people who are experiencing multiple types of discrimination has the potential to help disabled people who are more privileged to think about what it means to belong to the city and to think critically about their own experiences. Privileges related to race, class, gender and ability work against all of us and they are deeply embedded in this ableist city. A better understanding of ableism and how it intersects with other systems of oppression, such as racism and sexism, is necessary to start imagining the right to an anti-ableist city.

Finally, another interesting finding is that most participants have shown greater attachment to their neighbourhoods than to the city. In the introduction of this chapter, I have quoted Mia Arp Fallov, Anja Jørgensen and Lisbeth B. Knudsen (2013), who claim that “mobility resources result in different scales of belonging.” (p. 483) Participants’ testimonies offer an interesting perspective on this statement. Even though owning a car may be thought of as something that provides more mobility resources, it did not translate into a stronger sense of belonging for those concerned, in comparison with those who did not own a car. The “mobility resource” most valued by participants was the ability to get around their neighbourhoods by themselves either on foot or with their mobility aid. Some participants clearly have expressed the pleasure they have while wheeling. Through the wheeling interviews and the process of writing this thesis, I have come to understand wheeling as a source of pride and an activity where

belonging can flourish. This is an interesting observation at a time when urban policies put more focus on the creation of dynamic neighbourhoods, proximity services and active transportation.

## **Conclusion**

### **Rouler/Wheeling Montréal: Moving through, Resisting and Belonging in an Ableist City**

My thesis takes its roots in my years of navigating the world—Montréal in particular—as a disabled woman, as well as in my work as an activist, academic and filmmaker. Due to my passion for issues relating to disability, urban mobility and media, I chose to dedicate my doctoral research to the everyday mobilities of disabled Montrealers and to explore their sense of belonging in the city, something I have struggled with and continue to struggle with daily.

Mobility studies scholars have established the relationship between mobility, conceptualized as a resource and as a sense of belonging. Mia Arp Fallov, Anja Jørgensen and Lisbeth B. Knudsen (2013) claim that mobility practices shape our attachment to the spaces we move through. Tovi Fenster (2005) argues that the concept of the right to the city developed by philosopher Henri Lefebvre is flawed because it ignores patriarchal power relations. She claims that these power relations jeopardize women's right to the city, which includes their right to belong. Inspired by her article, I decided to investigate disabled Montrealers' right to the city and their right to belong by analyzing ableist power relations that manifest themselves in everyday mobilities. To conduct such a project, I absolutely needed to talk with disabled Montrealers about their experiences in the city. The subjective nature of their stories, one of the fundamental concepts of oral history, became the strength of my research. The only "truth" I was interested in when interviewing participants was their truth. Their testimonies have revealed something about them as individuals, but also about the city in which they live. From August to November 2015, I wheeled a total of 319.87 kilometres with 15 Montrealers.

My doctoral research journey started with the following methodological question: What does it mean to conduct walking interviews when you do not walk the way society expects you to? As a disabled researcher using a motorized wheelchair and actively engaging in disability activism, I have felt the need to embrace the possibilities created by the way I move in the world. I have coined the term "wheeling interviews" to emphasize the value of wheeling as a mobile practice that falls under the umbrella of walking practices. In doing so, I have sought to challenge ableist conceptions of walking and, more broadly, active transportation in the city. This is important, since wheeling is still largely perceived as something to avoid at all costs and as something inherently negative. Reclaiming wheeling as a valid and complex mobile practice that offers unique insights on how mobilities are shaped and lived has allowed me to see Montréal

from a perspective that has been neglected so far. Paying attention to how I move gives me the opportunity to recognize my role in the research process, as well as my active participation in the stories that are told by participants. Moreover, I have highlighted my presence through personal stories relating to the issues discussed.

Inspired by the work of Arseli Dokumaci (2013; 2014a; 2014b; 2018) on disability as method, I have sought to make visible what is often rendered invisible or slipped under the ableist radar. “To apply disability as method is to recognize the hard labor that disabled people do every day in order to create their own space for action in competition with an ableist *habitus* that constantly exhausts that space,” as Dokumaci so eloquently writes (2018). In other words, using disability as method makes political what is otherwise presupposed as natural or neutral. By mounting a GoPro camera on my wheelchair and, if they had one, the participants’ wheelchairs, together we have turned our gaze towards the city and have revealed its affordances as well as its flaws. Furthermore, thinking about how the participants and I filmed the wheeling interviews is a good starting point to think critically about mobile methodologies. Together, we have performed a series of mundane gestures that are generally ignored in mobilities research. The acts of assembling the recording equipment, talking, and monitoring the recording while moving and navigating various obstacles have been an integral part of developing the method itself. Together, we have crippled the traditional walking interview and have explored new possibilities for media-making where bodies and technologies weave in and out of one another.

### ***Moving through***

One of the main objectives of my research project has been to explore the everyday mobilities of disabled Montrealers who wheel (or walk, in the case of Laurence and Luc) the city. Throughout the wheeling interviews, the participants and I have encountered dangers that non-disabled pedestrians and cyclists face, in addition to obstacles such as sidewalks in disrepair, construction sites without proper accessible and safe pedestrian detours, restricted public transit options, and inaccessible buildings, such as shops, cafés and restaurants. Altogether, disabled Montrealers move through an urban environment that is less safe and hospitable than the one experienced by their non-disabled counterparts. Some barriers were put up a few decades ago, such as métro stations built without elevators, however new ones continue to appear, such as shops with front steps and temporary inaccessible pedestrian detours. The appearance of new barriers highlights the fact that ableism continues to play a central role in the construction of this

city space, a point which has been argued by many scholars before me. We have observed, together, significant differences between boroughs regarding the condition of pedestrian infrastructures, and some participants have expressed that they prefer wheeling in certain boroughs over others. They have argued that deteriorated streets and sidewalks are not only more difficult to use but they can also cause physical pain.

When I asked participants if they feel included in the term “pedestrian friendly,” many said they can never assume it also means “disability friendly.” Marie-Eve explains, “Je me sens de moins en moins incluse parce que je dois souvent faire des détours que les piétons debout doivent pas faire.” Jacynthe echoes this sentiment: “Sémantiquement, je me sens incluse car je me considère piétonne quand je me déplace. Mais par expérience, je sais que je suis oubliée, comme piétonne, aux yeux de la Ville.” Pierre argues that he feels somewhat included but he always has his doubts. The numerous obstacles that have been encountered, combined with participants’ stories about how they get around in the city, clearly demonstrate that Walk Score’s walkability rating of Montréal does not take into consideration the experiences of disabled people and is based exclusively on a non-disabled perspective. Furthermore, many participants report fearing for their safety in areas where automobile traffic is heavy, something that is denounced frequently by organizations representing pedestrians, such as Piétons Québec.

The *Projet-pilote relatif aux aides à la mobilité motorisées* (Projet-pilote) adopted in 2015 by the government of Québec, which changed the legal status of motorized mobility aid users—who are no longer considered pedestrians—in the *Code de la sécurité routière*, has also been critiqued by some participants. While the Projet-pilote allows motorized mobility aid users on bike paths and certain roads, it also adds a series of new rules that mobility aid users must follow when using sidewalks. Disabled people argue that these new obligations are exaggerated and have limited their independence. They claim that instead of criminalizing their behaviours, the government should focus on building accessible and safe infrastructures to facilitate and secure the mobility of disabled people.

The lack of a strong accessibility law also is an issue. Some participants testify that it is common for existing minimum accessibility standards to be disregarded. In many cases, these violations remain unchallenged due to various obstacles in the human rights and justice system. We have introduced the importance of considering the weather as an important actor that influences how one belongs to the city. The participants and I talked about how getting around

the city becomes more complicated during the winter. I met four participants during a heat wave and I faced obstacles that I had not initially anticipated when I decided to conduct interviews during the summer. For instance, in some parts of the city, it is almost impossible to find shaded areas and accessible indoor places to shield ourselves from the burning sun, which seriously compromises our safety and ability to stay outside for a long period.

Discussions about encounters with other pedestrians reveal that ableism not only manifests itself in the built environment but also in ableist attitudes towards disabled people. Even though most participants say that they enjoy being out in public and sharing public space with fellow pedestrians, some have told me how they are sometimes pitied or infantilized by other citizens. Nabila confides that she feels that most people dismiss her because of her disability and her religion. Marie-Eve argues that many people seem scared of her wheelchair and overreact by moving out of her way even when they both have plenty of space. Is the solution to these problematic encounters simply to increase the visibility of disabled people in the public space? After all, it is often argued that if non-disabled people are awkward around disabled people—and even, in some cases, hostile—it is because they are not used to being in contact with them. I suggest that it would be a mistake to believe that the more disabled people are present in public space and encounter non-disabled people, the fewer prejudices there will necessarily be. As Gill Valentine (2008) argues:

proximity does not equate with meaningful contact. While taken-for-granted normative codes of behaviour in public space mean that people do commonly behave in courteous and sometimes kind ways towards others, this is not the same as having respect for difference. Indeed, there is often an uncomfortable gap between some people's professed liberal values and their actual practices, and *vice versa* those who hold prejudiced views can none the less willingly exchange public civilities with individuals from the minority groups despite their politics. (p. 334)

This means that any policies that aim to include disabled people in the city must address issues of discrimination and recognize power inequalities. Disabled women, for one, have identified additional sources of danger because they are women. Some of them have faced street harassment. For example, a man insulted and threatened Nabila for wearing a hijab. She explains that she felt targeted because of her religion and her disability. Male participants have not reported similar harassment incidents and all have argued that they take pleasure in circulating in the public space (when they do not encounter physical obstacles, of course). Testimonies from Isabelle, Marie-Eve and Nabila powerfully illustrate, once more, the limits of policies and

discourses that are focused exclusively on “accessibilité universelle” and the built environment and overlook other issues such as sexism, racism and ableist attitudes.

Overall, participants’ stories demonstrate that their right to the city and their capacity to move through it are severely compromised because ableism is embedded in Montréal’s built environment and culture. This is why I claim that Montréal—my city, with its enviable reputation around the world—is an ableist city. Throughout my thesis, I have demonstrated that disabled people are not all equal in the face of the ableist city’s barriers. For example, it is easier for France, who is self-employed, to arrange her work schedule during winter than it is for Nabila, who must get to work every day no matter the weather conditions in order to keep her job.

### ***Belonging***

I have explored two different dimensions of participants’ sense of belonging: their belonging in Montréal disability communities and their belonging in the city. Even though all participants have been visibly disabled for many years—for some of them, this has been the case for all their lives—few feel like they belong to Montréal disability communities. Internalized ableism, as well as a lack of stories that challenge common disability stereotypes, deters participants from proudly identifying as disabled and claiming their sense of belonging to disability communities. Marie-Eve, for example, has discovered disability pride through English-speaking online disability communities where stories and various resources are easily accessible. Some participants have faced discrimination in the disability and deaf communities themselves. Nabila has confided that she often fears advocating for disability rights publicly, because she worries she will be told that she should be grateful for having been able to immigrate to Canada. Marie-Josée explains that her hearing impairment tends to not be recognized in groups of people with physical disabilities, which makes it difficult for her to participate; likewise, she often feels out of place in the deaf community because of ableist attitudes towards her. This reveals that Montréal disability communities are not equally accessible to all disabled people. Moreover, there is still little discussion on intersectional discrimination and privilege in those circles.

In my thesis introduction, I ask: “If walking is a means to build belonging in spaces, as argued by Michel de Certeau (1984), does this mean that disabled Montrealers, who face countless obstacles when moving through the ableist city, are likely to feel like they do not belong?” The answer to this question is far from being straightforward and is, yet again, influenced by participants’ different positionalities. Although all participants mention several

examples of facing exclusionary and discriminatory attitudes in their everyday mobilities, few question their belonging in the city or proudly declare their attachment to the city. In fact, talking about a sense of belonging in the city has proven to be particularly difficult: it is an emotional topic.

Furthermore, I have argued that most participants have never thought about their own sense of belonging in the city as disabled individuals in part because of their multiple privileges in terms of race and language. In Québec, issues of belonging and identity have so far revolved around debates on language, race and religion. Even though able-bodiedness has been at the heart of constructing the average Montrealer (Parent, 2010), disability is still generally thought of as a personal matter without cultural, political and social implications. The lack of vocabulary in French for talking about ableism also makes it difficult to discuss a sense of belonging from a critical perspective. The seriousness and the political significance of disability discrimination is harder to establish without a word to identify it, just as gender inequality used to be particularly difficult to critique before the identification of sexism as a system of oppression (Cherney, 2011). Recognizing ableism is particularly challenging at a time in Western history when oppression is often difficult to notice as it is generally embedded in the “everyday practices of a well-intentioned liberal society” (Young, 1990, p. 41).

While participants have struggled to talk about their sense of belonging in Montréal, they are more comfortable talking about their attachment to their neighbourhoods. They explain why being able to wheel (or walk) their neighbourhoods is extremely important to them. Some feel like they are able to do so despite several obstacles, while others claim that they feel disconnected from their community because getting around is unsafe and difficult. The lack of accessible shops also severely limits the participants’ capacity to develop a sense of belonging with their local communities. It is interesting to note that Geneviève and Kéven, both car owners, would prefer getting around Montréal without a car. They argued that using their car isolates them. They feel like they were missing out on the city life they would like to have. Kéven explains how much he prefers wheeling over driving in the city: “C’est pour ça que je suis venu à Montréal. Pour explorer des rues, avec un itinéraire changeant, pouvoir m’arrêter spontanément dans une boutique, rencontrer des gens dans la rue, et cetera.” Geneviève observes that there are parts of the city that remain unknown to her because she only drives through them. She confides that she feels particularly conflicted between feeling proud of living in Montréal because of its rich

culture and history and feeling like a stranger in her own city. Geneviève and Kéven's testimonies demonstrate that even though they have more flexibility and options for getting around the city compared to the participants who rely exclusively on Transport adapté, they do not have a stronger sense of belonging. On the other hand, they point to the fact that non-disabled people are exempt from multiple barriers that complicate the development of a sense of belonging in the city.

### ***Resisting***

In order to wheel and walk the city full of obstacles, participants have to find creative ways to do so. Dokumaci (2018) uses the term “micro-activist affordances” to describe the “creative workarounds” disabled people must perform to “make up for what the environment does not readily provide.” Throughout my thesis, I have identified several strategies participants have developed to move through the city. There is Laurence who, in order to keep her balance, walks on the residential streets of her neighbourhood instead of the cracked and uneven sidewalks. There is Luc who listens for the echo of sounds bouncing off walls and uses both his white cane and his smartphone to situate himself in a space. There is Marie-Eve who regularly uses Transport adapté to save her energy, since wheeling long distances is too demanding physically and regular transit does not yet offer sufficient access. There are Kéven and Christian who navigate the métro and bus systems as much as they can and have developed their own transit itineraries despite the absence of planning tools. There is France who wheels at full speed in her favourite alley to avoid pedestrian and car traffic on the way to her dance studio. The examples are numerous. Participants are not passive in the ableist spaces through which they move. They are actively engaged.

Finally, all participants have talked about the pleasure they have when they wheel (or walk) the city, whether specific pleasurable moments or parts of the city they prefer. Asserting that wheeling the city is pleasurable disrupts dominant discourses about disabled people's mobility and should be understood as a form of resistance to compulsory able-bodiedness, which dictates what types of mobility are to be valued or devalued. France and Caroline explain how they are able to express themselves through their wheeling practices. France claims that she likes to wheel the same way she likes to live—at full speed: “J’ai tellement de fun à aller vite. Je suis quelqu’un de speedée dans ma tête dans le sens que quand je m’en vais travailler, c’est go, go, go! [...] C’est *rock and roll*. Je peux aller à Lucie Bruneau de chez moi en 10 minutes environ.”

Caroline proudly asserts that after using her wheelchair for a year, it is already quite “maganée”: “Je suis un peu anarchique [rires]. Je l’ai testée ben en masse là.” She also explains that she loves to be active and on the move as much as possible. Wheeling many hours a day is not unusual for her. For Marie-Eve, wheeling is a source of pride. She confides that wheeling through the city with confidence is deeply satisfying. “Je me trouve vraiment bonne,” she says with a smile. Luc also has developed a similar pride in walking the city by himself using his white cane:

Avant, je ne me serais pas permis ça parce que tsé, ça a l’air de quoi? Pis bla, bla, bla... Mais astheure, je me trouve cool parce que 1) Je sors. 2) Je m’écrase pas la face dans le camion. [...] Même chose tsé quand je tricote à Berri, pis que je passe à côté des gens, pis tout. C’est vrai que j’ai cassé trois cannes en un an et demi puis celle-là est tout croche tsé. Mais il y a plein de fois où je me trouve super cool de zigzaguer pis de trouver mon escalier. C’est comme un jeu. ([see video Fortin-3](#))

Other participants identify wheeling as a practice in which they find pleasure because it gives them the opportunity to meditate and reflect on their everyday lives. Christian shares with me his passion for long and exploratory strolls: “J’en ai de besoin comme d’autres peuvent avoir de besoin d’autre chose. Pour moi, rouler, ça me permet de décompresser, de réfléchir aux trucs sur lesquels je travaille, et cetera. C’est en quelque sorte un espace de relaxation.” These powerful stories demonstrate that wheeling can be just as pleasurable and beneficial as walking and biking. This needs to be recognized widely in order to build an anti-ableist city. A city that enables the practice of wheeling is more likely to create favourable conditions for the development of a strong sense of belonging for all of its citizens.

### ***Limitations***

As I mentioned in the beginning of my thesis, the people that I wheeled with do not reflect the diversity of Montréal disability communities in terms of abilities, age, class, race and sexual orientation. My memorable interview with Nabila, the only racialized participant, demonstrates the need to work with people living at the intersections of different systems of oppression. The lack of diversity among participants means that some important issues have not been explored. For example, wheeling with disabled queer Montrealers would certainly have led to discussions about ableism in the Montreal queer community, which mainly gathers in spaces and neighbourhoods that are not wheelchair-accessible. Attending queer events in Montréal usually means having to leave my motorized wheelchair downstairs or at home, which has a major impact not only on my mobility in the city, but also, more broadly, on my way of being in the world. Over the years, I have come to avoid these situations as much as I can. I am not alone.

More research needs to be done at the intersection of disability and queer communities in relation to mobility and urban life.

Another important limitation of my work is that I investigated issues of space and accessibility without paying attention to issues of colonialism. The spaces the participants and I seek to access are built on unceded Kanien'keha:ka (Mohawk) territory, and this reality deserves more than a simple introductory acknowledgement. In that regard, I look forward to reading disability activist and writer Aimee Louw's master's thesis on the interactions between accessibility and anti-colonial practices in Montréal and Vancouver. Moreover, I must recognize that most of the participants live in inner-city neighbourhoods that are increasingly gentrified. Despite this important fact, the participants and I did not talk about the impacts of gentrification on their everyday mobilities. This would have certainly been different if I had wheeled with more people in precarious financial situations. Finally, my thesis centers on the experiences of people with visible physical disabilities that use mobility aids, while disability communities are made of people with various and different disabilities, some of them invisible. Even though I use the term "disabled people," I certainly do not pretend to have explored the mobilities of all disabled Montrealers.

Finally, I want to recognize that even though the content of the wheeling interviews is at the core of my thesis and that the participants and I co-created the mobile method together, I did not work in close collaboration with the participants during the analysis and interpretation of their stories. The main reasons why I have chosen this approach were limited time and resources. However, I have had many discussions with Marie-Eve Veilleux because she is one of my closest friends. While I was writing, I also have gotten in touch with other participants to clarify if I have understood what they meant during the interviews or to ask follow-up questions.

### ***Issues raised and proposed actions for an anti-ableist city***

*The right to the city is, therefore, far more than a right of individual or group access to the resources that the city embodies: it is a right to change and reinvent the city more after our hearts' desire. [...] The freedom to make and remake ourselves and our cities is, I want to argue, one of the most precious yet most neglected of our human rights. How best then to exercise that right?*

—David Harvey (2012, p. 4)

As I finish this research, I think a lot about how my work can contribute to breaking down barriers. I also contemplate how my research can find its echo among Montréal disability communities as well as different actors that play important roles in shaping the city and the culture in which the participants and I live. Inspired by participants' stories, my own experiences as a researcher and an activist, and the work of critical disability studies and mobilities research scholars, I have chosen to reflect on five issues raised by my thesis and to propose 51 actions to address these issues—and, I must admit, to reinvent Montréal after my heart's desire. The proposed actions aim to reduce the obstacles disabled Montrealers face on their paths to belong in disability communities, in the city and in their neighbourhoods. “Academics can change the world—if they stop talking only to their peers,” claims Savo Heleta (2016). This is why most of the actions proposed are intended for people working outside of the academic world. Unsurprisingly, several of them are addressed to the Ville de Montréal, the media industry and the disability rights movement. However, nearly all proposed actions can be useful to anyone interested in making the city more accessible and learning how to combat ableism in their everyday lives.

### ***Issue 1: How can we build an anti-ableist city?***

In the past decade, Montréal's disability rights movement has succeeded in making the concept of “accessibilité universelle” known to a variety of public actors such as the Ville de Montréal and the Société de transport de Montréal (STM). Both of these organizations have adopted universal accessibility policies, and several boroughs have followed suit. These policies are short—not more than a page long—and provide the main orientations and objectives. The actions required to meet these objectives are detailed in annual action plans. Although universal accessibility policies are quite recent, other tools that aim to guarantee disabled people's rights in the city, like the *Charte des droits et libertés de la personne* and the *Loi assurant l'exercice des droits des personnes handicapées en vue de leur intégration scolaire, professionnelle et sociale*, have been in place for decades. However, they have had limited success regarding the accessibility of the built environment in particular. The movement for universal accessibility falls within this context. Despite the undeniable positive changes that universal accessibility policies are making, numerous critiques have shown that these policies are not a panacea.

The Ville de Montréal's universal accessibility policy, for example, does not include any enforcement mechanisms and has very limited impact on the private sector, which explains why

those who would supposedly benefit from this policy have claimed that access to their neighbourhood's shops has not improved that much. For example, businesses such as *Uber* have been operating without a legal requirement to meet any accessibility standards. The lack of enforcement mechanisms and regulations targeting the private sector has forced disabled Montrealers to fight each obstacle case by case, which is far from efficient. Most of them have explained that they very rarely complain when they face barriers because it is such an exhausting process. Moreover, the neoliberal context from which universal accessibility policies have emerged needs to be recognized. These policies stipulate that their implementation depends on the availability of financial resources. Even though this makes sense, it overlooks the fact that prioritizing the issues that deserve funding is a highly political act. To remedy these problems, some activists have been calling for the adoption of stronger legislation.

Two of the main arguments for the implementation of universal accessibility are that it will benefit everyone and it is economically profitable. These arguments, even if they are true in most cases, pose two problems. The claim that universal accessibility is important because it benefits everyone risks minimizing the fact that accessibility is a question of human rights for disabled people, which makes the difference between their inclusion and marginalization. That claim also suggests that some standards can meet the needs of all individuals. Ravi Malhotra and Morgan Rowe (2013) have argued that universal design “seems to inherit from the Enlightenment a rational paradigm of universalism that may not be sufficiently sensitive to the need to accommodate individual differences.” (p. 5) Professor and designer Aimi Hamraie (as cited in Persaud, 2018) claims that under the universal design paradigm, “everyone” generally means non-disabled people. Furthermore, selling universal accessibility as being profitable raises the following question: Does universal accessibility need to be economically profitable in order to be implemented?

Finally, I am particularly concerned to see that the concept of universal accessibility is establishing itself as the only solution for eliminating obstacles encountered by disabled Montrealers in the city. The Ville de Montréal just recently launched a public consultation on universal accessibility. The briefing document on the consultation process and the proposed action plan makes no mention of disability discrimination, and it mostly focuses on the built environment. Throughout my thesis, I have demonstrated that ableism and its intersections with other systems of oppression must be addressed if we want to build an inclusive city, since it plays

a major role not only in the shaping of urban environments but also of Montrealers' attitudes towards disability.

**Proposed action 1: Amend the *Charte montréalaise des droits et responsabilités* to include the City's commitment to eradicate ableism**

Article 16 of the *Charte montréalaise des droits et responsabilités* stipulates that the Ville de Montréal is committed to combatting “discrimination, racial profiling, social profiling, xenophobia, racism, sexism and homophobia, ageism, poverty and social exclusion, all of which serve to erode the foundations of a free and democratic society.” This article needs to be amended to include ableism. This change is necessary for recognizing that disabled people's inclusion should not be limited to making the City's services accessible and promoting universal accessibility. Similar to other types of discrimination, ableism is complex and requires comprehensive actions to be eliminated.

**Proposed action 2: Recognize that ableism intersects with other systems of oppression**

This recognition is necessary not only to combat ableism but also to fight all other intersecting systems of oppression. Acknowledging that ableism is a system of oppression could help in building solidarity between movements.

On August 29, 2018, the Ville de Montréal's executive committee mandated the Office de consultation publique de Montréal to research systemic racism and discrimination within the Ville de Montréal and its relevant municipal powers. This mandate is an opportunity to investigate ableism in the City and its intersection with systemic racism, and to identify the actions required to eliminate these forms of discrimination.

**Proposed action 3: Adopt stronger legislation to eliminate obstacles**

Two of the main weaknesses of the *Act to secure handicapped persons in the exercise of their rights with a view to achieving social, school and workplace integration* are that it lacks enforcement mechanisms, and it does not apply to the private sector. In short, the law fails to efficiently eliminate obstacles. Most Québec citizens, including disabled people, are not even aware of the existence of this law. Other Canadian provinces and other countries have adopted stronger legislation that aims to eliminate barriers. A growing number of citizens and organizations are claiming a stronger accessibility law in Québec. For example, Québec

accessible, a grassroots initiative, has developed a [list of principles](#) that should form the basis for a stronger provincial accessibility law.

#### **Proposed action 4: Strengthen the City’s leadership by creating an Office for Accessibility and Disability Rights**

The office could be part of the department of *Développement social et diversité*, which has a mandate to foster equality and inclusion across the City. Recognizing that most disabled Montrealers experience multiple types of discrimination, this office would adopt an intersectional approach that fits perfectly within this department, which currently is responsible for expanding annual universal accessibility plans and ensuring the application of the City’s universal policy. In addition to continuing the work already being done, this office would have a mandate to combat ableism within the municipal infrastructures and across the City by aligning with its current commitment to combatting racism. This office would strategically advise the Mayor of Montréal as well as the City’s multiple departments and services on various disability issues. One of the main advantages of creating such an office is to enhance the visibility and leadership of the City’s actions on accessibility and the fight against ableism. The director of the office, who should be a disabled person, would play an active role and be known both within the administration and across the City itself.

Several cities in the United States have a [Mayor’s Office for People with Disabilities](#). These departments play important roles in their city administrations and contribute to the vitality of local disability communities.

As an example, Montréal’s universal accessibility webpage currently contains very little information. For example, there is a dearth of information on the *Programme d’aide à l’accessibilité des commerces* (PAAC). More than a year after its launch, this program remains mostly unknown across the city.<sup>98</sup> An Office for Accessibility and Disability Rights would have the leadership and the means to be proactive and ensure that the City promotes programs such as PAAC.

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<sup>98</sup>Between April 2017 and April 2018, only 11 demands have been received by the city between April 2017 and April 2018 and seven projects have been authorized. While the annual budget is \$350,000, only \$50,586.75 has been spent (Ville de Montréal, 2018b).

Office's priorities:

- Research best practices worldwide to build an accessible and anti-ableist city.
- Work closely with the provincial government to strengthen accessibility regulations.
- Adopt stronger provisions on accessibility into urban planning by-laws.
- Build a website where citizens, as well as public and private organizations, can find all the resources and information they need.
- Actively promote programs such as PAAC to make businesses accessible.

**Proposed action 5: Avoid disability simulations. Listen to and believe disabled people instead**

Disability simulations, such as navigating the city with a blindfold when you are sighted, are still a fairly common method for raising awareness about accessibility problems. However, many disability rights activists and researchers claim that these simulations do not work (Abreu, 2018; Ladau, 2014b; Lavalvani & Broderick, 2013; Nario-Redmond, Gospodinov, & Cobb, 2017; Young, 2014). As argued by Stella Young, a disability stimulation fails “to capture the nuance and complexity of living in a disabled body. And it certainly fails to give a deep understanding of systemic discrimination and abuse faced by disabled people.” (Young, 2014) Priya Lalvani and Alicia A. Broderick (2013) assert that:

By focusing cultural and societal awareness on certain facets of the disability experience (e.g., on impairment) to the exclusion or obfuscation of other facets of the disability experience (e.g., disability oppression and discrimination), it becomes clear to us that dominant approaches to disability simulation (e.g., simulation of impairment) serve to constitute and reproduce, rather than disrupt, disability oppression. (p. 469)

“You want to further your understanding of disability?”, asks Young. “No props required! Just talk to disabled people. And listen to us when we tell you about the barriers we face,” she claims. I could not say it better.

**Proposed action 6: Compensate disabled people for their work**

While the City and other organizations regularly consult disabled people on an individual basis, these consultations generally offer little or no pay. The labour of disabled people participating in these consultations should be recognized with appropriate compensation.

**Proposed action 7: Create job opportunities in the field of accessibility and disability rights, and prioritize hiring disabled people for these positions**

Outside of disability rights organizations, very few jobs are available in the field of accessibility and disability rights, even though a lot of work is required to make the city accessible. Clearly, a need exists to employ more people in the field of accessibility and disability rights. Considering the poor representation of disabled people in employment, even in jobs related to accessibility issues, measures must be taken to ensure that disabled people apply for these positions and are properly accommodated.

**Proposed action 8: Use the term “accessibilité universelle” carefully and provide detailed information about the accessibility of events and spaces**

This term is being used more frequently to describe events and spaces that only provide specific accessibility features, such as a ramp at the front door of a venue. This is not what “accessibilité universelle” means. A ramp at the front door does not magically eliminate all the obstacles that disabled people encounter. Careless use of the term “accessibilité universelle” erases the complexities of accessibility and risks the further marginalization of disabled people. It is better to include information about an event or a space alongside other information—such as the closest métro station and available daycare on site—so disabled people will be able to make their own decisions and let the event organizers know if they need additional accommodations.

***Issue 2: Disabled Montrealers’ mobilities in the face of climate change***

Conducting wheeling interviews during a summer heat wave gave me an overview of the impact of extreme weather on the mobility of disabled Montrealers. Furthermore, I am finishing my thesis just a few weeks after the warmest summer in Québec history. Dr. Pierre Gosselin, health coordinator at Ouranos, a Montréal-based consortium on regional climatology and adaptation to climate change, estimates that by 2050 Montréal will have 50 days a year of temperatures higher than 30 °C. This number is three times higher than current averages. During the 2018 heat wave, 54 people died in Montréal (Fleming, Michaelson, Holmes, & Youssef, 2018). Those who lost their lives had a lot in common: they were poor, isolated, and had physical or mental difficulties. Scientists and environmentalists warn that heat will be the next big inequality issue (*Ibid.*). While disabled people are, and will continue to be, particularly affected by the effects of climate change, literature on this phenomenon is scarce (Wolbring, 2009;

Wolbring & Leopatra, 2012). To fight climate change, numerous experts are calling for an economic revolution. They argue that global economic growth, as we know it now, is incompatible with the protection of the environment—which includes the survival of humanity—and that de-growth is our only way out (Hickel, 2018). Since disabled people are often the first to be hit by economic upheavals (e.g., austerity measures affecting access to health or budget cuts limiting major investments in accessibility projects) and are poorly represented in high-level decision-making institutions, there is a real risk in moving towards another economic system that would continue their marginalization. Lately, numerous disability communities have been confronted by green initiatives that do not take disabled people into account, such as the movement for the complete elimination of plastic straws from restaurants and bars (Habel-Thurton, 2018; Imgrund, 2018; Szklarski, 2018). In some instances, it has been argued that accessibility and environmental concerns cannot be reconciled.

To fight the irreversible effects of climate change, Montréal is taking measures to create more sustainable urban environments. This initiative inevitably means a walkable and bikeable city with good public transit options that reduce car dependency. Throughout my thesis, I have shown that these infrastructures are still hard to use for many disabled people. Those who get around the city by car said that they would much prefer to use public transit. Some of my research participants do not even feel included as pedestrians. Others have mentioned that even though they are legally permitted to use bike paths with their mobility aids, they do not always feel welcome or comfortable on bike paths because they have had bad experiences with cyclists' attitudes. These observations raise the following question: Does the movement towards a more sustainable Montréal include disabled people and accessibility issues? Even though the number of projects integrating accessibility principles is on the rise (i.e., inclusive parks, safer pedestrian infrastructures, retrofitted métro stations), the projects or new services aiming to create a more sustainable city still frequently overlook disabled people and accessibility issues. In the United States, many experts have expressed their concerns regarding the exclusion of disabled people from the movement for smart cities. Jason Plautz (2018) points out that “a 2016 survey by Smart Cities for All found 60% of the 250 experts interviewed felt smart cities were failing people with disabilities because current technology is not designed to be accessible and inclusive.” James Thurston, vice president for global strategy and development at G3ict, argues that “cities are transforming the way they do services and businesses but they're not thinking about the accessibility.” (Plautz, 2018)

MTL Trajet, one of the projects of the Ville de Montréal's *Smart and Digital City Action Plan*, failed to include disabled people. MTL Trajet, an app developed by Concordia University and Transportation Research for Integrated Planning (TRIP), "records participants' trips and travel times, no matter what mode of transportation they use." (Ville de Montréal, 2018a) The objectives of the app are to measure the impact of road construction on users and to better plan public transit network developments. Although the City claims that the app covers all modes of transportation, MTL Trajet does not include Transport adapté. Furthermore, the app does not ask users whether they are disabled or not, which assumes that everyone has the same ability privileges when navigating the city.

In terms of transportation services, there is also a risk of increasing the gap between the options available to disabled and non-disabled Montrealers. Despite the increased accessibility of Montréal's public transit network, its full accessibility likely will not be achieved for another two decades. Moreover, although new transportation alternatives such as car-sharing services do not offer accessible services to people using mobility aids, this situation has not yet been identified as an issue at the political level. The movement for Mobility-as-a-Service, which aims to combine different types of transportation services on one user-friendly platform and reduce solo driving, is well underway in many cities, including Montréal (Ferraris, 2018). The urgent call to reduce the catastrophic effects of climate change and the potential of smart cities to eliminate the barriers encountered by disabled people should motivate us to do better. The risk of missing this unique opportunity is real if disabled people remain on the margins and are excluded from new transportation services.

## **AXIS 1: Prioritize inclusive and sustainable urbanism to fight sustainable ableism**

### **Proposed action 9: Ensure that strategies and initiatives tackling climate change adopt a disability perspective**

Accessibility should be considered an integral part of sustainable urbanism. The United Nations' Sustainable Development Goals stress the importance of including disabled people and eliminating barriers for safer and sustainable cities (United Nations, 2015). According to disability studies scholar Erik Leipoldt (2006), an emphasis on interdependence stemming from a disability perspective is the way forward. "The disability perspective of interdependence is a practical guide from the margins for making new choices that may lead to a just and sustainable

world—a concept that reduces the distance between each other and our environment,” (as cited in Wolbring, 2009) he writes.

**Proposed action 10: Clearly indicate how initiatives tackling climate change include disabled people and take into account accessibility**

Measures to reduce automobile traffic in Montréal are a good example of this kind of action. Still, there is a tendency to put in place measures without providing information about accessibility for disabled people. For example, during the 2018 pilot project restricting car traffic on the Camillien-Houde/Remembrance axis, one of the project’s opponents argued that the restrictions would prevent disabled and elderly people from accessing the mountain. The official response of the City was that elderly and disabled people could still, like everybody else, park their cars in one of the two mountain parking lots. No mention was made of any alternative transit options for this population. The fact that the STM buses on the mountain route are wheelchair-accessible was ignored. Moreover, even though the axis remained open to STM buses, no mention was made as to whether or not Transport adapté vehicles were authorized on the Camillien-Houde/Remembrance axis, which created confusion. Most Transport adapté vehicles are not identified by STM colours, since private taxi companies own them. A few of my research participants told me that most of their Transport adapté drivers avoid the axis and that some of them were told that they could not use it.

**Proposed action 11: Invest in research on inclusive and sustainable urbanism**

Creating inclusive and sustainable spaces can be a challenge. More research is needed to identify the best practices around the world and to develop innovations that meet our local needs. In its brief on the future of Parc Jean-Drapeau, the Ordre des architectes du Québec (2018) has suggested that the park could become a space to apply best practices or a location for a research centre dedicated to projects advancing knowledge on inclusive and sustainable urbanism.

**Proposed action 12: Take advantage of the movement for smart cities to eliminate obstacles and discrimination**

Montréal is in a good position to be a world leader in the field of smart cities because many tech companies choose Montréal to develop projects based on new technologies and open data (Roulot-Ganzmann, 2018). To achieve the smart city’s promise to enhance the quality of life of

its citizens, accessibility should be at the heart of its commitments and initiatives (Korngold, Lemos & Rohwer, 2017). This requires hiring experts in the fields of disability rights, technology and accessibility. Existing tools such as the app Montréal-Services aux citoyens—which enables citizens to report obstacles like potholes, graffiti, and broken street lights—could also be used for reporting accessibility barriers. Other tools specifically dedicated to accessibility that are generally developed in other countries should be tested and promoted to increase their use by Montrealers; for example, [StreetCo](#) is a collaborative pedestrian GPS app created in France with accessible itineraries for disabled people.

## **AXIS 2: Take action to remove the obstacles and eliminate the discrimination disabled people encounter on sidewalks and bike paths**

### **Proposed action 13: Improve the accessibility of sidewalks**

Broken sidewalks are among the most common obstacles encountered by disabled people. Major investments are needed, and some areas of the city are particularly problematic. In terms of design, the document [Aménagements piétons universellement accessibles: Guide d'aménagement durable des rues de Montréal](#) produced by the Ville de Montréal contains best practices to build accessible and walkable paths.

### **Proposed action 14: Ensure the accessibility and safety of temporary construction detours and signage**

The rules and regulations regarding pedestrian paths near construction sites need to be revised to include accessibility provisions. Construction companies should be forced to integrate accessibility into the temporary pedestrian paths they build. Furthermore, construction signs on sidewalks are a safety hazard for blind people. In addition to often being placed on pedestrian paths, these signs also have sharp edges and are difficult to detect with a white cane. Research could be done to find a safer construction sign material.

### **Proposed action 15: Promote the use of bike paths by mobility aid users**

Since June 1, 2015, motorized mobility aid users have the right to use bike paths all across Québec. However, in Montréal, this right remains unknown to other users of the City's bike paths. The Ville de Montréal should include mobility aid users in its promotion of cycling and inform mobility aid users of their right to use bike paths.

**Proposed action 16: Include disabled people in initiatives aiming to promote active transportation**

Disabled people are rarely represented in initiatives aiming to promote active transportation in the city. Since the objective of such initiatives is to change people's perceptions of urban mobility, these initiatives are the perfect occasion to change people's perceptions of disability.

**Proposed action 17: Repeal the provisions of the Projet-pilote relatif aux aides à la mobilité motorisées that limit the pedestrian rights of motorized mobility aid users**

Motorized mobility aid users should have the same rights and obligations as other pedestrians when they use sidewalks, rights that they had prior to the adoption of the Projet-pilote relatif aux aides à la mobilité motorisées. The Projet-pilote imposed additional rules, subjected to fines if not respected, that are hardly enforceable and compromise people's freedom and dignity. For example, motorized aid users should have the right to carry a child of any age on their laps without having to use a restraining mechanism. They should also be able to go outside their homes without having to worry about whether or not their mobility aids have visible and functional reflectors.

**Proposed action 18: Adjust the speed of motorized mobility aids according to the abilities and life habits of the people who use them**

As of 2010, the Régie de l'assurance maladie du Québec has limited the maximum speed of motorized wheelchairs and scooters to 10 kilometres per hour without considering users' abilities and life habits. If we are to encourage non-polluting means of transportation and, therefore, encourage the practice of wheeling, maximum speeds should be determined by disabled people and their occupational therapists, which was the case prior to 2010. Being able to wheel at 13 kilometres per hour instead of 10 makes all the difference, especially when wheeling long distances in bad weather conditions.

**Proposed action 19: Improve accessibility during winter**

The City's snow removal policy needs to be revised to strengthen its accessibility norms. For example, while the policy currently gives priority to bus stops, it does not address the accessibility of Transport adapté pick-up and drop-off points. Therefore, many of these locations are not prioritized for clearing even though they are critical points for the mobility of Transport

adapté users. Furthermore, boroughs could follow the example of the Plateau Mont-Royal, which implemented a program that provides assistance to disabled residents who are not physically able to clear snow from the entrances of their homes.

### **AXIS 3: Develop more transportation options based on the model of Mobility-as-Service and eliminate obstacles in the existing infrastructures and services**

#### **Proposed action 20: Improve the accessibility of the métro and bus systems**

In its [\*Plan de développement d'accessibilité universelle 2016–2020\*](#), the Société de Transport de Montréal (STM) (2017) has already identified several actions and projects to make its network accessible. Long-term significant investments will be needed to make the métro fully accessible. The costs are expected to rise as the technical complexities of the stations to be made accessible increase.

In addition to the actions announced in the STM plan, I propose the following:

- Develop a continuous training program for employees providing customer services (i.e., bus drivers, métro operators) to enable them to identify and prevent ableist attitudes and behaviours. Disabled people should be hired to give this training.
- Survey best accessibility practices of public transit agencies where the ridership of disabled people is higher. This should include touring some of these networks to experience their services and learn from their best initiatives.

#### **Proposed action 21: Recognize Transport adapté as an integral part of Montréal's public transit system**

There is still work to do in ensuring that Transport adapté is systematically included in all City initiatives relating to public transit. The absence of Transport adapté as an option in the MTL Trajet app and from the pilot project restricting car traffic on the Camillien-Houde/Remembrance axis are good examples of Transport adapté's exclusion. A Mayor's Office for Accessibility and Disability Issues could prevent Transport adapté from being left aside.

#### **Proposed action 22: Invest in Transport adapté so that it can offer efficient service**

While the demand for Transport adapté grows every year, funding from the Ministère des Transports du Québec has stagnated. This means that Québec is not contributing as much funding

for Transport adapté as it did in the past. Even though the government announced a budget increase in 2018, it will not be enough to absorb the increase in demand. Technological improvements are expected to be implemented in 2019 to reduce waiting time for TA users and provide them with more accurate information about the arrival of their rides (Société de transport de Montréal, 2018a). Even though these improvements will certainly ameliorate the experience of TA users, they will not be enough to offer a service as flexible and efficient as the service offered to the non-disabled clientele. The Government of Québec needs to increase its investment in Transport adapté to meet the growing demand and to support the development of technological innovations to make the service more efficient for its users.

**Proposed action 23: Develop a service that combines the use of Transport adapté and the métro and bus systems**

Transport adapté users need to be able to use the métro and bus systems as much as possible. In order to make this possible, they must be able to book a Transport adapté trip to a métro station or a bus without booking in advance and dealing with the TA's usual unpredictability, as is currently the case. Such a service would benefit users as well as transit agencies. For example: Marie-Josée would like to use the métro more often. However, the métro station near her home is not accessible. She needs to use Transport adapté to get to the closest accessible station without booking in advance and enduring the frequent TA delays. The Toronto Transit Commission has a service called [Family of Services](#) that facilitates the use of Wheeltrans (Toronto's adapted transit) and the subway and bus systems.

**Proposed action 24: Implement free reserved parking spaces near accessible métro stations**

If disabled people who currently use their cars due to the métro's lack of accessibility could park near accessible stations, using the métro would become an interesting option. Parking spaces reserved for disabled métro users could be implemented around these stations.

**Proposed action 25: Offer shared adapted bikes**

The City could develop an adaptive bike rental program to make biking more accessible for disabled people. The BIXI fleet currently does not offer adaptive bikes. [Portland, Oregon](#), launched such a program in 2017; [Victoriaville](#), Québec, offers three types of adaptive bikes.

### **Proposed action 26: Make the taxi fleet more accessible**

Finding a wheelchair-accessible taxi without having to book a day in advance is still particularly difficult in Montréal. Montréal needs to work with the taxi industry, the disability community and the Government of Québec to increase significantly the number of wheelchair-accessible taxis. The experiences of cities such as Vancouver, London and [New York](#), where the proportion of wheelchair-accessible taxis is much higher, need to be studied.

### **Proposed action 27: Include adapted vehicles in car-sharing services**

Renting an accessible van is very expensive and out of reach for many disabled people. As car-sharing services gain popularity in Montréal and offer an alternative to car ownership, it is time to provide options for disabled Montrealers as well. The Australia-based car-sharing company [Go-Get](#) has included a wheelchair-accessible vehicle in its fleet. In France, an entrepreneur who uses a wheelchair launched [Wheeliz](#), a peer-to-peer wheelchair-accessible car rental program.

### **Proposed action 28: Ensure that measures aiming to reduce solo driving do not unfairly penalize disabled people**

Measures taken to reduce solo driving need to consider the fact that some disabled people do not have the same mobility options as non-disabled people and rely on cars to get around. For many disabled people, Transport adapté, as it is now, is not flexible and efficient enough to be an alternative to driving. Furthermore, Transport adapté also has to circulate on residential streets, since some people need door-to-door transportation. Here is a good example: in 2020, downtown Oslo, Norway, will be free of most cars. However, access to cars transporting disabled people will be maintained (Deshayes, 2018).

### ***Issue 3: Representations of disabled Montrealers in the media and civic and political life***

While Montréal often prides itself for its diversity and openness to differences, when it comes to better representation in the media, as well as civic and political life, disability has yet to find its place alongside gender, race and sexual orientation. For example, the lack of representation of disabled people in the celebrations of Montréal's 375<sup>th</sup> anniversary is rooted in the cultural context of Québec in which disability is left to the margins and seldom visible in media. As Jacynthe states: "Le handicap, c'est dans l'angle mort de la diversité au Québec." I argue that this phenomenon makes it harder for disabled Montrealers to proudly identify as

disabled because they do not see positive representations of themselves. “Media not only matter, in their pervasiveness and power; they play an important role in the power relations and shaping of disability,” write Katie Ellis and Gerard Goggin (2015). The negative impacts of the scarcity of media representations of disabled people are exacerbated by the fact that non-disabled people produce the vast majority of the representations that do exist. This means that more often than not, these representations reproduce stereotypes and prejudices. “It’s not that disability is erased from mainstream culture. It’s that disabled voices, representations, perspectives, narratives are erased from mainstream culture,” argues critical disability studies scholar Sara Acevedo (California Institute of Integral Studies, 2018). In addition to poor media representation, the participants and I have observed differences between Anglophone and Francophone media coverage of disability issues in Montréal. The Francophone coverage is less abundant, and it tends to use more ableist language and to depoliticize disability issues. When *La Presse* launched a scholarship to support emerging journalists from marginalized groups in spring 2018, it failed to include disabled people as a marginalized community.

At the civic and political levels, the situation is no better. In Montréal, only one self-identified disabled candidate got elected in the 2017 municipal elections.<sup>99</sup> Following the elections, the City organized a roundtable on diversity. One of the objectives was to address the issue of representation within political life (Cambron-Goulet, 2018), since “organizations and decision-makers regularly make better and more comprehensive decisions when a diversity of voices is included” (Ellison, 2018). One disabled person was elected to the 15-person board. On October 19, 2018, the Ville de Montréal announced that, in order to fill vacant positions on municipal and para-municipal boards of directors and committees, it would recruit people from a candidate bank representing Montréal’s diversity (Ville de Montréal–Cabinet de la mairesse et du comité exécutif, 2018). The bank developed by Concertation Montréal, a partner of the City, includes women, people under 40, visible minorities, immigrants and First Nations people (Concertation Montréal, 2018). Disabled people are not identified as a group that falls under the umbrella of diversity, even though this population is underrepresented in political roles and the

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<sup>99</sup> Disabled people are disproportionately underrepresented in Canadian politics. “Out of a possible 2,084 candidates over the last three elections in each province, 20 of them had a disability according to the survey respondents—roughly 0.01 per cent,” explains Mario Lévesque (Thomson, 2014).

job market. It should also be highlighted that the disability rights movement and other social movements promoting diversity in Montréal have not yet managed to create strong solidarities and relationships. On the one hand, other social movements often organize events without paying attention to accessibility issues; on the other hand, the disability rights movement often overlooks the realities of disabled people living at the intersections of different systems of oppression.

Finally, some participants have explained that they face obstacles when trying to participate in various public consultations, which highlights the fact that disabled people's participation in civic life cannot be taken for granted. They have reported lack of accessibility, in addition to consultations that simply ignored disability issues altogether. In short, disabled people's right to participate in decision-making processes, a major component of one's right to the city, is regularly restricted. Considering that many of the issues raised in my thesis necessitate political actions and, in some instances, legislative changes, the poor representation of disabled people in political life is alarming.

### **AXIS 1: Take action leading to better disability representations in the media**

#### **Proposed action 29: Support disabled media makers and journalists**

The media industry has a role to play in combatting negative representations of disability. Since disabled people are underrepresented in the media, new initiatives are needed to support disabled media makers and journalists in Québec.

Here are three examples:

Since 2013, [AMI-télé](#), a French-language digital cable specialty channel based in Montréal, has been broadcasting shows on accessibility and disability issues. One of its recent shows, [Mission Accessible](#), features three young disabled Montrealers who patrol the city, finding solutions for the obstacles they encounter. This show was created by Kéven Breton, one of my thesis participants. In the United Kingdom, the government has launched a plan [aiming to double the number of disabled people working in television by 2020](#). In the United States, [Rooted in Rights](#) produces videos and social media campaigns on disability rights issues. The majority of their team of filmmakers, writers, designers and communicators is made up of disabled people: "In the spirit of 'nothing about us without us,' the stories we tell must be authentic representations of the people and communities we serve." (Rooted in Rights, n.d.)

### **Proposed action 30: Invite disabled experts to comment on disability issues**

It is not uncommon for media to discuss issues concerning disabled people without actually inviting disabled people to comment, or by inviting people who have little knowledge about disability rights to address these issues. In reality, there are many experts in disability rights organizations and academia who could be invited to speak.

### **Proposed action 31: Develop anti-ableism resources and training for journalists**

Most journalists are unfamiliar with disability politics, let alone ableism. Existing resources such as the [Recommended Guidelines on Language and Terminology – Persons with Disabilities: A Manual for News Professionals](#), developed by the Canadian Association of Broadcasters and available both in English and French, need to be promoted and consulted. Furthermore, more comprehensive and up-to-date resources should be developed. For example, the [National Center on Disability and Journalism](#), based at Arizona State University, provides support and guidance for journalists. Housing a similar project in one of Montréal's universities would be more than useful.

### **Proposed action 32: Hire disabled actors and actresses to play disabled roles**

In addition to being extremely rare, disabled characters in Québec are often played by non-disabled actors and actresses (Breton, 2016a). Furthermore, disabled actors and actresses seem condemned to solely play characters whose storylines revolve around their disabilities. The industry needs to hire disabled people not only to play disabled roles but also roles that are not necessarily destined for disabled people.

## **AXIS 2: Foster the participation of disabled people in civic and political life**

### **Proposed action 33: Amend the *Charte montréalaise des droits et responsabilités* to promote the representation of disabled people within consultative and decision-making bodies**

Article 16 of the *Charte montréalaise des droits et responsabilités* stipulates that the Ville de Montréal is committed to “promoting representation by women of all origins, Aboriginals, visible minorities and members of ethnic and cultural communities and young people within consultative and decision-making forums.” This article needs to be amended to include disabled people. This

would help to reverse the long history of underrepresentation of disabled people within the City's consultative and decision-making bodies.

**Proposed action 34: Increase the representation of disabled people on municipal and para-municipal boards of directors and committees**

In order to reach this objective, the Ville de Montréal needs to make sure that Concertation Montréal includes disabled people in their candidate bank of individuals representing Montréal's diversity. Disabled people with skills and experience to serve on a board of directors or a committee are not currently allowed to register to the candidate bank that is used by the City to ensure the diversity of these bodies.

**Proposed action 35: Examine the structures, practices and policies of political parties to ensure that they are not discriminatory towards disabled people**

Political parties should examine their own structures, practices and policies to ensure that they are not discriminatory towards disabled people. To attract disabled people within their ranks, political parties must be aware of how they might reproduce ableism without necessarily being aware of it. A disabled expert in accessibility and anti-ableist politics should conduct such work.

**Proposed action 36: Recruit disabled people as candidates for elections**

Brooke Ellison (2018) argues that “[p]eople with disabilities are often forced by circumstance to adopt the types of leadership, creativity, problem-solving, and resilience skills that excellence in elected office demands.” Political parties should aim to recruit disabled candidates and give them the appropriate support to run their campaigns.

**Proposed action 37: Provide appropriate accommodations to disabled politicians**

Considering that disabled people encounter multiple obstacles in their everyday lives and that being a politician requires attending multiple events and meetings and facing unforeseen situations, there is no doubt that being a disabled elected official in Montréal is a challenge. To address the absence of disabled elected officials and make a political career possible for them, it is imperative to provide disabled politicians with the accommodations they need.

### **Proposed action 38: Improve the accessibility of the City’s public consultations**

The Ville de Montréal recently launched its first public consultation on its action plan for universal accessibility, which includes several measures to ensure its accessibility, such as the presence of LSQ interpreters and attendants on site. Promoting the accessibility measures in advance is essential to encourage the participation of disabled people. Furthermore, online consultation surveys should be designed in a way that’s easy to understand for as many people as possible. The City’s consultation on its action plan for universal accessibility includes a 19-page survey with 65 questions; for many people, this is not accessible.

### **Proposed action 39: When appropriate, include accessibility and disability issues in public consultations**

Even when public consultations are about issues directly affecting disabled people, it is not uncommon for surveys or questionnaires to be designed in ways that completely ignore accessibility and disability issues. For example, in 2018, the Conseil jeunesse de Montréal invited people between the ages of 17 to 30 to fill out an online survey about their mobility needs. None of the questions specifically sought the input of disabled youth. There was no way for respondents to indicate if they were disabled. Furthermore, Transport adapté was not included in the long list of modes of transportation, and there were no questions on accessibility issues. People developing consultation tools need to think about ways to get disabled people’s input.

### **Proposed action 40: Support initiatives that aim to foster civic life and solidarities between local communities**

The vitality of civic life and the solidarities between different local communities are essential components of a city designed on a human scale. However, several obstacles restrict the participation of disabled people in civic life and create gaps between communities. For example, most non-profit disability rights organizations survive on tight budgets and struggle to make all their events accessible to the deaf community by providing sign language interpreters. Conversely, other non-profit organizations struggle to find affordable wheelchair-accessible venues to host their events. These problems reveal larger issues: sign language interpreters are only covered for very limited activities such as medical appointments, and affordable wheelchair-accessible venues are scarce. While we need to find solutions to the roots of these problems,

specific support programs should be developed to assist local communities wishing to make their projects and events accessible.

***Issue 4: The participation of disabled Montrealers in the City's decision-making processes and disability rights organizations***

Over the last decade, a group of Montréal disability rights organizations established themselves as the representatives of disabled Montrealers. They are what we now call the “milieu associatif”. The City regularly consults with them on matters relating to disability and accessibility, and a few consultative committees, such as the Comité des partenaires en accessibilité universelle, have been set up. In the French-speaking disability community, there are growing tensions between the “milieu associatif” and new activist initiatives concerning issues of representation and advocacy strategies for making the city accessible. While the “milieu associatif” has a privileged relationship with the City and is actively involved in the development of policies, action plans and projects, disabled people working in new activist initiatives, which mostly use social media to get their voices heard, are often left in the dark. Information about the activities of the City’s committees is extremely hard to find—if it is available at all. This makes it nearly impossible for people outside of the “milieu associatif” to know about the work being done by these groups. Furthermore, previous research demonstrated that young disabled people tend to be less involved in the established disability rights organizations. Those who are generally busy during the day because they work or go to school can hardly get involved in those organizations because the majority of their meetings take place during business hours. Online disability activism offers young disabled people a flexibility they have not found in the “milieu associatif”. This raises the important issues of the sustainability and succession of the movement. There have also been disagreements on what strategies should be used to advocate for accessibility in the city. For example, members of the “milieu associatif” are often reluctant to comment in the media on municipal disability issues because they work in close partnership with the City, while disability activists outside of the “milieu associatif” have sought to make the same issues visible in the media. Without a common strategy, they often find themselves at odds.

In short, the tensions between the “milieu associatif” and new activist initiatives reveal an interesting phenomenon. It is currently up for debate as to who has the legitimacy to represent the interests of disabled people at the municipal level and which strategies should be used. As I write this, the Ville de Montréal is announcing the first public consultation on its action plan for universal accessibility. Prior to this public consultation, disability rights groups—including

members of the “milieu associatif”, but also RAPLIQ, an organization at loggerheads with the city and the “milieu associatif”—have been consulted. The public consultations will enable people inside and outside of the “milieu associatif” to have their say in the elaboration of the action plan.

## **AXIS 1: For the Ville de Montréal**

### **Proposed action 41: Enhance the transparency of the City’s consultative committees**

To enhance the transparency of the City’s consultative committees on accessibility and disability issues, documents such as agendas, meeting minutes and a list of committee members should be made accessible on the City’s website. Citizens should be able to contact the person responsible for the committee.

### **Proposed action 42: Ensure that the diversity of Montréal’s disability communities is represented**

In Montréal, the Francophone and Anglophone disability communities are quite divided. Furthermore, the French-speaking disability community rarely addresses disability issues from an intersectional perspective. The City needs to be proactive in narrowing the gaps between Francophone and Anglophone disability communities and ensuring that a diversity of disabled Montrealers is represented on consultative committees.

## **AXIS 2: For disability rights organizations**

### **Proposed action 43: Revise the working principles of organizations to enable the participation of a wider sector of Montréal’s disability communities**

In order to reach out to more disabled Montrealers, young disabled people in particular, disability rights organizations need to find ways to accommodate people who are busy during weekdays. This can be achieved by increasing the number of consultations and the work done online, and by organizing in-person meetings in the evening.

**Proposed action 44: Ensure that all actions are taken to combat all forms of discrimination within the organizations**

Disability rights organizations need to ensure that their members and representatives are well-informed of how ableism intersects with other forms of oppression and have the necessary resources to examine their own—generally unintentional—discriminatory biases. In addition to creating a welcoming environment for a diversity of disabled Montrealers, this will help ensure that their demands and orientations reflect this diversity.

**Proposed action 45: Develop strategies to be more visible and efficient on social media**

In 2018, it is hard to imagine how social movements can achieve their goals without actively using social media. In recent years, Montréal disability rights organizations have increased their presence on social media. This is an important development that needs to be encouraged and accelerated. There are many great examples of online disability activism: one of the most interesting is the [Crip the Vote campaign](#) in the United States. Crip the Vote is an online movement dedicated to engaging disabled people in U.S. politics.

***Enjeu 5: Le manque de recherche et de ressources en français portant sur les enjeux du handicap au Québec***

La rédaction de cette thèse m'a confrontée une fois de plus à une réalité trop familière depuis que j'ai découvert les études critiques du handicap: la littérature académique disponible en français est rare et les recherches menées dans des contextes francophones le sont également. De plus, les ressources accessibles (ex: publications écrites, films) à un large auditoire francophone sont presque inexistantes. Ce contexte fait en sorte que les enjeux du handicap sont rarement analysés de façon critique au Québec.

Par exemple, je n'ai pas trouvé de recherche sur les expériences de personnes obtenant une aide à la mobilité par le biais du système de santé public québécois, alors que mes recherches montrent que l'obtention d'une aide à la mobilité a des ramifications politiques, sociales, économiques et culturelles. De plus, mes recherches sur l'histoire du mouvement québécois des droits des personnes handicapées m'ont permis de constater que de nombreux événements de cette histoire nécessitent une exploration plus approfondie afin de mieux comprendre le handicap dans le contexte québécois. Par ailleurs, les entrevues avec les participant-es ont révélé que les gens de ma génération en savent très peu sur les luttes menées par les militant-es handicapé-es

dans les années 70, 80 et même 90. De plus, les quelques participant-es qui avaient entendu parler du concept du capacitisme et de fierté du handicap s'étaient renseigné-es en consultant diverses ressources produites par les communautés anglophones aux États-Unis.

Comme je l'explique dans ma thèse, il est difficile d'avoir un regard critique sur le sentiment d'appartenance dans un contexte où le capacitisme est omniprésent sans toutefois être nommé et reconnu. James L. Cherney (2011) affirme qu'il est pratiquement impossible de prendre au sérieux la discrimination fondée sur le handicap et de reconnaître ses racines politiques, sociales, culturelles et économiques si nous sommes incapables de la nommer tout comme il était très difficile de lutter contre les inégalités entre les hommes et les femmes avant l'émergence du concept du sexisme. Il ajoute qu'avoir un mot pour critiquer un système d'oppression n'est pas une solution magique. La preuve étant que le sexisme existe toujours. Toutefois, cela permet d'avoir un outil puissant pour mieux comprendre les causes de ces discriminations et critiquer les impacts de ces systèmes sur nos sociétés et nos vies. Selon Cherney, si nous ne parvenons pas à démasquer le capacitisme, celui-ci risque de se perpétuer sous le couvert du changement. La reconnaissance du capacitisme est d'autant plus importante étant donné que la plus grande partie des plaintes reçues chaque année par la Commission des droits de la personne et des droits de la jeunesse concernent la discrimination fondée sur le handicap.

#### **Action proposée 46: Mener des projets de recherche portant sur le capacitisme, ses causes et ses impacts en contexte francophone**

Beaucoup d'efforts ont été consacré au cours des dernières années aux recherches sur la participation sociale des personnes handicapées dans la société québécoise. Toutefois, très peu d'études se sont intéressées plus particulièrement au capacitisme, à ses causes et à ses impacts. Elles sont pourtant nécessaires pour outiller les personnes handicapées et leurs allié-es, et combattre le capacitisme à petite comme à grande échelle. Les études critiques sur le handicap dans le monde francophone connaissent actuellement un développement sans précédent. C'est l'occasion idéale pour de s'assurer que le capacitisme est au cœur de ce champs d'études. La participation sociale des personnes n'est possible que si l'on s'attaque aux racines du problème qui ont, en premier lieu, rendu leur participation difficile.

**Action proposée 47: Répondre positivement à l'appel des personnes handicapées multi-marginalisées à mener des recherches s'intéressant au handicap et à ses intersections avec d'autres systèmes d'oppression**

Rares sont les recherches dans le champ des études critiques du handicap adoptant une approche intersectionnelle. Il est temps pour les chercheur-es de considérer les perspectives des personnes handicapées multi-marginalisées et, du même coup, d'évaluer leurs propres privilèges. La reconnaissance des privilèges de la part des chercheur-es francophones dans le champ des études critiques du handicap demeure marginale.

**Action proposée 48: Soutenir les étudiant-es et chercheur-es handicapé-es et leurs allié-es travaillant en français et étant engagé-es dans la lutte contre le capacitisme**

Étant donné qu'il n'existe pas encore de programme formel d'études critiques du handicap au Québec, il peut être difficile pour les étudiant-es et chercheur-es de mener leurs projets et de trouver le soutien nécessaire. Pour y remédier, il est possible de créer des groupes de travail, comme nous l'avons fait à l'Université Concordia avec le *Critical Disability Studies Working Group* en 2014. De plus, bien que différents programmes de soutien financier aux étudiant-es handicapé-es aient été mis sur pied par le gouvernement du Québec, certains besoins ne sont pas encore comblés et ce, particulièrement pour les étudiant-es qui poursuivent aux niveaux supérieurs. Par exemple, à titre d'étudiante au doctorat, j'ai eu l'occasion de participer à des conférences dans plusieurs villes et pays. Ayant besoin d'assistance pour accomplir certaines tâches de la vie quotidienne, je devais absolument être accompagnée pour voyager. Or, aucun programme ne couvre actuellement ces dépenses additionnelles. Par ailleurs, ce type d'aide est essentiel aux étudiant-es de toutes les disciplines.

**Action proposée 49: Reconnaître l'importance de nommer la discrimination fondée sur le handicap et d'utiliser le mot « capacitisme » dans les publications officielles**

En Ontario, la Commission ontarienne des droits de la personne a adopté en 2016 une Politique sur le capacitisme et la discrimination fondée sur le handicap. Cette politique a remplacé la *Politique et directives concernant le handicap et l'obligation d'accommodement* initialement adoptée en 2001, ce qui montre une évolution au niveau de la compréhension du handicap dans la société ontarienne. La définition utilisée par la Commission ontarienne est celle de la Commission du droit de l'Ontario qui se lit ainsi :

[Le capacitisme] peut se définir comme un système de croyances, semblable au racisme, au sexisme ou à l'âgisme, selon lequel une personne handicapée est moins digne d'être traitée avec respect et égard, moins apte à contribuer et à participer à la société ou moins importante intrinsèquement que les autres. Le capacitisme peut s'exercer de façon consciente ou inconsciente et être inscrit dans les institutions, les systèmes ou la culture d'une société. Il peut restreindre les possibilités offertes aux personnes handicapées et réduire leur participation à la vie de leur collectivité. (Commission ontarienne des droits de la personne, 2016)

Cette longueur d'avance de l'Ontario sur le Québec s'explique fort probablement par la plus grande reconnaissance du capacitisme (*ableism*) dans le monde anglo-saxon. Les instances jouant un rôle important dans le respect et la promotion des droits de la personne au Québec, tels que la Commission des droits de la personne et des droits de la jeunesse et la Ville de Montréal, doivent, elles aussi, reconnaître l'existence du capacitisme et s'engager clairement à le combattre.

### **Action proposée 50 : Soutenir des projets et initiatives qui contribuent au développement de la fierté handicapée**

Dans les communautés anglo-saxonnes, la *disability pride* passe surtout par les [disability arts](#) et la célébration de l'histoire des droits des personnes handicapées. Depuis plusieurs années, des militant-es organisent une [Disability Pride March](#) dans les rues de Toronto. En [France](#), des militant-es handicapé-es se mobilisent de plus en plus pour affirmer leur fierté d'avoir des corps et des esprits différents. Bien que l'expression claire d'une fierté handicapée peine à émerger au Québec, le nombre grandissant de militant-es et d'artistes pourrait favoriser l'apparition d'un tel mouvement de fierté. Il est cependant nécessaire qu'ils et elles aient accès au soutien nécessaire pour mener à bien leurs projets.

### **Action proposée 51 : Créer des courts documentaires en français sur le capacitisme**

Je termine cette série de propositions d'actions par le projet qui m'attend à la fin de mon doctorat. En 2019, je débiterai un projet de recherche postdoctoral à l'Université d'Ottawa au cours duquel je réaliserai de courts documentaires destinés à un large public abordant le capacitisme dans la francophonie canadienne et québécoise. Ces courts documentaires seront principalement composés d'extraits d'entrevues avec des chercheur-es, des activistes handicapé-es et des allié-es provenant de différentes communautés francophones et reflétant la diversité de ces communautés, notamment en termes de genre, d'orientation sexuelle et de race. Je souhaite y aborder des enjeux qui ont été soulevés dans ma thèse et dans mon militantisme comme le capacitisme et ses intersections avec d'autres formes de discrimination, la *crip theory*, les représentations

capacitistes dans les médias (p. ex. l'*inspiration porn*) et l'aide médicale à mourir. Je souhaite ainsi contribuer au mouvement pour la lutte contre le capacitisme au Québec et dans la francophonie.

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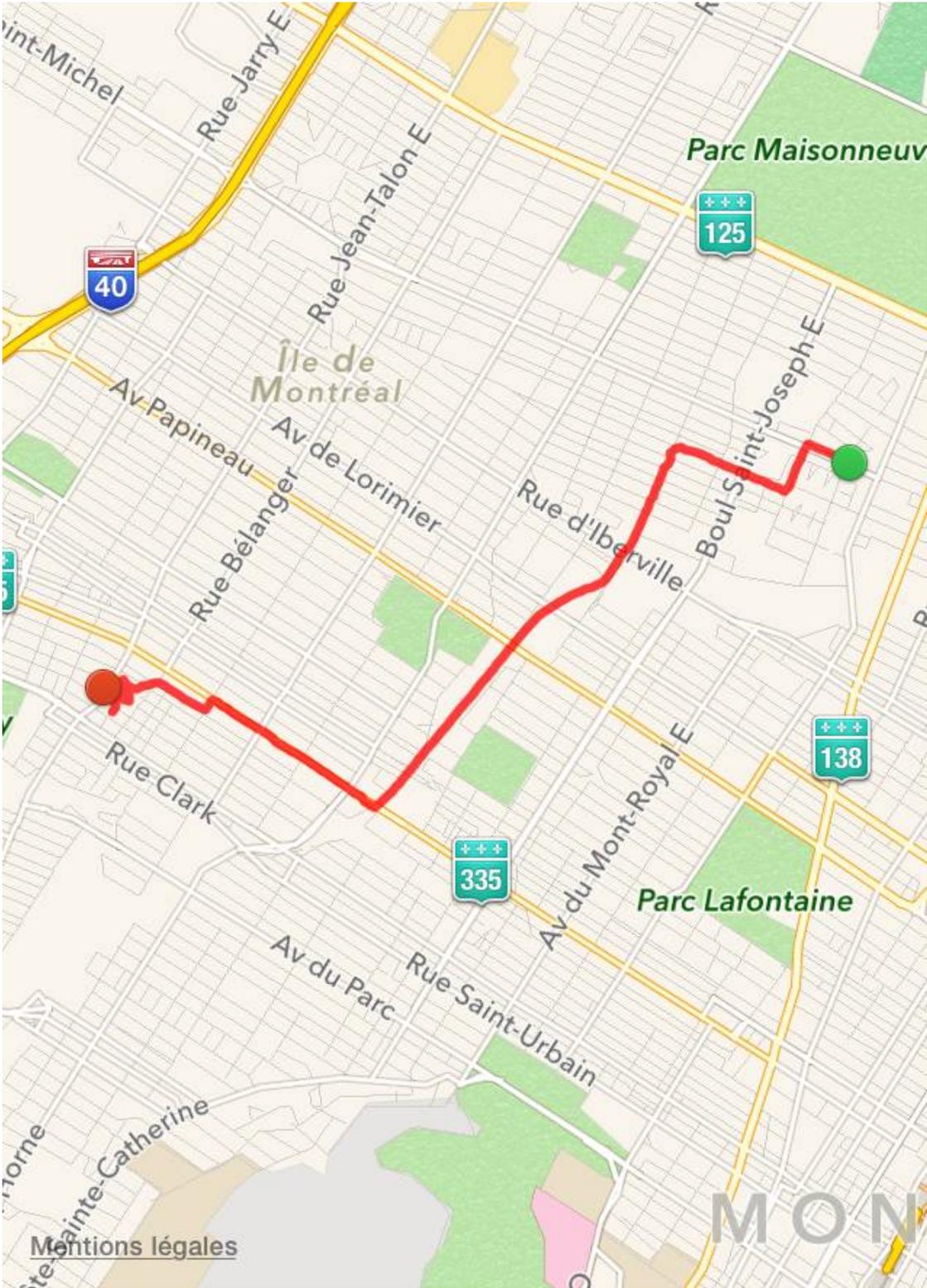
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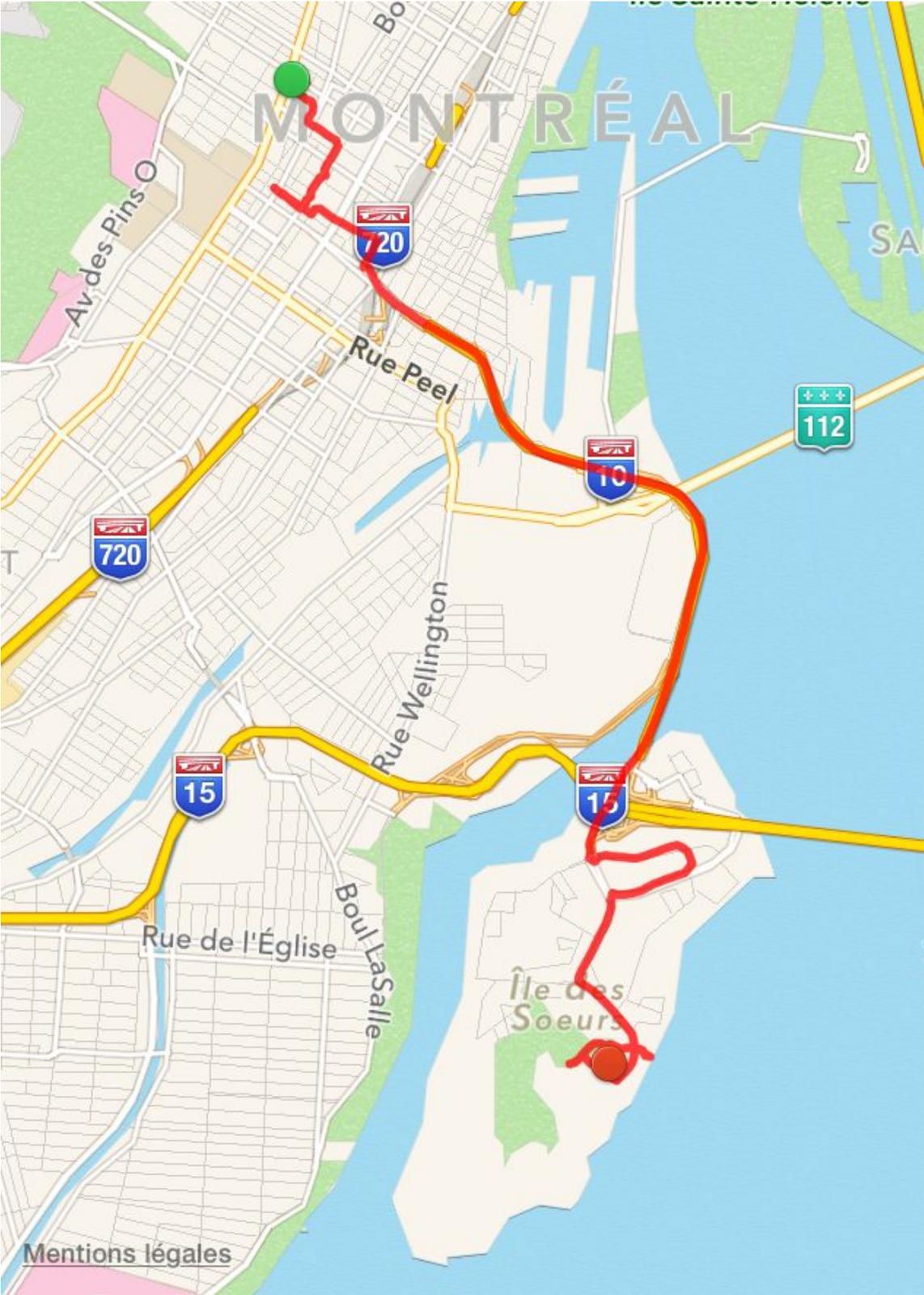
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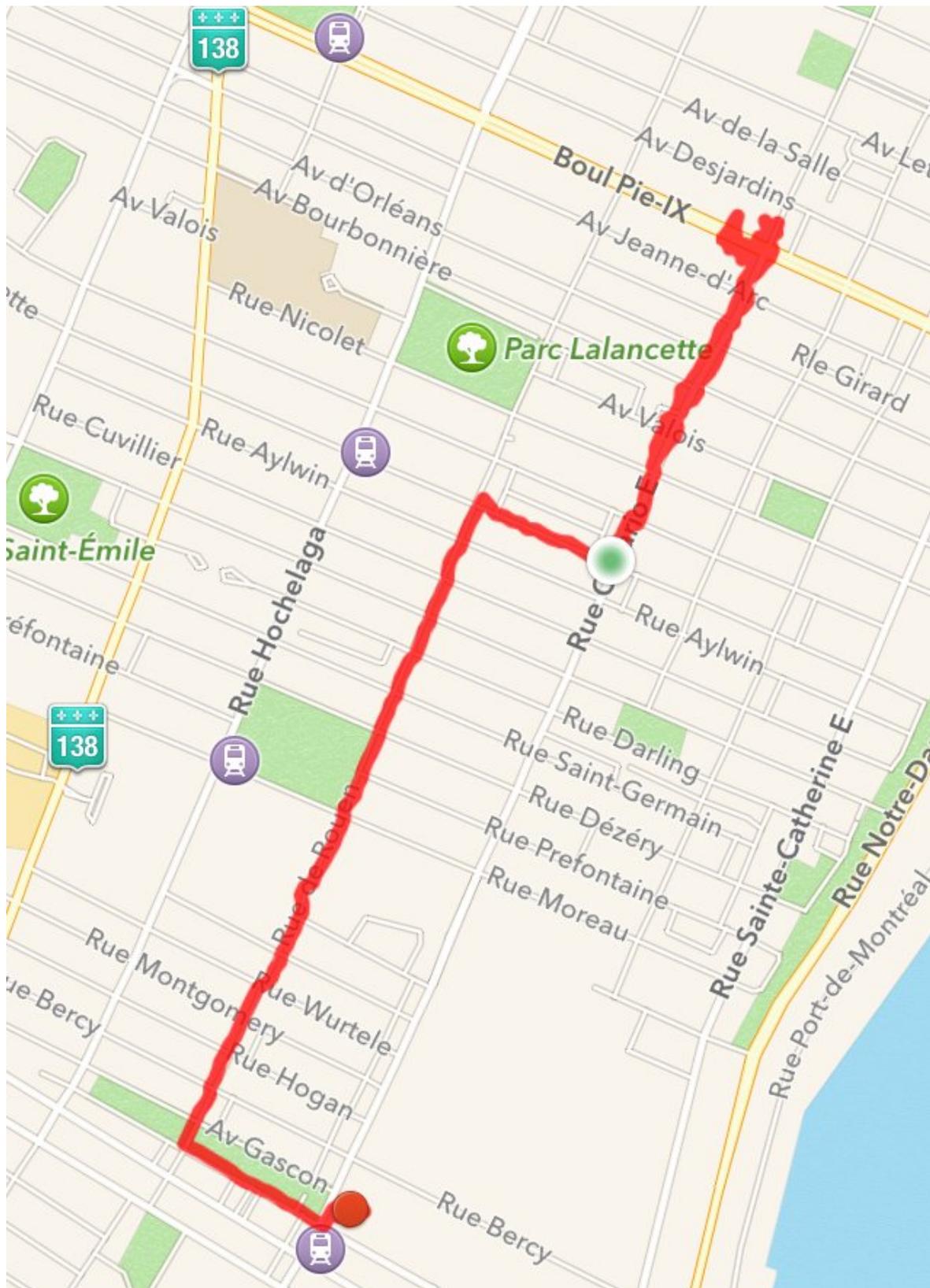
Participant: Pierre Lemay



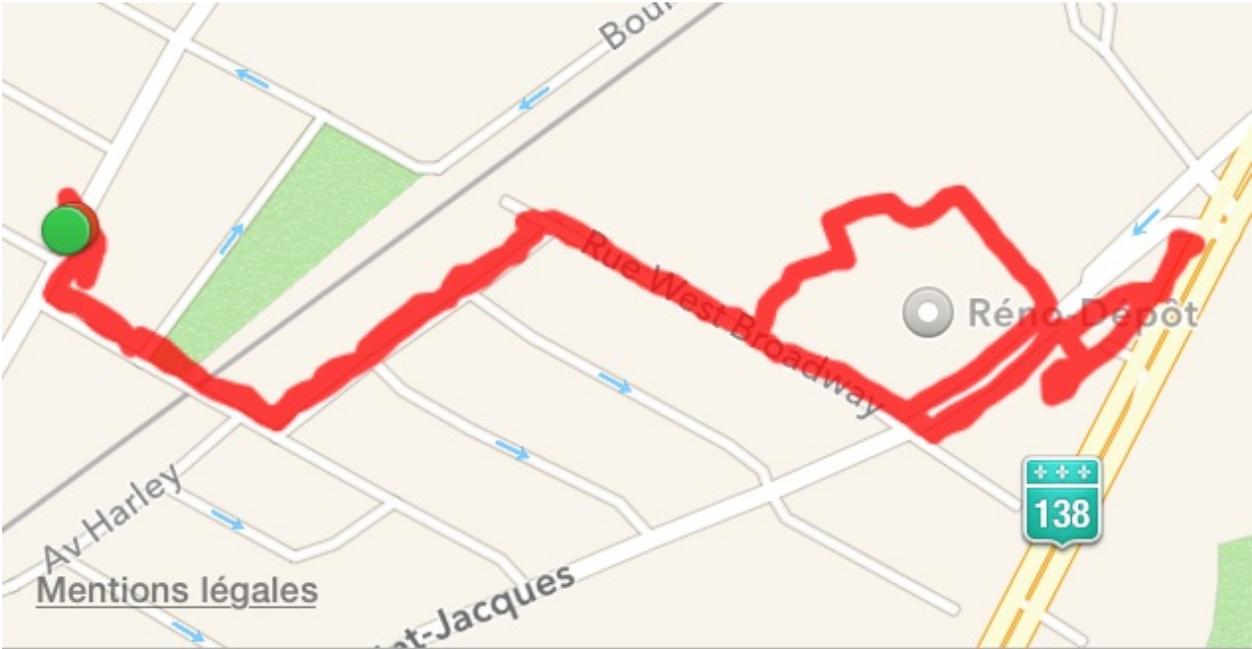
Participant: Isabelle Boisvert



Participant: Jacynthe Ouellette

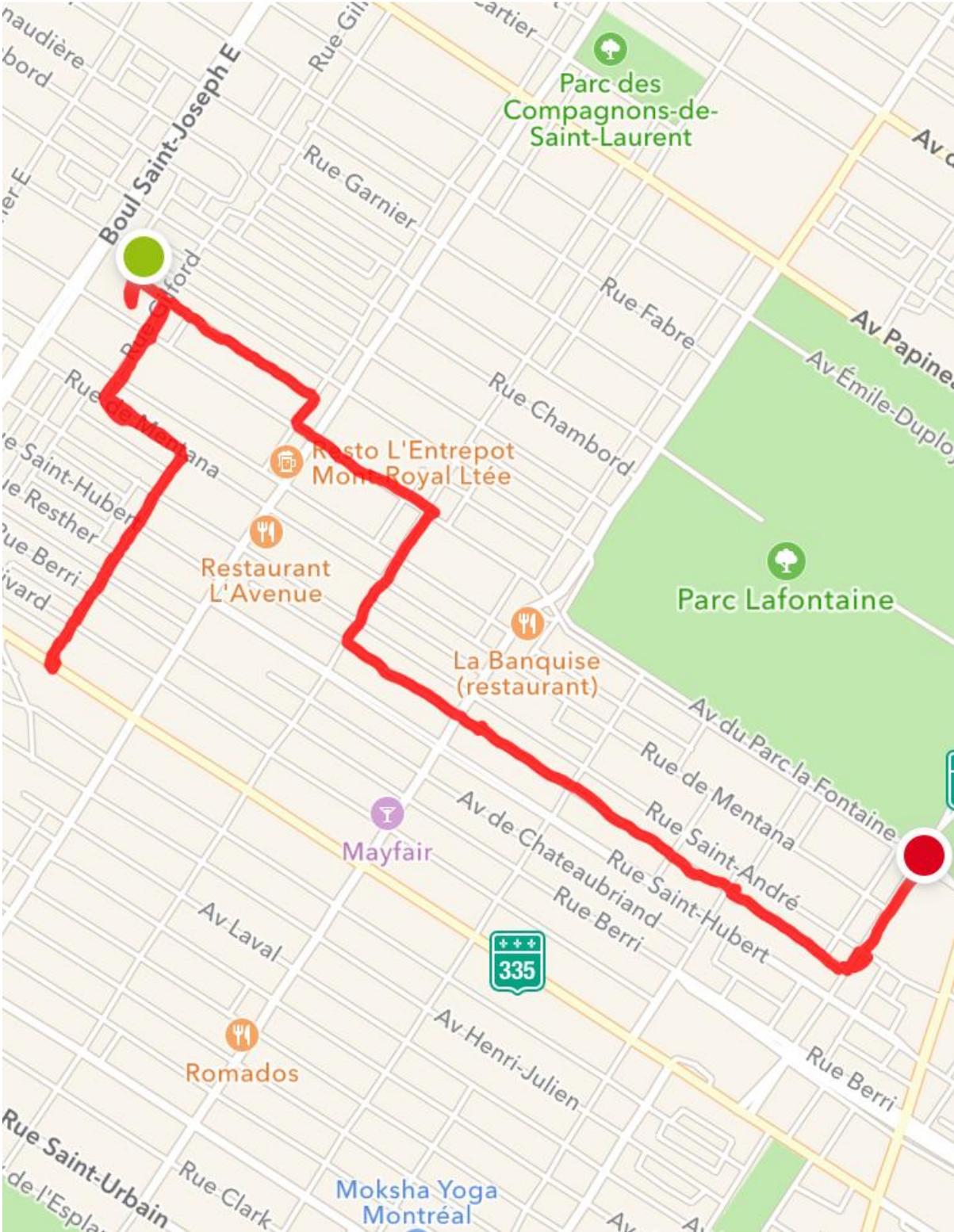


Participant: Sandra Gualteri

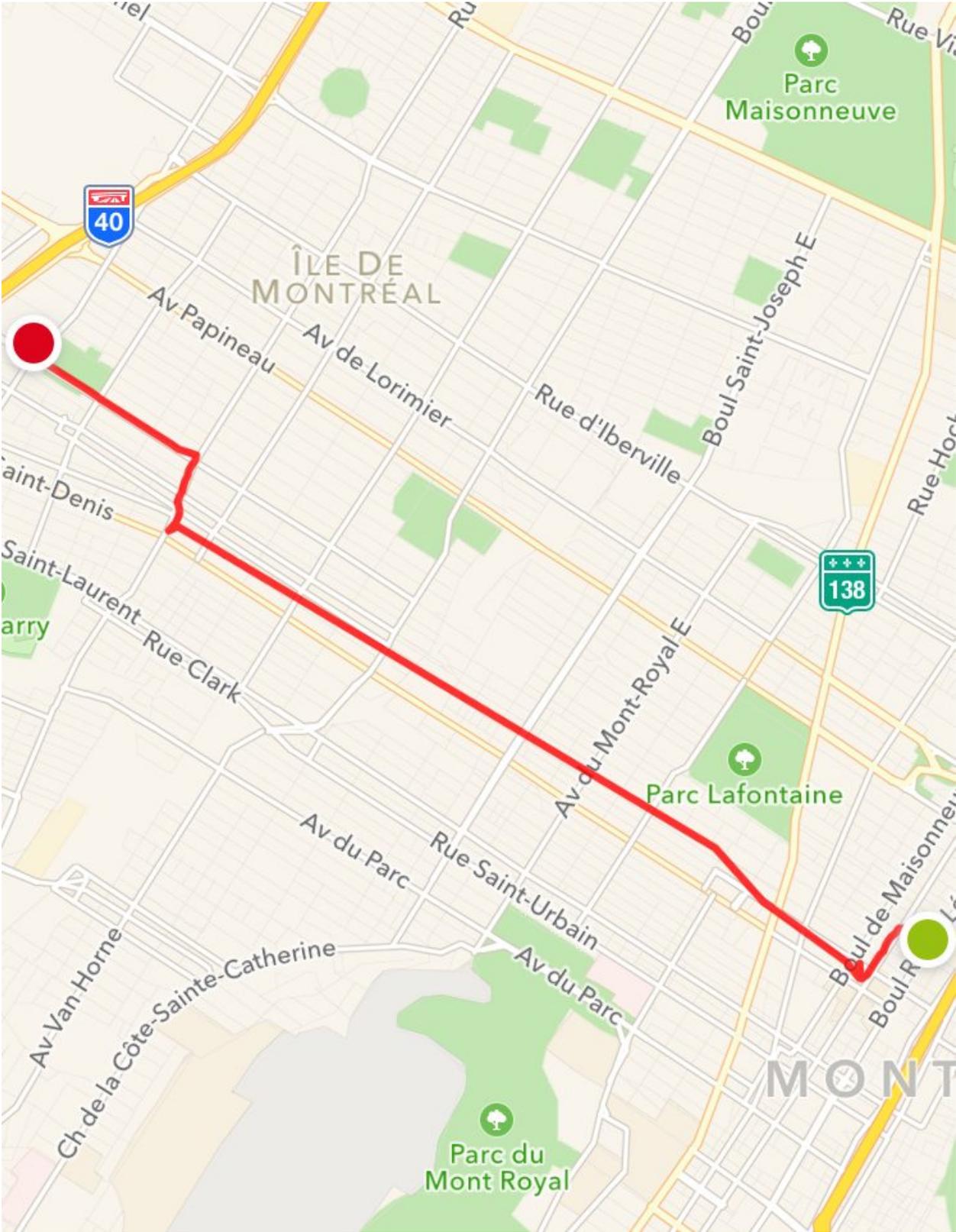




Participant: France Geoffroy

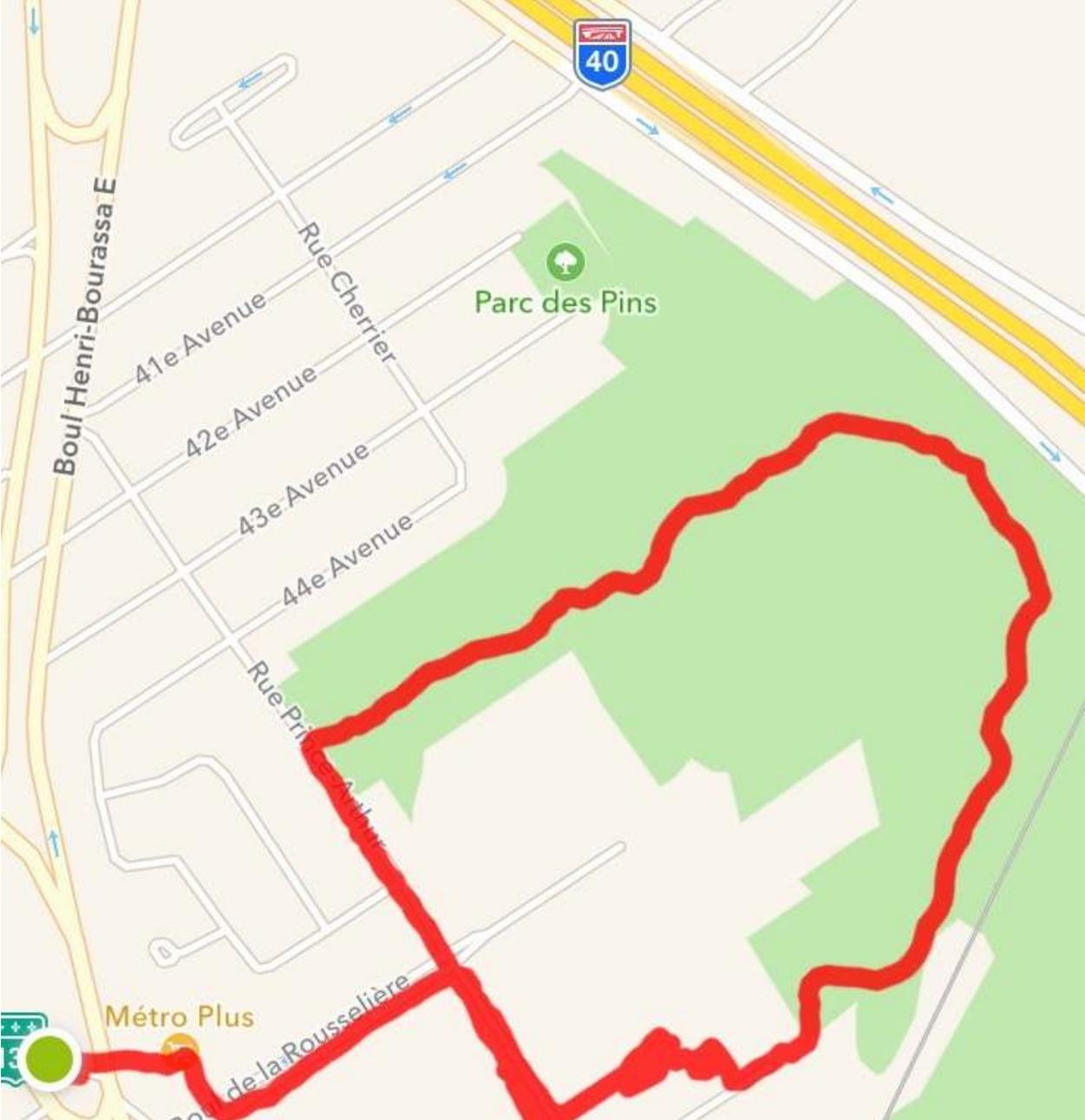


Participant: Kéven Breton





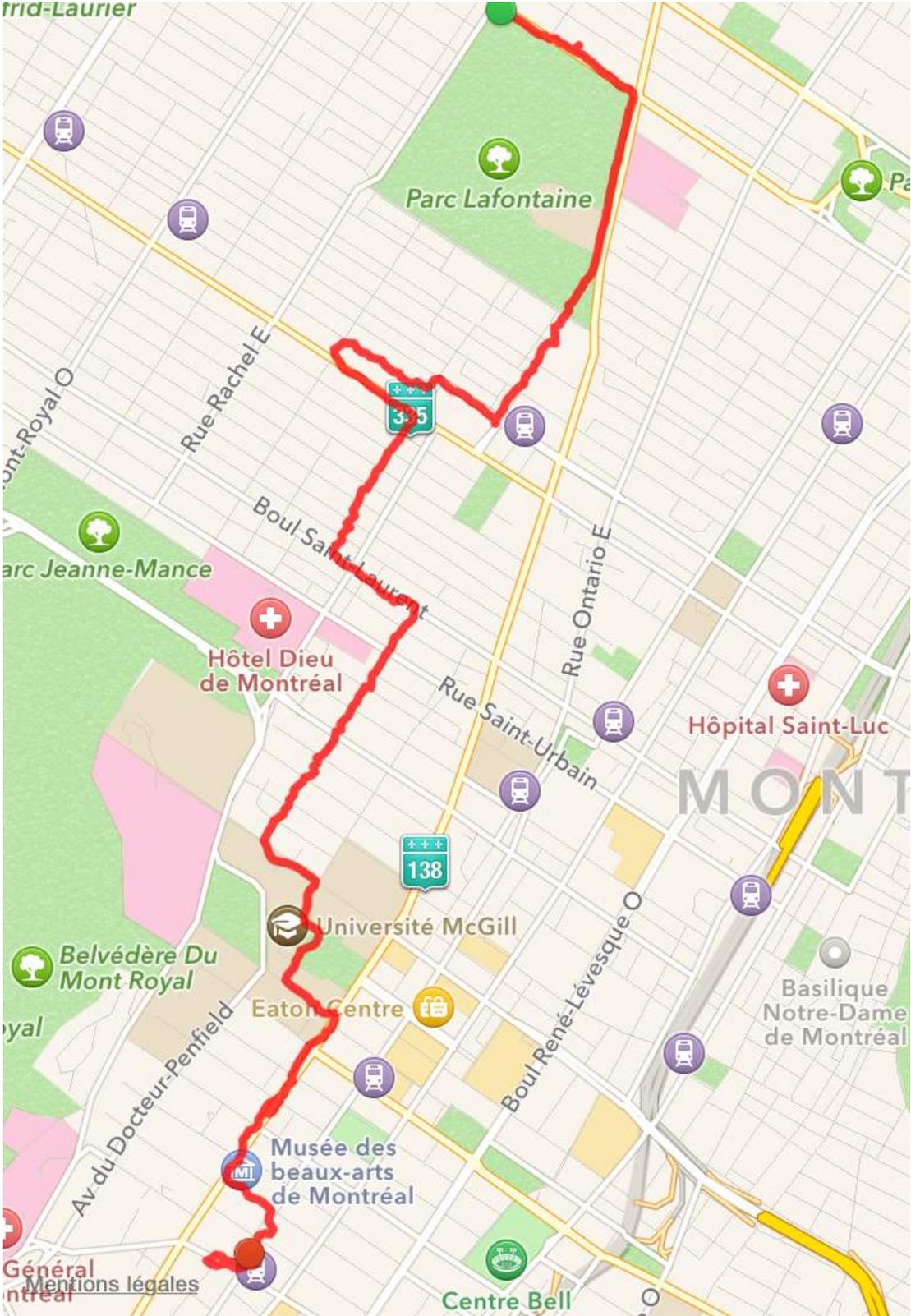
Participant: Caroline Goyette



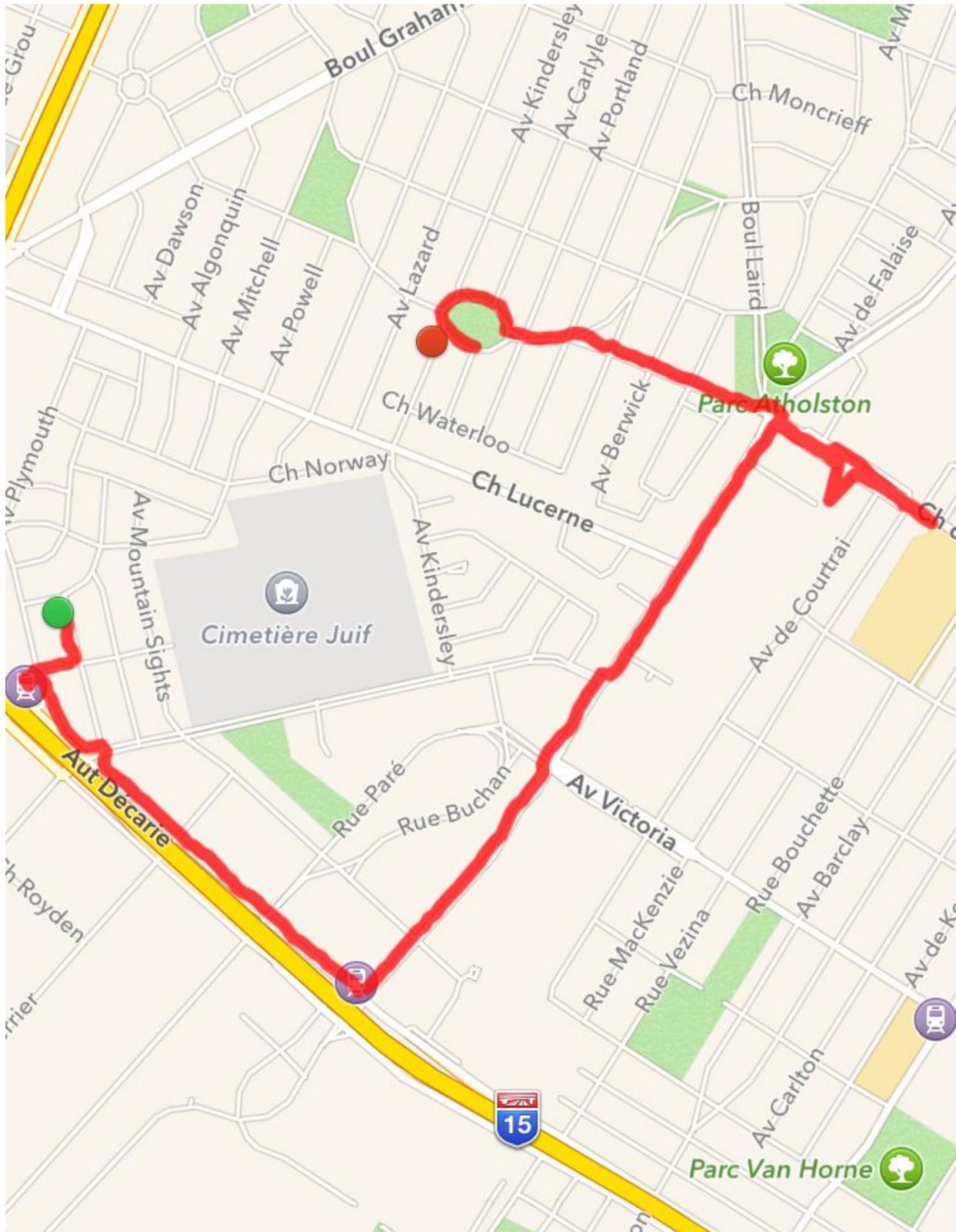




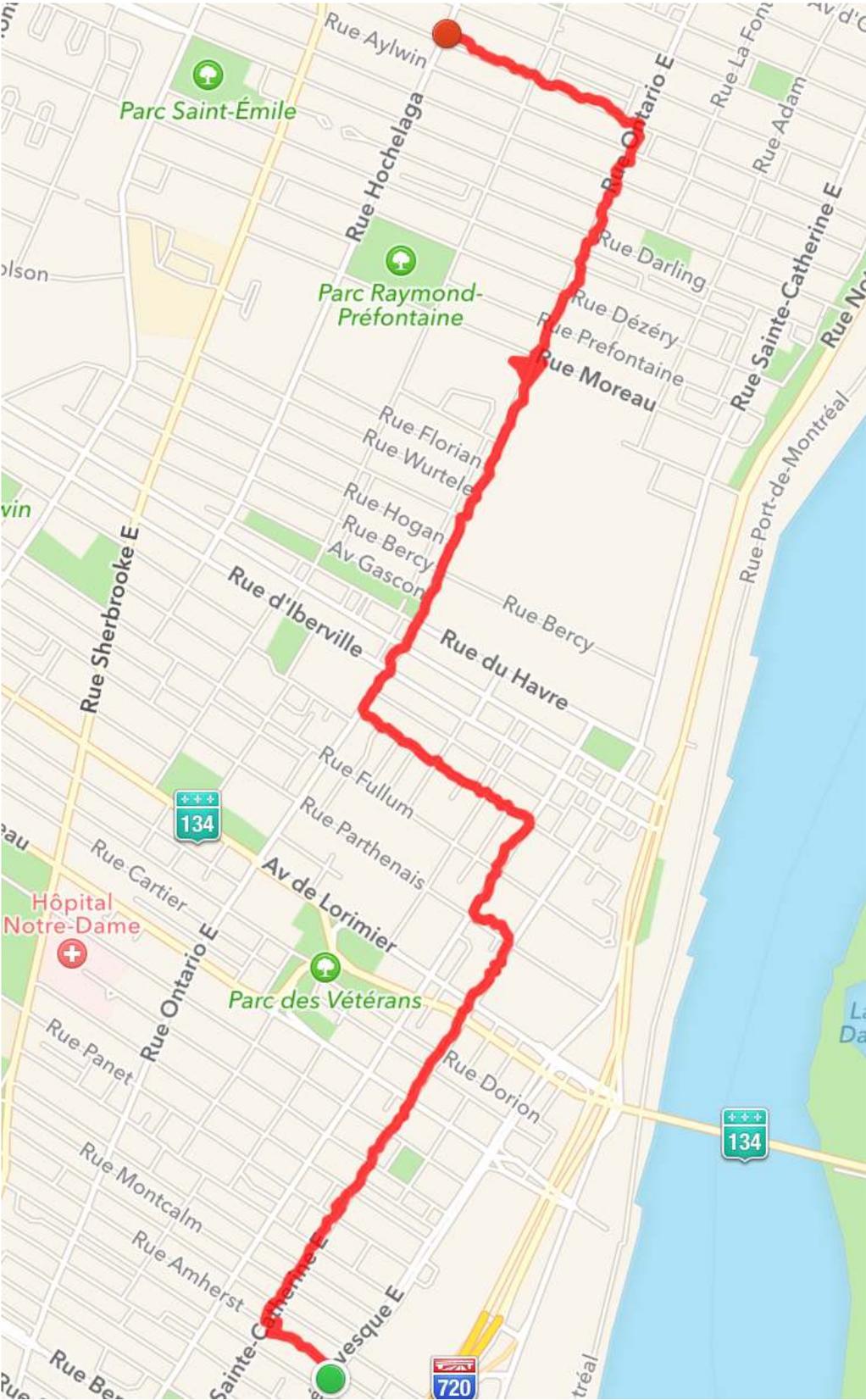
Participant: Marie-Eve Veilleux



Participant: Nabila Nouara

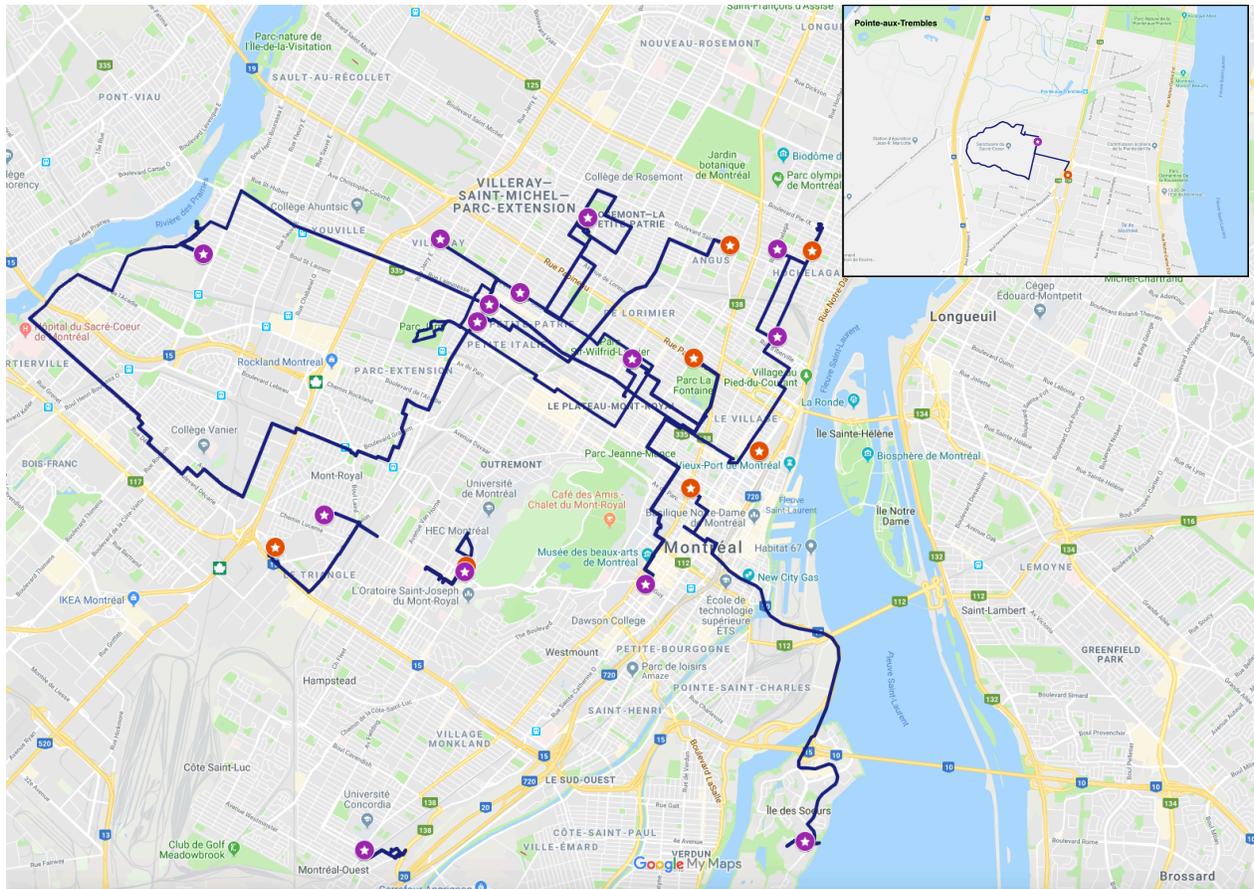


Participant: Luc Fortin



## Appendix B – Itineraries of Wheeling interviews

(Drawn with Google maps based on the data collected with the application MapMy Walk. The map is [available online](#).)



## **Appendix C – Disability Organizations Glossary**

### **Accessibilize Montreal**

Founded: 2013

Membership: No. Everyone just gets involved whenever they want.

Structure: There is no board and no staff.

Participants who are currently members or supporters: -

Participants who have been members or supporters: Kéven and Marie-Eve participated in a protest organized by Accessibilize Montreal for the accessibility of the métro in 2014.

This initiative is a grassroots group based in Montréal that challenges ableism in the city through direct action. In the past few years, the group has been actively advocating for accessible transit and for making ableism known as a system of oppression. Most people involved in the group are students at Concordia and McGill universities

### **Action des femmes handicapées de Montréal (AFHM)**

Founded : 1986

Membership: Yes (individuals)

Structure: There is a board, an executive director and a small team of staff.

Participants who are currently members or supporters: Louise, Isabelle, Nabila, Laurence

Participants who have been members or supporters: France, Sandra

AFHM works for the full participation of disabled women in Québec society. It adopts a feminist intersectional approach to its analysis and demands. This is unique within the Québec disability rights movement. The most important issues have been, and unfortunately are still, access to accessible healthcare, appropriate services to fight against violence and abuse and employment. Another particularity of AFHM is that its activist core is mainly composed of disabled women of colour or with an immigrant background (Masson, 2013).

### **Association multiethnique pour l'intégration des personnes handicapées (AMEIPH)**

Founded: 1981

Membership: Yes (individuals and organizations)

Structure: There is a board, an executive director and a small team of staff.

Participants who are currently members or supporters: Nabila

Participants who have been members or supporters: -

This association helps disabled people from different cultural backgrounds. They mostly work with people who have recently immigrated to Canada and need assistance to get the services they need but also to find a community. They advocate for the elimination of the numerous barriers non-white disabled people are facing.

### **Alliance québécoise des regroupements régionaux pour l'intégration des personnes handicapées (AQRIPH)**

Founded: 1995

Membership: Organizations

Structure: There is a board and an executive director.

Participants who are currently members or supporters: Christian  
Participants who have been members or supporters: -

This organization is composed of fourteen regional groups across Québec. The main objective is to promote and advocate for the rights of disabled people and their families.

### **Association québécoise des personnes de petite taille (AQPPT)**

Founded: 1989 (The Club du Petit Monde du Québec was founded in 1976. It changed its name and mission in 1989)

Membership: Yes (individuals)

Structure: There is a board, an executive director and a small team of staff.

Participants who are currently members or supporters: Marie-Josée, Laurence

Participants who have been members or supporters: -

This association is administrated by people with dwarfism and parents of children with dwarfism. It provides individual support to its members, advocates for the rights of people with dwarfism and works to break down prejudices and discrimination against its members. One of the greatest fights led by AQPPT is to make dwarfism recognized as a disability.

### **Association québécoise des étudiants ayant des incapacités au post-secondaire (AQEIPS)**

Founded: 1991

Membership: Yes (individuals and education institutions)

Structure: There is a board, an executive director and a small team of staff.

Participants who are currently members or supporters: Nabila, Laurence, Isabelle

Participants who have been members or supporters: Marie-Eve, Christian, Geneviève, Louise, Marie-Josée

The organization advocates for equal opportunities in post-secondary education. One of the main issues is the lack of accommodation and resources to ensure disabled people a fair access to education. The majority of the board members are disabled students at the post-secondary level.

### **Confédération des organismes de personnes handicapées du Québec (COPHAN)**

Founded: 1985

Membership: Yes (disability organizations)

Structure: There is a board, an executive director and a small team of staff.

Participants who are currently members or supporters: Laurence (as AQEIPS representative)

Participants who have been members or supporters: -

COPHAN is composed of more than sixty disability organizations in Québec. It works on a variety of disability issues every year. Organization members participate in COPHAN's different working committees such as health and social services, education and transportation. COPHAN only works on issues related to the provincial and federal jurisdictions.

### **Ex aequo**

Founded: 1980

Membership: Yes (individuals)

Structure: There is a board, an executive director and staff.

Participants who are currently members or supporters: Laurence, Isabelle

Participants who have been members or supporters: France, Marie-Eve, Christian, Marie-Josée

This organization is based in Montréal. It promotes the rights of disabled people with physical impairments. However, a lot of its recent work has been on universal accessibility, which is a concept that considers a variety of impairments. The organization is also active on issues related to housing and home care support.

### **Québec accessible**

Founded: 2015

Membership: No. Supporters (individuals and organizations) can join by signing up online.

Structure: There is no board but a small team of five volunteers.

Participants who are currently members or supporters: Marie-Eve, Nabila, Laurence, Marie-Josée, Isabelle, Geneviève

Participants who have been members or supporters: -

Québec Accessible is a grassroots initiative advocating for a strong provincial accessibility law for people with disabilities. (Québec accessible, 2016) In contrast with the other organizations in this glossary (with the exception of Transport mésadapté) it does not have members but supporters (individuals and organizations). It is mostly active on social media.

### **Regroupement des activistes pour l'inclusion au Québec (RAPLIQ)**

Founded: 2009

Membership: Yes (individuals and organizations)

Structure: There is a board. All people involved with RAPLIQ are not paid.

Participants who are currently members or supporters: France, Nabila, Isabelle, Luc

Participants who have been members or supporters: Marie-Eve, Louise, Marie-Josée, Sandra, Geneviève

RAPLIQ is a disability rights organization particularly active on issues of physical accessibility. Since its foundation, it has organized many protests and filed hundreds of complaints at the Commission des droits de la personne et des droits de la jeunesse.

### **Regroupement des organismes de promotion du Montréal métropolitain (ROPMM)**

Founded: 1985

Membership: Yes (disability organizations)

Structure: There is a board, an executive director and a small team of staff.

Participants who are currently members or supporters: Laurence (as representative of AQEIPS)

Participants who have been members or supporters: -

ROPMM is composed of thirty non-profit disability organizations representing people with physical impairments based in Montréal. It works in close collaboration with other organizations such as RUTA, Ex aequo and COPHAN.

### **Regroupement des usagers du transport adapté et accessible de Montréal (RUTA)**

Founded: 1980

Membership: Yes (individuals and organizations)

Structure: There is a board, an executive director and a small team of staff.

Participants who are currently members or supporters: Nabila

Participants who have been members or supporters: Laurence, Marie-Josée, Sandra

RUTA advocates for the right of disabled people to have access to public transit in Montréal. RUTA used to solely focus its energy on issues related to Transport adapté. Its mission changed in 2007 to include access to, what is called in the community, regular transit (buses and métro).

### **Transport mésadapté**

Founded: 2013

Membership: Facebook users join by submitting a request.

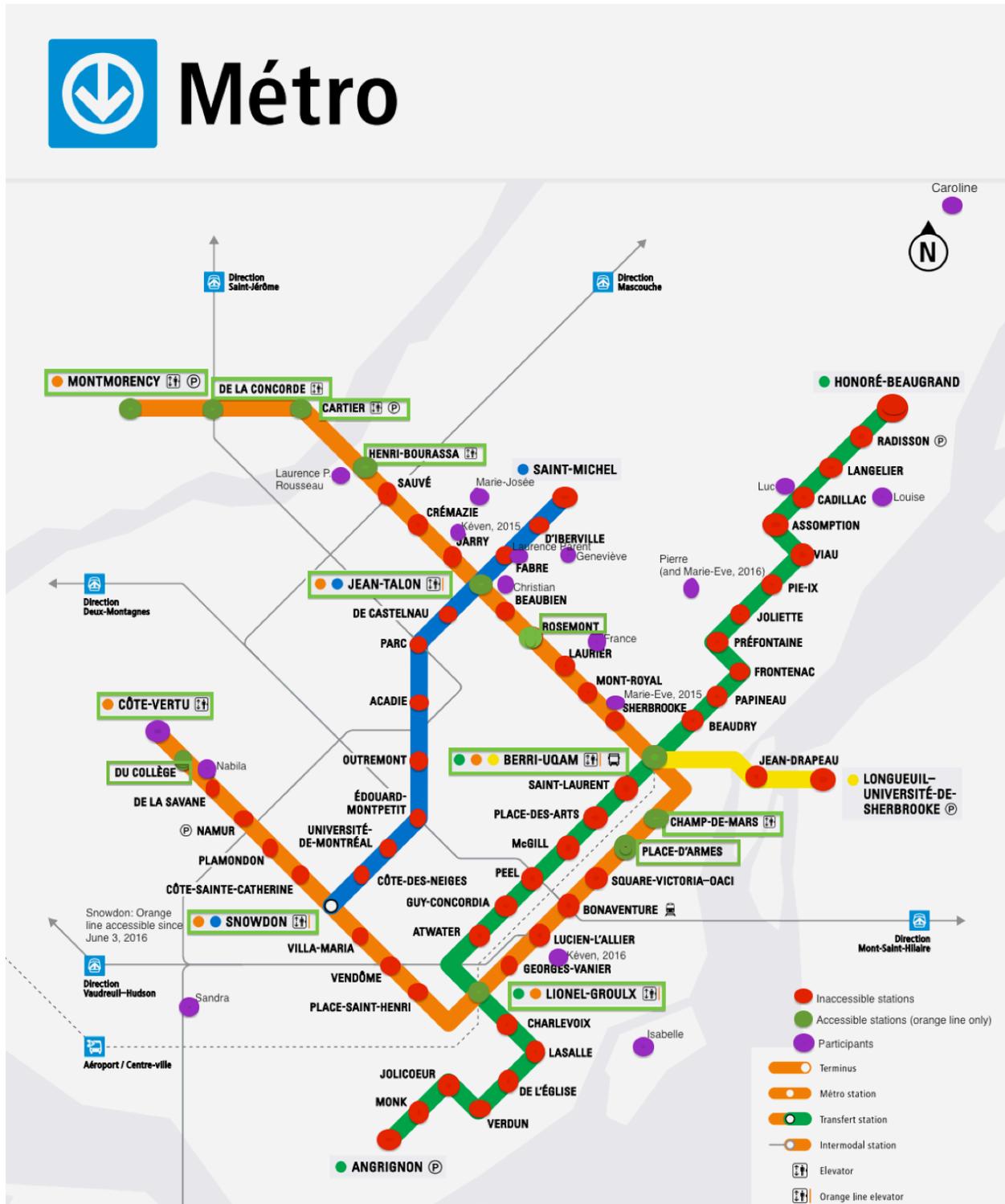
Structure: There is no board and no staff. Two persons administrate the group.

Participants who are currently members or supporters: France, Marie-Eve, Christian, Nabila, Laurence, Marie-Josée, Isabelle, Sandra, Geneviève, Kéven, Caroline

Participants who have been members or supporters: -

Transport mésadapté is a Facebook group created and administered by Marie-Eve Veilleux and I. It is a virtual space where members share stories and information about public transit. There are also discussions and debates. Most of the posts are about issues in Montréal.

**Appendix D – Map of métro’s accessibility and participants’ place of residence**  
(updated in November 2018)



**Appendix E – Accessible métro stations at the time of the wheeling interviews**  
(Credit: Kéven Breton)



**Appendix F – Accessible métro stations when I completed this thesis**  
(December 2018) (Credit: Kéven Breton)

