

Paved Trails:  
Crip Poetics as an approach towards decolonizing accessibility

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## ABSTRACT

Poetry is a gentle but relentless coach, a lover, personal benchmark, and record for growth. She shifts beliefs, practices, and emotions, tracking pitfalls, steps back, steps around, stillness, like a smooth laketop or slow-streaming river. In this Research-Creation thesis, I develop my version of 'Crip Poetics' through autoethnographic methods including video poems and hybrid prose-poetry writing. Drawing on Critical Disability Studies, Indigenous Studies, and Mobility Studies, I bring questions of white supremacy and settler colonialism into conversation with accessibility in Canada. I interview Indigenous people with varying relationships to disability and disabled people of multiple settler cultures, using qualitative methods including Hangout as Method and Wheeling Interviews. Engaging with interview transcripts as text, to continue conversation and exchange (with interviewees), this study offers reflections on interviewing as a method. Reflecting on the limits of participant-action research and representation, I interrogate the role of researchers in marginalized knowledge production, engaging with the limits and possibilities of 'unsettling research'. I aim to redirect eugenic trends in disability discourse and history towards prioritizing the telling of our own stories. It's my hope that these conversations and the intersections of these struggles are brought to the fore—this thesis being one avenue among many to further this work. Come with me as I play with mainstream, heteronormative, settler framings of dichotomies between accessibility and nature. Dance with me between words and beyond political affiliation, witness my searching for ancestors in the words of an earlier generation of People with Disabilities, on waves actuated by water taxi, towards my interviews.

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## Chapter 1: Introduction

### 1.1 Deciding the shape of your future body, aka Euro Canadian logics of correctionalism

Physio is really weird, it's like I appreciate it and I was waiting a long time on a waitlist to get access to it and then she's very thorough and she has a good eye for physical things and everything, and also she's telling me things that I definitely already knew, like 'you have to engage your ass muscles' and you know, 'stretching is all about how it feels, one stretch might work for someone and not the other.'

Her um, evaluation of me, it's like she's literally holding me up to like the actual literal norm, like she's comparing the way that my body moves and looks and stretches and everything to an actual standardized norm, and then anything that's different from that norm is called a 'deviation'. It's a bit hard to reconcile the desire and need for physio that will hopefully reduce my pain and give me good physical practices for long term use, with my constant work on self-acceptance and appropriation/ celebration of "deviance", as a crip, as a queer, as someone who loves nonconformity. I find it kind of jarring to be in this state where I'm like, 'please evaluate me against this two-dimensional of a little gingerbread man on a piece of paper and then show me exercises to do on that piece of paper, and then I'll go out of this gym and walk within my defiant pro-disability embodiment.' My embodied knowledge knows that chronic pain and mobility considerations are personal and social and environmental and interpersonal and determined by our capitalist socio-economic system.

As a child, I was privileged to have access to a lot of medical attention. Whether all of the treatments were ideal is questionable, probably not because nothing is, but I had access to a lot of doctors and a good medical team. My family fought for me. In thinking about the language that this physio uses, saying: 'oh we could improve this flexion,' or whatever the words are, I think that it harkens back to some pretty early memories or sub-memories where the details are vague, but the language sounds really familiar. Way more familiar than reading Foucault. Is there a way to cite a pre-memory from when you were in kindergarten in an academic paper? It's important to me to parse out the distinctions of sources of desires for my body and social norms or imperatives. (Field Notes Jan 11, 2018)

Then I leave physio, and I walk within my defiant pro-disability embodiment towards my Soviet-era appearing apartment block, half-moved to Vancouver, half still living in Montreal, focusing on my hamstring muscles contracting with each step. Julien, my partner, had accepted a post doc in Vancouver, and my Masters research was based on field work in Vancouver, so we



relocated there in January, 2016, to a condo building in False Creek that I would never have afforded alone.

I'm thinking about activating my muscles in my head and in my body; outwardly, I'm saying 'what are you looking at?' with my body language - now more based on who I might encounter than what feels good for me internally. I put up my access guard against motorists who might come up behind me, cyclists coming towards me, and the generalized/generalizable outside world I'd refer to as 'people' when bitching about them to my crip friends. This guard (I can hear the voice of the girl I recently started dating - "you're so guarded Aimee!") is not always conscious, and sometimes it feels necessary or the best coping strategy at my disposal, as a form of 'micro-assertions.'<sup>1</sup> (Field Notes Jan 11, 2018)

But my access guard is not only about fear of being knocked over or insulted or hurt. It's my Central Canadian Public Persona, and it is the way I carry myself out in places like public spaces in Montreal and airports. I'm proud of it, but it's exhausting. It's this haughty air that is tied into my femme identity and my whiteness and my middle-class upbringing. I worked hard to develop this persona after moving to Montreal as a young adult (age 19). I did. And now, a decade later, I notice this persona explicitly when I go away to the west coast and come back to Montreal. A few days back and it flies back after me, engulfing me, protecting and making my experiences a bit more opaque.

By being historically and currently excluded from public spaces due to barriers and discriminatory attitudes and practices, disabled people are often in the position of needing to assert our rights to space for ourselves in literal ways (on paths and sidewalks, on transit, in daily navigation of institutions, in communication, in interpersonal relationships, between crips, with 'people'. My participation in leftist protests of various sorts (student strike, 2012, missing and murdered Indigenous women, disability movement), introduced me to the common slogan, "who's streets, our streets?" It feels particularly cathartic yelling in the streets of Montreal as the streets often feel decidedly not ours/ mine (those of us with mobility aids, canes etc.) because they are so inhospitable by design due to wear and lack of adequate upkeep, cracks in sidewalks, insufficient or too-step curb cuts, one-step access to so many shops and spaces, poorly placed signs which block the sidewalks. (Acton, 2019; Louw, et al., 2014) That's the discourse that the disability movements have been largely using in Canada. But where do we get this idea that, in terms

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<sup>1</sup> Woo & Gallagher, 2011 use the term 'micro-assertions' in the context of citizens' use of the courts, which they argue is "necessary for the realization of equal citizenship" in the democratization of modern day China. (400) I extend this term to include the micro-practices taken by individuals and communities to assert their belonging in a space, and their 'right' or sense of calls for access.

of physical accessibility or communicational accessibility, we should be able to access whatever we want at whatever time and whatever day in whatever way we desire?

Physio and the process of shaping my body in a way that was aiming at that gingerbread shaped cut out, the normative form, was an early introduction to policing from medical professionals, and self-policing via internalized medical goals. (Garland-Thompson, 1997) It informed, and informs, my questioning and pushing back against institutions and dynamics that contort certain subjects to conform. Conflicting personal experiences interfacing with medical professionals inform my inquiry into accessibility and embodied experiences in public space. I experienced myself focusing on my own struggles related to accessibility and ableism, and having a level of tunnel vision; desiring to reach other people and communities of different experiences of marginalization. I was aware that my disability activism revolved around mobility, infrastructure, and gender as a white woman with a physical disability. My motivation came from activism I was engaging in, (Radio-Canada, 2013) and in some instances, instigating (Bachelder, 2014; Lastinger, 2015). I found that the omission of discussions of equitable space-sharing beyond the disabled/non-disabled divide (murky as that may be), such as intersections of First Nations land-stewardship, race, and poverty, felt like a level of complicity in the replication of oppressive systems of power based on EuroCanadian/Western values. Mingus highlights the structural role ableism plays in minority oppression by “[cutting] across all of our movements because ableism dictates how bodies should function against a mythical norm.” (2011) However, that commonality between movements does not manifest in the same way between movements or communities.

I wanted to address the basic question that I felt myself and the disability communities I was, and am a part of, were largely overlooking: what about the land occupation that we participate in, these cities we’re advocating for more access in and to? How do calls for accessibility acknowledge, relate to, or ignore that integral element- land- in their understanding of urban space? I set out on this thesis journey hoping to find alternative ways of viewing accessibility that could provoke less hierarchical and more equitable lines of thought and action within existing and future disability movements. The implications of disabled settler activists and academics seeking access, the contradictions, desires, conflicting needs and approaches are all part of this exploration. This thesis became a mixed method autoethnographic and interview-based exploration about the cultural expectations of others, and myself and about access and our places in Canada. Personally, I was driven by the question of how could I address Canadian colonialism in my accessibility activism, creation, and analysis as a white 2nd generation settler, and disabled, queer woman. I was guided by Tuck and Yang’s observation of “the reluctance of some settlers to engage the prospect of decolonization beyond the metaphorical or figurative level...

[and how some settler activists] reveal the limitations to “solidarity,” without the willingness to acknowledge stolen land and how stolen land benefits settlers.” (2012, 26)

Assembled in hybrid form, this thesis contains an engagement Indigenous studies and post-colonial theory and writing with critical disability studies and mobility studies. I ask what a less colonial access-politic could look like, be like. I do this by hosting conversations with six relevant participants, production of short videos exploring this theme through auto-ethnography and presenting key moments from my interviews. In addition, I present theoretical prose and poetry alongside one another, interspersed among and throughout the thesis to bring video poetry, prose and interview into conversation with one another. My hybrid form of research creation, informed by scholars such as Peers (2015, 2014), Dokumaci (2018, 2015, 2014), Clare (1999), and Anzaldúa (1987) challenge the linear conventions of academic writing and experiments with a hybrid form of knowledge production and dissemination. The form that I feel best transmits the message is used, be it poetry, video, prose essay, creative nonfiction.

In chapter 2, I present the theoretical framework of this thesis, introducing race-based critiques of disability rights discourse and presenting different epistemological understandings of disability based on cultural world-views and understandings of bodies and mobility and divergence.

The methodology of the thesis evolves through the process of writing it. Articulating my original methodology in chapter 3, which then later evolves throughout the thesis, allows the reader to follow the trajectory that my thinking and learning took in terms of methods. I outline the methodological approach that I set out to engage with and worked with for the development of my framework, production of interviews and videos, and analysis. Of note, the final product of this research involves an expansion of media and engages additional theory than was proposed. This is because of findings during the recruitment process and reflections on my personal and embodied experiences of interviews in the news media about accessibility/ transit ableism. I ended up experimenting and developing an articulation of crip poetics as a major contribution and this involved bringing other theoretical and artistic voices into the project, as well as grappling with the methodological and positionality-based considerations of allyship research. These considerations are presented in the Crip Poetics section within chapter 7.

In chapter 4, I present the films that I produced for this research creation as well as related poetic and auto-ethnographic creative non-fiction texts based on fieldnotes that I kept from 2015 to 2018, during the research process. A theme that emerged as I explored foundations of racism and ableism in Canada are explored in Chapter 5, as I analyze discourse control with a focus on eugenic foundations of correctionalism present in discourse control.

Continuing in the evolution of my methodology in this research, chapter 6 presents an ethical conundrum that I faced about recruitment of disabled indigenous participants, questions of intellectual labour and models of knowledge, and a problematization of my position as an outsider, white, disabled researcher seeking disabled indigenous participants. From this problematization and intellectual and personal work, I present a response to this problem in forms of crip poetics in chapter 7. Following this, themes from interviews are shared in poetry, prose and in a final film. In chapter 8, I present a synthesis of my critique and related methodological provocations to community-based, allyship research. In chapter 9, I reflect on possible ways forward, building on communication practices, such as crip poetics and witnessing. Finally, in chapter 10, I conclude with reflections on the possibility that crip poetics, as a way of relating and co-creating realities holds.

## **1.2 Sites of research**

I had been introduced to colonial systems of forced isolation and policies of division/ dehumanization through self-directed studies during my undergraduate degree in Political Science.<sup>2</sup> Following this, from 2012-15 I had co-hosted a community radio show featuring grassroots Indigenous land struggles and events. (Louw, 2013) In 2014, I travelled across the country, visiting 5 major Canadian cities with a friend-now-partner, Julien, documenting our experiences, and interviewing disability activists. Based on this experience and research, I determined that out of those cities, based on transit, social perceptions and the personal experiences of Julien, interviewees, and myself that Vancouver was the most accessible city and Montreal was one of the least. Each city has its own barriers and strong areas (Eg., Vancouver has one of the highest cost of living, Montreal, one of the lowest, Vancouver rarely has snow, Montreal has snow-related accessibility barriers several months of the year). (Gallagher in Louw, 2014) As someone who lived in Montreal for the first 10 years of my adult life, and came into my disability analysis during those years, I have embodied experience that offers important insight. Moving away to Vancouver for 2 years, as Julien completed a post doc, meant that I gained embodied knowledge of the city as a pedestrian, passenger, observer, 'misfit'. (Garland-Thomson, 2011)

For this Masters, I am developing a methodology for inquiry and a prototype of media experimentation. Many findings, both methodological and qualitative, came from this research

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<sup>2</sup> Unfortunately at the time I was doing this degree there were few courses that acknowledged/ addressed Canada's colonial structure.

process and I will share some here in written form and others in the words and actions of the generous people who participated as volunteers in this study - through video poems.

This research-creation thesis contains analysis of literature, placing in conversation Indigenous Studies, Critical Disability Studies and Mobility Studies. In this theoretical work, I draw links between settler colonial totalizing discourses of desirable humans, working to show links between settler colonialism and accessibility in the Canadian context. (Peers, 2015; Snyder, 2005; Siebers, 2010) I draw heavily on autoethnographic methods for findings on place, public space and observations of self within this question. Creative writing expresses autoethnographic experiences and reflections. Videos, as finalized and iterations of experiments, represent an additional form to writing, of spatial interrogation, adding visual, audio and geographic elements.

This research creation project combines prose, poetry and film in a hybrid form. The film and poetry complement one another in terms of the content offered in each form and also in the conversation between both. I place videos and related auto-ethnographic and poetic writing together: this assemblage is the intellectual contribution of this thesis. I draw heavily on crip, research creation scholar Danielle Peers (2015, 2014). Peers' live performances, videos and writing combines personal reflections with a Foucauldian genealogical analysis, offering one model of hybrid thesis research creation writing. (2015) Eli Clare's poetics greatly inform my experimentation as his writing speaks across historical lines and genre lines. (1999) My communicational practice, between bodies and landscapes, draws on Gloria Anzaldúa, whose poetics uses imagery that combines landscape, personal history and lineage, and revolutionary and social movement implication. (1987) These crip scholars have created space in the field of Critical Disability Studies to experiment with this hybrid approach. It leads me to ask: what can a crip poetics do? How might this poetics provide CDS and Media Studies with unique and generative forms of expression? How might a crip poetics contribute to the work in research-creation that challenges how knowledge is articulated and shared in the University? Finally, how might we put into conversation critical disability studies and post-colonial critiques of settler cultural assumptions about territory, and space?

Non-homogenous in style, medium, discipline and creative relationship, this thesis is held together and offered together in this format because I believe that placing different media and ideas together shows things that linear prose can't. It is offered together because I have faith in the tickling in my mind that says 'throw it together, take a step back and look at it'. An ethic of non-sameness calls for a non-uniform presentation of creation and ideas and perspectives. This is my creative nonfiction voice. I offer it and present my intellectual progress, fallbacks, troubles, findings, questions and ethical screw-ups in the most accurate way that mediation through words

and videos will allow. I offer it in hopes that it will spark a conversation on our privileges, oppressions, complicity, friendship and future/ current possibilities for a more equitable way of pursuing/ enacting accessibility.

## Chapter 2: framework

### 2.1 Theoretical framework

Theoretically, this thesis sits at the intersection of Critical Disability Studies (CDS), Indigenous Studies (IS) and post colonial theory, and Mobility Studies (MS), looking at the tension between calls from disability justice activists for increased access to public spaces, and title (right) to unceded territory by Indigenous peoples. (Garland-Thomson, 1997, 2009, 2011; Kuppers, 2013; McRuer, 2006; Peers, 2014; Hickey, 2014; Adelson, 2014; Alfred, 2009; Barker, 2012; Anzaldúa, 1987; Harding, 2004) Critical Disability Studies (CDS) is a growing field in which scholars research how disability is constructed and reproduced in social norms and interactions, physical infrastructure, language and media representation, among other modalities. Scholars from the USA and England are considered to have initiated the field, now with centres and departments having been developed internationally. CDS has strong roots in, and connections to, activism. Within disability activism and CDS, there are multiple 'models' of understanding disability. In the 1960s, stemming from the civil rights movements and rhetoric of equality and post-WWII discourses of human rights, disability rights became a rallying point for many groups and organizations. In 1976 in England, the Union of the Physically Impaired Against Segregation (UPIAS) delineated a distinction between impairment and disability, which formed the basis of what became known as the 'social model of disability,' wherein it is considered that the environment disables. UPIAS asserted that "disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society." (UPIAS, 1976)

Within this field, which contains multiple divergent perspectives, a shared perspective and aim is to disrupt and oppose a medical understanding of disability as purely a diagnosis to be cured and normalized. (Imrie, 1996) CDS is anti-conformist by design, critiquing conventional disability studies for its lack of social analysis on the construction of disability, and its medicalized analysis, centered around rehabilitation and conforming disabled people to 'normate' status. (Garland-Thompson, 1997) "In [the medical model paradigm] any negative experiences, which disabled people encounter in, for instance, moving around their environments... is conceptualized as linked to individual impairment rather than resulting from forms of social and political discrimination. (ibid, 397) CDS scholars show that discrimination and accessibility are important considerations in scholarship about disability. Another shared tenet is that the dichotomy between non-disabled and disabled is shifting and shiftable, meaning that the definition of disability

is contingent on cultural and historical context, as well as an individual's state at a given moment. (McRuer 2006)

From a research standpoint, CDS aims to center disabled people and communities in its research agenda-setting as, “[historically], disabled people and their representative organizations have been denied the opportunity to influence the agenda for disability research, let alone take control of it.” (Zarb in Gleeson, 1996, 400) CDS provides an important basis of literature and methods to interrogate my auto-ethnographic experiences in the research sites and also the interviews that I conducted.

Garland-Thomson's (2011) materialist analysis of disability points out that not all effects of disability come from the environment, or have completely environmental responses. Collecting and producing knowledge “for marginalized people... rather than for the use of dominant groups in their projects of administering and managing the lives of marginalized people.” (Harding, 2004, 45) AJ Withers, a Canadian DS scholar and anti-poverty advocate argues that “rather than fighting for our piece of pie while working to enforce existing oppression on others, we need to bake a new pie. We have to build new models”. (2012, 107) Similarly, Chouinard (2009), a scholar who writes about disabled women's experiences, argues that “processes of differencing locate [people marginalized by multiple oppressions] in prevailing socio-spatial relations of power and oppression”. (219)

## **2.2 Race-based critique of disability rights discourse and CDS**

Criticism of disability movements and DS in contemporary settler colonial states (such as the U.S.A., Australia, and New Zealand) has been that it reinforces white standards and repeatedly leaves out perspectives of people of colour. (Moore, 2017) Given recent critiques of ‘disability too white’<sup>3</sup> in the public discourse (Thompson, 2017) and critiques of lack of racial analysis in Disability Studies and CDS, (Miles et al., 2017) the necessity for racial analysis has been articulated and pursued by scholars and activists of colour.

Indigenous peoples have unique and fundamental relationships to territory in settler colonial Canada, as stewards of the land (Alfred, 2009, 47). They also experience the burden of settler-colonialism in specific forms of oppression related to territory such as “dispossession... from the land and their subsequent oppressive treatment on reserves and the Indian Act system and in residential schools, and through other government policies.” (ibid.) This causes or contributes to experiences of psychosocial and psycho-physical traumas on the individual and on

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<sup>3</sup> hashtag created by Vilissa Thompson on Twitter



the collective levels. (ibid) Kirmayer & Valaskakis (2009) studied the psychological effects of “historical loss and possible linkages to PTSD symptoms,” finding that the social oppressions Indigenous people experience are related to dispossession and the position settler colonial practices and policies have attempted to place them in. (In Alfred 2009, 51) They found in a study of Canadian Indigenous people that “collective trauma, disorientation, loss, and grief, ... are major determinants of mental health problems faced by many Aboriginal communities.” (XV) Tanner (2009) found that other disabling factors included “nutrition and the [effects] of reserve life.” (in Alfred, 2009, 50)

### **2.3 Culturally-based epistemological differences in understanding disability**

Differences in epistemology exist between settler and Indigenous understandings of disability, in that disability understandings “commonly depend on the notion of universalism and individual rights, regardless of any cultural-specific identity, [while] the concerns of Indigenous persons with disabilities are related to discussions of group rights and cultural relativism that are intertwined with collective identities.” (Hickey, 2014, 158; Adleson, 2005; Durst and Bluehardt, 2001) Hickey (2014) has found that disability is conceptualized as a “Westernized concept”.<sup>4</sup> Within international rights discourse, which informs Canadian national discourse and legislation of signatories (Canada signed UNDRIP in 2010) there is a framework for conceptualizing disability oppression and appropriate responses and safeguards that rests on individualistic conceptions of disability. (Hickey, 2014, 161-162) This dominant discourse is upheld in international treaties, national legislative projects, such as the current drafting of the Canadians with Disabilities Act<sup>5</sup>, (Canada, 2017) and through narrative in culture and rights-based approaches within disability activism. In this framework, one of the major ways individuals can seek justice is through courts based on individual claims, which in turn, reinforces Western understandings. (Hickey, 2014) Hickey (2014) argues that Indigenous peoples’ definitions of disability “have [therefore] been characterized by resisting Westernized concepts of impairment and disability.” (161) Conceptualizing disability in this Westernized way “sacrifices the specificity of others to global equality that denies the historical context of its own emergence and interests.” (Beck in Hickey, 167)

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<sup>4</sup> Hickey’s (year) analysis of disability in the international context of Conventions of the Rights of Persons with Disabilities (UNDRIP)

<sup>5</sup> While the legislations is currently being drafted, the documents emerging from the ‘Accessible Canada’ policy project so far, focus on access to employment and education, reinforcing individualised and capitalist goals - which leave out collective and community considerations. (Canada, 2017)

## **2.4 Alternatives to disability rights**

In the United States, scholars, racialized disability advocates, and disability communities have offered critiques and alternative models to the rights-based approach. Within the last 12-15 years, disability justice has emerged as a grassroots concept led by disabled people of colour, largely originating in the performance and social innovation organization, Sins Invalid, of the San Francisco Bay area. The concept has spread in online forums and publications, and has grown into an expansion of/ alternative to the rights based framework to interconnectedness models based on mutual aid within and amongst disability communities. (Mingus, 2011; Sins Invalid, 2017; Moore, 2017) In Aotearoa/ New Zealand, post-colonial theorists have held conferences and published on setting goals for benchmarks towards disabled Maori researchers increasingly taking lead of research about them and their communities. (Tuhiwai Smith, 1999; Hickey, 2014) Shifts in disability culture have taken place alongside those in academia. For example, disabled Maori people have created new words in Maori for neurodivergence. (News Hub, 2017) Disabled people in Canada have joined in this critique. Intersectional research within CDS in Canada has been undertaken, placing disability history and politics in the Canadian context linking the production of disability to Canadian institutions that reinforce the body as a site of social control. (Withers, 2012, Dolmage, 2015, and Peers, 2014) Danielle Peers' (2015) PhD dissertation provides a genealogy of histories and links between disability and the "white Canadian nation." However, an in-depth qualitative study of the tensions between access to territory and public space for Indigenous people and disabled people of multiple racial/ cultural backgrounds has not yet been undertaken in the urban Canadian context. Given the high rates of disability and the unique relationship Indigenous peoples have to public space in Canada, as original inhabitants and stewards of the land, the connection of disability and Indigenous relationships to public space is an area that warrants further research. (Alfred, 2009)

Disability rights to accessing territory could be seen as a space of tension with Indigenous access to territory, such as paved paths on unceded territory. The present claims and micro-practices for accessibility used by disability activists in specific Canadian locations often disregard the displacement and land appropriation (by settlers), of those places. I ask what other accessibility practices are possible, that don't follow in the tradition of access at the expense of erasure of Indigenous history and access to territory, and asks what a less colonial access politic could look like in two Canadian cities.

## **2.5 Indigenous relationships to territory and landscape in Canada**

IS and post-colonial theory provide integral anti-colonial theory, contemporary findings and methodology for this study. Theoretically, an analysis of the social, political and cultural system of settler colonialism provides context for analyzing access to public space in urban Canada. (Barker, 2012, 1) The Euro-Canadian colonial concept and driving force of European settlement in Canada, the terra nullius doctrine, stated that prior to Europeans there were no people on the land where Canada now sits. This is an important underlying concept, and historical reference, which both confronts and ties in to this study. (Alfred, 2009, McAdams, 2015) It empowered “explorers... to lay claim to territories uninhabited by Christians [by declaring discovery if] the lands were [considered, by this metric], vacant.” (Joseph, 2016) Historically, this ‘Doctrine of Discovery’ provided justification for claims to territory and the dispossession of Indigenous peoples. (Alfred, 2009, 47) “[It] continues to impact Indigenous Peoples in Canada” as a pervasive cultural belief of settler entitlement to land, and as territorial lines are debated in courts, legal and of public opinion. (Joseph, 2016; Tsilhqot’in, 2014, at para. 69) Here, an understanding of title to territory is vital. From what I understand, Indigenous title to territory means that First Nations of a specific territory are the decision-makers and primary people responsible for that territory. “Aboriginal title is a common law ownership interest in the land that Aboriginal Peoples have.... it is a legal concept; the Canadian state says Aboriginal title derives from a set of legal documents like the royal proclamation of 1763.” (Defenders, 2017; Canadian Charter, 1982) This means that all others must seek “free, prior and informed consent” to access it. (Canadian Charter, 1982) This is an important theoretical and practical consideration as it comes into contact with claims that disability communities make for ‘equal access’. Equal access to space in Canada for non-Indigenous disabled people could clash with Indigenous land rights to be sovereign in their own territories. ‘Equal access’ in some ways could mirror/ follow the same logic as state/ industry projects which pit economic and state-building goals against Indigenous title in service of further colonizing, displacing and disconnecting First Nations from their home territories.

## **2.6 Indigenous peoples’ compounded experience of disability**

Contemporary studies of health inequities in Canada demonstrate the systemic discrimination experienced by Indigenous people, who experience disability and illness at rates higher than the generalized Canadian population, and those inequities stem from and are “entrenched in the history of relations between Aboriginal peoples and the nation-state.” (Adleson, 2005, S45; Alfred, 2009) Within the Canadian context, the health inequities and higher incidence of disability among Indigenous peoples, and at the same time the lack of qualitative study of it within disability studies (DS) in the Canadian context, exposes an area where DS and CDS would deeply

benefit from an intervention and involvement of IS. As an alternative to historical and contemporary colonial research practices, Snelgrove, Cornthassle et al. (2014) offer a theoretical framework for ‘unsettling’ research. (26) For them, recognizing the material effects of constructed racism exposes both the practices of oppression that converge to lead disabled Indigenous people to be ‘doubly marginalized’, and the possibility to subvert those practices. (Harp, 1994, 54; Durst & Bluechardt, 2001; Garland Thomson, 2011; Fineman, 2005)

## **2.7 Western and Indigenous epistemological understandings of disability**

Hickey (2014) highlights the importance of research that “[bridges Indigenous and]... Westernized conceptions of disability. This is due to the exclusion and double-marginalization that disabled Indigenous people feel within their own communities and nations as well as within settler communities and nations. She calls on researchers to parse through and point to positive elements of each, and the role they could play in benefitting one another. (162) I draw on CDS for crip theory, contemporary interventions into mobility studies, and to further inform my methodology. I place literature relevant to embodied experience in public space, from IS and CDS, with the aim of taking up Hickey’s call. I ask what other accessibility practices are possible, which don’t follow in the tradition of disability access at the expense of Indigenous access to territory, and which don’t contribute to the further erasure of Indigenous access to specific sites. I hosted a series of interviews with disabled people of multiple racial and cultural backgrounds, and Indigenous storytellers with diverse relationships to disability in order to better understand their micro-practices of accessing public space and their access desires, with the aim of better understanding this tension.

## **2.8 Disabled people of multiple backgrounds, fitting and misfitting on Indigenous territory**

Theoretically, an important contribution of CDS involves making visible the “compulsory able-bodiedness” that underlies our cultures and the perceived “non-identity” of able-bodiedness in order to expose the way that it’s produced and reproduced. (McRuer, 2006; Garland-Thomson, 2011, 597) Ableist systems of thought mean “able-body status continues to be assumed, helping to render disabling differences and their socio-spatial outcomes relatively invisible”. (Chouinard, 1997, 382) McRuer (2006) describes the invisible, social and interpersonal forces that reinforce barriers to access, such as the presence of prejudicial social interactions based on a culture that valorizes a particular normative body and modality of cognition. (1) Garland-Thomson’s (2011) notions of “fitting” and “misfitting” serve to provide a framework to explore “[the] discrepancy between body and world”, an important distinction that incorporates physical, social, and affective

elements of embodied experiences in public space. (593) The concept of misfit emphasizes the lived realities of disabled experience, because it focuses on material constructions in addition to purely linguistic/ social constructivist ones,<sup>6</sup> “[recognizing] their mutually constituting entanglements.” (593) Siebers (2010) asserts that it is through “disqualification” that people are dehumanized on the basis of disability; “mental and physical properties of bodies become the natural symbols of inferiority”, therefore providing a logic for the naturalness of excluding disabled people. (24-25) Gleeson (1993; 1995) outlines a socio-political perspective, asserting that environments disable. Similarly, Kitchin (1998) writes that “disability is spatially, as well as socially, constructed,” pointing to a sense of belonging wherein “spatial structures and places within the landscape provide a set of cultural signifiers that tell us if we are ‘out of place.’” (343, 349)

## **2.9 CDS interventions into Mobility Studies and the navigation of public space**

Hughes et al. (2005) write that the “world in which we live is about impermanence, flux, flow, plasticity, networks and mobilities” and argue for mobilities-based social sciences. (4, see also Sheller & Urry, 2006) Büscher, Urry et al. (2011) claim that “bodies sense and make sense of the world as they move bodily in and through it, creating discursively mediated sensescapes that signify social taste and distinction, ideology and meaning”. (6) These authors point to the knowledge that inhabitants of a place gain from being physically present in it and base analysis on walking in public space. The value of research that incorporates mobility in its analysis and method, recognizes that “surveys of routes miss what was: the act itself of passing by.” (De Certeau, 1984, 97; Solnit, 2001; Lefebvre, 1974; Lefebvre, 2009; Evans et al, 2011)

However, it is asserted by some disability scholars within Mobilities and Urban Geography, that a “segregationist ethos has been created that serves to perpetuate discrimination against persons in the built environment.” (Park et al., 212, see also Büscher, Urry et al. 2011, Kitchin, 1998, Imrie, 1996) Concerned with the erasure of disabled people from public space, CDS scholars intervene into contemporary mobility studies, critiquing the presumed ablebodiedness of researcher and interviewee, and adapting the methodologies of walking interviews to a crip methodology and aesthetic. (Evans, 2011) Imrie (1996) articulates a system of architecture and design that amounts to “design apartheid.” (4) Prior to these disability scholars’ involvement

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<sup>6</sup> (Such as the debate between person first language, which occupies much of the public discourse around disability on online forums (such as The Mighty)? (Kim: *should I save this distinction for discussion?*)

in the field, little attention was paid to differential mobility based on mobility aids, sensorial divergence, or disability of any kind. To this end, Sawchuk (2014), highlights, “if indeed we experience the world as we move through it, then how we move through it –by foot, bike, car, by wheelchair– and at what speed, in what form, and using what practices in those environments matters”. Kitchin (1998) writes that disabled people have to take alternate routes and therefore do not have access to the same choice of routes and freedom of mobility as non-disabled people, and prior to CDS interventions, these alternative routes were not considered in study or development of urban infrastructure. (348) Parent proposes to “disrupt the erasure of disabled bodies in city maps and urban discourses” by involving disability and accessibility in content and creation of videos. (Parent, 2014, 4) Her work has been influential, as she has developed new methods for documenting disabled people’s experiences in public space, and has filled a need of diversity of bodies in urban geography through her development of the “wheeling interview”. (2016) Crip theory intervenes in mobilities literature as Sawchuk (2014) and Parent (2016) draw more attention to the varieties of ways people mobilize, and to the richness of the knowledge of cities that research conducted from a critical disability studies standpoint can highlight. (Haraway, 1988; Harding, 2004)

## **2.10 Combating ableism in public space**

"Ableism refers to ideas, practices, institutions and social relations that presume ablebodiedness and, by doing so, construct persons with disabilities as marginalized, oppressed, and largely invisible 'others'" (Chouinard, 1997, 380) Simply put, Ableism can be defined as systemic discrimination based on disability. (Louw, 2017) Combating or transforming ableism in public space requires working towards an undoing of Siebers’ (2010) concept of disqualification. Siebers argues that using bodies as metrics of humanness, including racism, is based on ableism and the classification of bodies according to deemed value. If this claim that disqualification is also a process by which other groups are marginalized, Indigenous calls for justice on their own territories could be supported by a subversion of disqualification as well. (2010; Dolmage, 2015; Snyder, & Mitchell, 2005) Here, Garland-Thomson (2011) flips marginalization, articulating that experiencing marginalization based on disability can provide a certain “epistemic privilege” in that “[the] experiencing of misfitting can produce subjugated knowledges from which an oppositional consciousness and politicized identity might arise.” (601, 597) The transformative potential of this epistemic privilege motivates my framing of this research project, based on the embodied experiences of people marginalized in public space by disability and settler colonialism.

Recognizing oppression as “individually enforced, hierarchically structured subjugation” (602) allows for analysis of individual experience in the social context of ableism and anti-Indigenous racism. This prompted me to ask interviewees how they feel and navigate those oppressions and the impact they have on their responses and micro-practices of space-taking/ “micro-assertions” of space-taking. (Woo & Gallagher, 2011, 400) Including some of those practices resulting from crip, Indigenous, and disabled Indigenous epistemic privilege will allow me to feature and honour, through poetic engagement, the ways that interviewees assert their entitlement/ title to space, and the epistemological foundations that those assertions are based on. (Garland-Thomson, 2011; Kuppens, 2013; McRuer, 2006 Peers, 2014; Hickey, 2014; Adelson, 2005; Alfred, 2009; Barker, 2012)

## **2.11 Mediography**

My videos are situated in a growing and vibrant body of work created by disabled and Deaf filmmakers. I draw on disabled and Deaf film-based research-creators such as Laurence Parent, Vero Leduc, Jason da Silva, and Danielle Peers who use new media and mobile media techniques to interrogate landscape in the form of a video as it mirrors or communicates with bodies and the environment, and mobile media techniques to interrogate landscape in the form of video as it mirrors, interrupts or communicates with bodies and the environment. These filmmakers, whose experimentation in the film medium has made my research-creation possible, reflect the messiness in the involvement of their methods into the content of their work. Elements of their physicalities converse with, or juxtapose against, the ‘content’ of the films, at times modelling the topic being discussed - for example, sidewalk inaccessibility through bumpy shots or embodied experiences of chronic pain through voice-overs. (Parent, 2016, Dokumaci, 2014) Out of a combination of necessity for accessibility reasons and aesthetic and academic choice, Dokumaci confronts the fourth wall, moving past border between filmmaker and audience, as she tells the audience that her hands hurt as she types the first words of the film script. (ibid.) Similarly, Parent (2014) implicates her interviewees in filming, attaching GoPro cameras to their aids or bodies, thereby including them in the research process as co-creator rather than simply interviewee or subject. Here “Wheeling Interview” provides a clear focus and practical advice on the specificities of wheeling as a methodology, including the challenges in setting up cameras and the collaboration this necessitates. “[Wheeling] interviews are very much negotiated between the researcher, the participants and the politics of the space through which they are moving.” (Parent, 2016, 522) This methodology has been revolutionary for me as a researcher, because, through its existence and Parent’s transparency of method and struggles with the emergent

method, I felt permitted to experiment and film in my own way, showing what is filmed through the mediation of my wheelchair and mobile gear. (Parent, 2016) Analytically, this methodology deepens the analysis of public space as more layers to the analysis are present: cameras document not only the visual surroundings, but the physical surroundings as well, through the bumping of wheel on pavement or the alternate routes that are necessary because of barriers in infrastructure. Interactional layers are also added, such as the interaction between researcher and passerby in setting up camera.

I draw on these filmmakers who move past boundaries of audience/ filmmaker, subject/ researcher, that are often (re-)created and upheld in film industries. These crip video productions invoke creation in ways that are more accessible, utilizing mobile media tools that I can kind of use, hold and move with. By example, these filmmakers show the importance of narratives that disabled people ourselves, and marginalized people ourselves tell about our own experiences. In studying 'micro-assertions' in public space, the modeling of my own micro-assertions into the space of filmmaking, as well as into the public sites in which I film, is an important personal lesson in this research-creation, which I will expand on more in section 6.1. The results of filming while wheeling, experimenting in the vein of "creation as research" reveal findings about the research sites, the divergence between the experiences of my interviewees and myself - as (differentially) mobile, and enriched, added texture and in some cases, made my research more difficult. (Chapman & Sawchuk, 2012) I reflect on this in my autoethnographic field notes, with key sections interspersed in the body of this thesis. With this film-based element of my research creation methodological approach I experiment with practicing accessibility and an ethic of non-sameness. I show my interviewees in an embodied way, showing how we collaborated and moved together to select locations, maneuvered the terrain,. Research sites in these locations were based on public transit, shorelines, and interviewee-significant sites of micro-assertions, access tensions, and convenience.



## Chapter 3: Methodology

### 3.1 CDS and IS in conversation, methodologically

The following is a description of the original methodology that I used in researching and production of interviews and videos. It was the initial guiding methodology drawing on indigenous studies, critical disability studies, post-colonial theory and mobility studies. This starting point guided the evolution of my methodology, which will be explored further in chapter 7. There, I draw on crip theorists and post-colonial theorists and writers to expand towards crip poetics. Placing my original methodology which then later evolved early in this paper allows the reader to follow the trajectory that my thinking and learning took in terms of methods.

Methodologically, CDS provides key literature based in autoethnography, filmmaking and mobile methods. IS provides digital-recording methods for capturing oral history, as well as methods of unsettling research. Autoethnography offers “an autobiographical genre of writing that displays multiple layers of consciousness, connecting the personal to the cultural” (Ellis & Bochner, 2000,739) Autoethnography requires me to situate myself as a white, disabled, queer, cis woman, documenting and using my experiences in the research sites as part of my analysis. IS leads me to oral history and methods of storytelling, which informed the interviews I conducted. I was motivated by Willox et al.’s “community-driven methodological strategy: [an] indigenous method that [unites]... digital media with storytelling... [in an attempt to build onto alternatives to] colonization of research and the Western analytic project”. (2012, 1) “[Storytelling] can procure fleeting moments to experience who [ancestors] were and how life felt long ago” (Silko, 1998 in Brown & Strega, 2005, 242) In addition, storytelling offers a space that “[tells] us as much about the present as about the past, as much about ideas of community as about individual experience,” “telling 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.” (Cruikshank, 1991; Portelli 1991) Drawing on these methodologies I explore individual experiences and reactions to systemic phenomena. By putting into conversation Indigenous Studies, post colonial theory, Mobility Studies, and Critical Disability Studies, I have begun to explore each discipline’s perspective on embodied experiences in public space, with a vision of future investigation and collaborative experiments in transformative access politics. This is vital, as

[Historically], disabled people have been the objects of study but not the purveyors of the knowledge base of disability. (Snyder & Mitchell, 2005 in Dolmage, 2017,1)

My experience as a producer of community media, zines and media art such as live web archiving of creative practices (Louw et al., 2015) has shown me firsthand the transformative potential of research-creation: “a strong form of intervention, contributing to knowledge in a profoundly different way from the academic norm” (Chapman & Sawchuk, 2012, 21) that has great potential in encouraging empathy and perspective-taking. (Miles, 2013) Building on this, in the research-creation process I expanded Laurel Richardson’s notion of writing as a method of inquiry, by using found poetry as a way to engage with interview transcripts. Filming, not just as a way of recording, but as a component of my writing practice, or as a “method of inquiry” offers space for alternative modes of knowledge creation and transfer in production and public distribution. (2005) Justin Spinney offers grounds for mobile video research-creation to explore interaction with landscape and embodied experiences of mobility, which Parent (2016) takes up. (175) For Spinney (2011), as for Parent (2016), video acts as a “tool to access the more fluid and fleeting aspects of urban cycling [and wheeling] as a mobile practice.” (Spinney, 2011, 175).

Part of why I choose to self-represent in my media work and writing is because of the pervasive and frustrating stereotypes in the dominant discourse of disability. There’s a creative potential for imagining those things that you want, and I find that very generative, and an important part of my accessibility and activist work. Critique, in this sense, is not criticism, (sure criticism is part of it, if we look at some of the activism that is happening in Montreal around transit or homecare, people criticize ableist policies and behaviour), but a way of understanding the potential within what are commonly perceived of as “limits”. Another element of a crip critique of normative bodies is its affirmation of creativity: it’s imaginative, it’s generative. As I critique something, like ableism or racism, I look at all the different elements being presented in a moment to have a more global understanding of it. Then I work at offering the way that I imagine it, so it will be awesome.

In addition, I take direction from Tuhiwai-Smith’s (1999) methodological notion of ‘unsettling research’ and the interview process, by actively resisting academic traditions and practices which extract knowledge from Indigenous communities and people for outsider-settler-researchers’ benefit. I focused on being transparent about my research and my research-creation objective of future “cross-community solidarity”, as well as the academic and professional benefits I will gain from the outcome of this project (MA, potential publications). (Miles et al., 2017) I asked questions with the aim of sparking ideas/ stories/ experiences for the interviewee to then direct and determine.

Decolonizing Methodology by Kupperts (2013) combines autoethnography, ‘hangouts’ and embodied knowledge, which directly relates to my mixed methodology. In it, Kupperts cri-

tiques Disability Studies' engagement with postcolonial issues, asking how access narratives and "sovereignty perspectives might clash." (191) Through a collaborative poetry reading and writing project with Maori women she articulates her version of "hangout as method". This method seeks to "[abstract] patterns from lived reality" in a way that the researcher is "not becoming a transparent recorder, instead, gathering and witnessing activity becomes akin to a choreographic presence, a curatorial gaze or ear, opening up the parsing activity of the researcher." (180, 187) This informed the semi-structured interview style I went into interviews with, wherein I bring a research question and related questions, and also offer space for interviewees to share aspects of their embodied experiences.

Crip solidarity is based on an ethic of divergence, an understanding and expectation of non-uniformity; it is anti-conformist by design. (Kafer, 2013; Mingus, 2018, 2011a, 2011b; Carmargo, 2018; McRuer, 2006) In this research-creation I ended up experimenting to find prototypes that apply this ethic of difference, and a cautious appreciation of discomfort, to explore what alternative, less hierarchical/ colonial access politics could be like. In chronological order, I have written and produced videos using autoethnography to situate myself. I then have hosted a series of filmed conversations inspired by oral history traditions, exploring experiences between disabled settlers and Indigenous storytellers from territories mostly in and around Montreal and Vancouver, with varying relationships to disability, in order to better understand this tension. (Parent, 2016; Koppers, 2013) Based on these conversations and autoethnography, I experimented with prototypes and produced short videos, creative writing and poetry.

I used the combination of snowball method and targeted invitations for participants. I posted a call for participation on my professional website and key Facebook groups such as Montreal and Vancouver spoon share, which are groups populated by disabled people and people with chronic illnesses. All but one interviewees were either disabled of diverse cultural/ racial backgrounds, or Indigenous and disabled, or Indigenous and not disabled. One interviewee did not identify as disabled or Indigenous - she works with some disabled or Indigenous. I interviewed Dylan Hickey, a crip, white artist friend I originally met in a Skytrain elevator; Q, a genderqueer disabled spoken word artist; Sam Sullivan, former mayor of Vancouver and current Liberal MLA who is disabled; Caroline Macgillivray founder of the non-profit called Beautynight; Amanda Nahanee, a descendant Squamish and Nisga'a storyteller and Vancouver Public Library's first Storyteller in Residence; and Lynn Gehl, disabled Anishinaabe writer.

### **3.2 Episodic autoethnography<sup>7</sup>: Fragmented by Design**

In her performance at the Qualitative Research in Sport and Exercise conference, Lindsay Eales (2018), introduced the concept of “episodic autoethnography.” (thesis performance) She explains that she didn’t see herself in a lot of the autoethnographic methods because a lot of existing conventions in autoethnography are linear, beginning with a description of an event or experience and then theorizing and expanding towards the social, then presenting a teachable moment. The structure of this starts local and personal and then expands outwards. Eales explains that this type of methodology is not reflective of her experience, and describes her autoethnographic method as episodic. (2018) This concept of the episodic resonates with me. Much in my life is episodic such as my energy and pain levels and therefore my capacity and endurance for certain types of work. The work on my Masters has been episodic due to physical accessibility, energy levels and financial accessibility (needing to take on other contracts etc.), to fund my academic work.

When I return to my thesis after an episode of either rest or temporary employment, in some instances I have gained new perspectives on the work that I did a few months ago or a year ago. Part of my autoethnographic method has been turning toward its episodic nature, as opposed to ‘putting up with it’; incorporating and learning the lessons that come with temporary distance from a project, as well as the lessons that come from pain, fatigue and upsurges in energy and excitement and creativity.

Accepting and honouring this part of my methodology is not always easy. At times it’s really difficult, especially financially. Having Eales’ leadership and modeling is helpful in seeing episodic autoethnography as a benefit to my research, not a failure, as conventional timelines of academia and internalized ableism would have me believe. Eales’ episodic autoethnography is a significant contribution to autoethnography because it makes crip and mad methods more possible and celebrated. Her autoethnographic methodology is an offering that is fragmented by design.

### **3.3 I Am Magic**

I am magic

I can turn a bed into a sailing ship

White sheets become billowing sails on a glass-like surface; waves only enough to gently rock

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<sup>7</sup> Eales, 2018

I am magic

Blemishes in my bedroom wall paint: flecks of stars, glimpses of the outer reaches of Eridanus  
Constellation on a backdrop of clear, blue-black night sky

I can disappear

Still, I'm there at the end of the day to make dinner-  
Pots and pans moved by invisible arms,  
Fuelled by ice cold breath

I am powerful

Reemerging after days, weeks,  
Filling time in on what he has missed  
Teaching the ocean that absent ripples don't alter her tide  
Whispering to billowing sails that skipped/ dropped stitches won't necessarily unravel

I sail forward without foam lines left to trace my path

I am tricky

I can live in a place for years without coming home to it,  
Looking back now  
from the corners of the stars

My magic's rewritten yesterday, last week

Feeds herself from across low-chin spoon bow  
Feeds family from across the continent.

I point towards Polaris

Noticing my once smooth nail polish crinkle and lift; butterflies beginning their migration to the  
Messier 6 cluster.

When this ship's bow fails to keep growing waves off deck, I breathe deeply;

Hold my breath in anticipation - a human habit -

I am becoming

Human skin has given way to a permeable, moist material, new, not foreign.

I am metamorphosis/ becoming  
Graceful upon contact,  
readying myself for an amphibian future.

## Chapter 4: Videos and related texts based on Field notes

Is it weird to have all that infrastructure relatively in place to make you feel welcome but still not feel at home in a place? And to go to another place where you struggle to get access to the basic things but yet it feels like home?

My autoethnographic videos deal with questions of home and interrogate my role in Vancouver and Montreal, the two homes I lived in when in my thesis research-creation stage, and Edmonton, my hometown. I do this by exploring how my embodied and sensorial feelings of belonging and unbelonging, entitlement and awareness of my social privileges interact with landscapes. Exploring the questions related to disabled Indigenous and settlers of various backgrounds' experience of space has compelled me to explore in depth my positionality and personal experience and growth that has come through space away from Montreal and research-creation experiences in Vancouver. Filmmaking has been extremely spotty, for different reasons. As a new filmmaker I was learning how to shoot with efficiency of footage in mind. Also for two years during my MA I didn't have gear that I could edit on. Part of my learning process was/ is developing the personal methods or practice of editing in an accessible way to me.

The effect of the videos being episodic also leads to an interesting effect for me, where I feel I have a level of audience perception of the videos, because it's been a good two years since I made the first one, and a year and a half for the second. When I relieved myself of the pressure of creating videos that would stand up to aesthetic standards of filmmaking (eg smooth, steady camera, intentional angles, good 'quality') film production went better. Each medium I experiment with offers me new ways and opportunities to unlearn and challenge internalized ableism in the field. As Parent (2016) states, "using a technology to do something different than what it was made for requires adaptation and creativity." (525) What would be considered interruptions, bad aesthetics or distractions in conventional filmmaking are where some of the major moments of learning and revelation occurred. (Parent, 2016)

In this section an introduction to each video is provided, and related creative, autoethnographic writing and poetry stemming from field notes and is included. My intention is for the videos to be watched in the order that their titles appear below as they document a process of learning that I went through in this project.

### **4.1 Bodies of knowledge Explores Sites of Mobility, Urban Development**

In urban settings, common solutions to inaccessible terrain for mobility aid users are linked to

paving and development. Safe navigation for blind and low-vision people is tied to electric crosswalks and auditory signals. Urban development is often tied to increases in accessibility. Much of the sense of history within DS and CDS comes from the mythology around protests such as the 'Capital Crawl' in Washington, 1990, which are pointed to as having strong effect on the passing of the Americans with Disabilities Act (ADA). (Eaton, 1990) Similarly, history of disability is drawn along lines of social/ rights based models based on UPIAS and British activism. (UPIAS, 1976) In Canada and Quebec, there is less of a sense of history in academia and activist environments.

#### **4.2 Crip ancestors I**

Crip ancestors is a concept that Leroy Moore and other social media contacts introduced to me in terms of the people who came before us and made our environments and societies more accessible, less ableist. (Sainte-Marie, 2017; Lamm, 2015; Berne, 2015; Moore, 2018) I explore my understanding of this concept in relation to public spaces in Vancouver and Montreal. In *Bodies of Knowledge*, I ask in part, what efforts by crip ancestors brought accessibility ideas and spaces into being, and how do I connect to those crip ancestors through the landscape? I explore the notion of crip ancestors in this film, a theme that returns in this thesis. It came from my searching for connection to landscape, and the felt, strong and immediate effect landscape has on my experience of a place. When writing the poem that was a precursor to this video poem, I was reflecting on heritage, home, and how my crip ancestors fought hard for these curb cuts and door buttons. I was thinking that because we are not connected by blood - not blood lineage, in a way the deepest connection I have to them is through the landscape and policies that now shape my life and access. It was their persistence of existence and resistance that got us here. Warren Cariou states that "land [is an] interlocutor"<sup>8</sup>; land is a character or force in stories. Acknowledgement and communication with crip lineage could be accessed through engagement with landscape. Questions about tensions of access are illustrated and explored in *Bodies of Knowledge*, as a way to make material/ illustrate observations of discursive and political processes of pitting needs against one another. (This is explored further in section 5.2 of this thesis).

#### **4.3 FILM: [Bodies of knowledge]** Film link: <https://youtu.be/c-cWMkGNpC8>

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<sup>8</sup>Cariou, 2017



#### **4.4 Choices are contingent on the options available**

From living and mobilizing in Montreal and Vancouver I've found that standards and desires and strategies are contingent on location - geography, mobility aid in use, etc. I'm in a car nervous about a man in a wheelchair riding in the street in Vancouver. When I'm in Montreal, I'm not nervous in same way when doing that. Choices are contingent on the options available. In Montreal often the best option open to me has been wheeling on a bike path because bus ramps are so unreliable, with approximately only 60% functional as of 2012. (RAPLIQ in Louw, 2014) Only 13 out of the 68 Metro stations on one line are accessible by elevator in Montreal. In Vancouver, only if I really wanted to get some fresh air or just feel the speed and wind in my hair would I do the distances that I used to do in Montreal daily to get to school or work or visit friends. In one city, it is out of necessity that I would wheel for long distances, whereas in Vancouver it's for pleasure because I have the options of taking the SkyTrain, the bus, calling a Wheelchair accessible cab: all of these are spontaneous options just don't exist in Montreal at this point.

The question, how does Vancouver compare to Montreal in terms of accessibility, or 'oh, I guess it's a lot more accessible here than in Quebec?' comes up quite naturally amongst people with mobility aids when I mention my project. For example, May 10, 2017 I was waiting for the bus to go to UBC because I was going to meet up with J to go swimming, and there was an older gentleman who came to the bus stop where I was to also take the same bus as me. He was using a manual chair and I was using my mini power chair. I asked if he had a preferred spot to park on the bus, because manual chairs are generally less stable than power chairs, so I thought I would give him priority of choosing the spot. I smiled and nodded when he asked me that and he said yes I guess it's a lot more accessible here than in Quebec. He mentioned that he is been using a wheelchair for about 13 years and not that long ago some of the routes on the accordion but did not have ramps in Vancouver. This kind of "local knowledge" comes naturally because it's a common experience or shared area of expertise. (Field notes may 10, 2017) It wasn't long ago that the crip ancestors were working hard to make transit more accessible in Vancouver. Many of these ancestors are still alive and I interviewed one, Sam Sullivan, disabled agitator-turned-politician, former Mayor of Vancouver and current Liberal MLA for False Creek, to gain his perspective on this recent history that makes my current mobility reality so seamless.

#### **4.5 Double consciousness**

Could this apply to the double reality of living in arguably the most physically accessible and crip-acceptable city and the least accessible major city in the country?

The double reality of the class differences I experience when living with J and alone?

Double reality of advocating to get needs met in Montreal and Vancouver?

The month-long adjustment period of switching mindsets

I feel this viscerally has a stronger effect than for normates, (Garland-Thompson, 1997), who's access needs are invisibilized cause they're expected, acceptable, less public; they have less imperative to interface with the city / service providers / passers by in daily life. (Field notes Aug 1 Mtl)

It's like I know what is normal in Vancouver and what should be normalized in Montreal but yet when I go back to Montreal I have to get back into the survival mindset of lack of mobility options. It's both a source of motivation to push Montreal and Quebec to get better at access, and a source of visceral frustration and sadness. I think having this mentality of what it's like to live in one of the most - if not the most - accessible city in Canada can inform my activism in Montreal, but it's extra intellectual and emotional labor to switch mindsets or get into the survival mode mindset of Montreal in order to just get where I need to go. The emotional and mental switching that I do in order to move between these cities is extensive. It's like I have to take regression of 100 m, it's like I'm choosing to place myself farther back in the line by going back to Montreal. And as stated above, is getting farther ahead in the social privilege line a fair desire? Or could doing away with the line be my desire? It's hard to seek a good life for myself while also opposing some of the means to getting the things that would make life great, namely a seat at the middle class table and the money to be afforded comfort and security.

#### **4.6 I've watched marches from the window before**

J and I are in bed talking about how much we love each other and how we'll take care of each other when we're old. As I'm readying myself to get out of bed and towards coffee, I hear drumming: oh it's the walk for reconciliation today! I go out on the balcony but don't see anyone yet. Helicopter sounds. Drumming, occasional cheering. Flute sounds.

On the overpass, the walkers stretch for over a kilometer in my view and they keep coming, some with nation flags, metis flags. Some are wearing matching orange union shirts. Seeing how big this walk is I get what is commonly called 'fomo' (fear of missing out), thinking, I should have gone. I try to capture the enormity but this my iPhone and my shaky morning hands aren't going to make that happen. I breathe a sigh of relief thinking, this news helicopter will get good shots. I can google and borrow some of theirs. I think, you know, all these people walking over this overpass street in front of a tent encampment, which normally has nothing, but cars and some panhandlers, showing their support for reconciliation, is a statement.

I come inside to blow my nose and J says, “I read that apparently the price for a one bedroom in Vancouver has been increasing 1.2 percent over the past month. And 12 percent over the year.”

“Holy shit!” I say. “Come and look!”

I go out alone and take a few still shots as the end of the walkers slowly cross my field of vision, a sort of TV screen through the see through panel of our balcony. From up here on the 18th floor we see far but it all seems detached, like we’re not totally a part of what’s happening on ground level. We’re temporary Vancouverites, touched down but not landed. Not settled.

I look over: the encampment has been moved, but some garbage and a patted down ground has been left. I wonder where they went? I mean, have they been gone for awhile?  
(Field notes, Sept 24, 2017)

#### **4.7 My Shoreline: real time documentation on transit trauma due to inaccessibility**

“Microaggressions are a site of trauma” (Eales, 2018)

My Shoreline is shot almost as though I were in like Facebook Live activist mode, like, this shit’s happening right now. It’s really current. At the same time, I sandwiched that bit into shots of myself meditating and water and reading my Underwater City poem, which is reflective and more peaceful. (Louw, 2014) I had always imagined this swimming scene to be the opening scene of a feature length, magic realism documentary about accessibility in Canada. My Shoreline was a way to experiment with that scene and also fulfilled the requirements (kind of) of going to the shoreline in Montreal, for Liz Miller’s shoreline assignment in which she asked us to go to the shoreline in Montreal and create a piece of media about the shoreline. For me, the environment also includes transit, and it also includes the sidewalks and it also includes the need to mobilize through the urban environment, which is a perspective that comes from my embodied experience of access barriers, and which might not be a consideration for someone who’s mobility styles are afforded and invisible due to their matching with the normative way of mobilizing (by foot) in the Montreal context.

**4.8 FILM: [My shoreline]** Link available here: [https://youtu.be/lpd0Y\\_tYOU](https://youtu.be/lpd0Y_tYOU)

#### **4.9 Episodic reflections on My shoreline**

As an extension of my auto-ethnographic method I think now that I've made this video and kind of forgotten about it, it feels really distant for me, like me trying to get on the 105 bus, or whatever it was. See? I already forgot, I think it was the 24, and just having the ramp beeping in my face - it just seems so far away because of time and distance, being in Vancouver with its 100% wheelchair accessible Transit System, and that has been healing for me. There's a part of me that's blocked some of that actual pain and just the effects of all those daily access barriers. (Field Notes, May 15, 2017) I've let down my access guard because it is less necessary for me here in Vancouver.

#### Collaborative world building I

Collaborative world building - when asked my thoughts on revolution.

Driving around Stanley Park.

Destruction as a tool can be useful. Not a good state to stay in. Not healthy.

She wasn't expecting a serious answer.

I fancied myself a teenage revolutionary - little did she know

In Vancouver, running out of structural things to be frustrated with

Merde.

Turning inwards,

frustration calls me to acknowledge her

the days I can't do what I want

Surrender - when asked do I feel pain all. The. time?!

Surrender

She grew to always expect a serious answer -

I grew to laugh at them.

#### **4.11 Three year anniversary: relocation/ geographic distance as a way to relax access guard**

The other day I realized that J and I had forgotten about our three year anniversary. I realized this after a really fun date night where we spent, like, pretty much the whole day just running errands and getting him glasses and stuff. And then we ended up going for dinner and then we went to go see Bon Cop, Bad Cop at the theatre and it was really hilarious. And he had waited to use the washroom at the movie theatre and I had used the washroom at the restaurant prior to leaving. The washroom at the restaurant was really small, it was the world's smallest toilet. It

was like a closet. But it was well maintained but it was just really tiny. But I had gone on foot because I left my chair at the table that we were seated at.

So, this got me to thinking about toilets and anniversaries and drinking and having to use Restrooms in various locations - public, private, and commercial. And it got me thinking about how, last year, on our anniversary, the restaurant that we went to was wheelchair-inaccessible to start with, but we went there anyway. And then the washroom at that place only had a toilet down a flight of stairs, so we ended up being like, "oh, let's just go somewhere else," after our dinner. And, anyway, it turned into this unfortunate debacle where it basically landed up in the Québec Human Rights Commission office ten months later, because the manager at the McDonalds that we went to refused J access to the toilet because he was opposed to J bringing his scooter into the washroom. So anyways, all of this happened and it was this whole traumatic thing where we literally could not find a place to use the washroom in the old port of Montréal. #toiletsarcity.

The way that I reacted to that versus the way that I imagine myself reacting to it if it had happened here would be completely different. I imagine that if it had happened here I would probably just laugh or brush it off and go somewhere else. But because of the high level of access guard that I had up last year, it literally pushed me over the edge. It's like there's a certain amount of ableist behaviour that I can tolerate. And then, after that point, I unfortunately lose my ability to cope and I just lose all sense of dignity, pride and decorum.

And that's what happened last year with the McDonalds manager. I mean, I ended up screaming at the guy and freaking out. I had an indignance about me that I don't like at all. But because I'm here and my access guard is seriously let farther down, and as time passes it goes deeper and deeper down, I can just laugh it off a bit easier. I was having a hard time remembering the last time that I cried in public about ableism stuff.

There is a lot of emotional turmoil that goes along with ableism and discrimination - or whatever you wanna call it. And I feel like in our communities, at least the disability activist groups that I'm a part of, we don't really talk about that emotional side of it. We don't really talk about how it takes a year to get over the emotional shock and humiliation of being denied access to a toilet in a raunchy McDonalds at 1AM. Like, it kind of seems preposterous, but at the time it was actually the worst thing in the world.

From where I am at now, I want to talk - to look at these issues and from not just a political standpoint but from an emotional one. I'm feeling so hardened by these experiences, and that's not how I wanna be, I don't wanna live with a huge access guard for the rest of my life. But, you know, it's a defence mechanism, for sure, you know? (Field Notes, May 15, 2017)

Lindsay said in her PhD thesis dance autoethnography that “microaggressions are a site of trauma.” (Eales, 2018) When Lindsay said that in her performance I was like, holy shit, because, you know, ever since last year I’ve been reflecting on why I’ve have such short, or extreme reactions to kind of minor situations. It made me reflect on this toilet memory and how live microaggression is contained in My Shoreline. The film is basically a real-time witnessing of my reaction to cumulative microaggression-based traumatic experiences. After all the bus activism in response to acute discrimination in 2015-16 (outlined in section 6.1), my motto used to be ‘don’t get mad get political’. I’m realizing how that distanced my feelings or didn’t give space for me to feel emotional responses to ableism trauma.

Had nightmares about going to meet friend in Mtl

Nervous about buses as I get ready to go back soon (Field notes, May 18, 2017)

#### **4.12 Social landscape**

“The border determines your state of being” (Personal correspondence, May 29, 2017) Dylan Hickey and I met in a Skytrain elevator a year before J and I moved to Vancouver. We bonded through searching for the elevator to get from the concourse to the ground level. We stayed in touch and talked about writing over the year, and he agreed to be interviewed for my thesis when asked. During our interview, Dylan told me about his move to Canada after having lived in the USA. For him, Canada and BC mean survival for him. (Personal correspondence, May 29, 2017) “[He] knew if [he] stayed [ in the USA he] was not going to survive another couple years.” (Personal correspondence, May 29, 2017) Dylan pointed to the importance of social services to support aid for daily living, and the “degree in communications” it takes just to manage navigating the system and managing one’s own care. (Personal correspondence, May 29, 2017) He described the way that finding crip community in the building he lived in when he first came to Vancouver gave him power. Things like finding out about a life-changing medication that a friend told him about, and a contact who helped him “speed... into a place [to live],” skipping “normal processes” to fast track to a manageable living situation. (Personal correspondence, May 29, 2017) After hearing about the unsupportive and edge-of-survival conditions he lived with before moving to Vancouver, it gives me even more of an already completely [sympathetic] love of the Skytrain. He said that first after moving he was afraid to go out and didn’t know how to manage his own mobility using transit. It got me noticing how unremarkable seeing people

with mobility aids in the Skytrain is - deliciously mundane. (Personal correspondence, May 29, 2017)

This is the motivation behind the video Crips, Crips Everywhere, which uses footage from mobile interviews, a stationary interview and exciting access to what became mundane and expected for me - access to transit and public space in Vancouver over the last 1.5 years give or take. It is a love song to crips, a shout out to crips saying 'yo, I see you.' It is aspirational - a dream for crips, all the crips who want to be mobilizing exactly how they want, actively working against ableism in their practices of living, expressing their freedom through their mobilizations, going to buy toothpaste and looking fabulous. I wrote the lyrics and sketch of beats and chords. My attendant, friend and collaborator, Mark Beach brought the song to life with blend of digital and live instrumentation and form, as well as mastering. Paul Tshuma, my friend who I've made music with before, audio recorded and sang with me. Crip collaborators who I invited via email and facebook and text, sent me selfie recordings to include. My friend and Gift Tshuma beatboxed. It is and was a group effort and I am grateful to everyone's contributions. It is still a work in progress, so in the meantime, here are the lyrics.

#### 4.13 **FILM LYRICS: [Crips, crips, everywhere]**

Intro

Climbing Bass in

Chorus x2

Crips crips everywhere

Crips crips everywhere

Crips crips everywhere

Crips crips everywhere

Verse 1, 2

Crips are here

Crips are there

We're not going anywhere but

We are getting everywhere

You're a robot  
I say no-bot  
Slow the flow bot  
We will not go!

Chorus x2

Verse 3,4

Crips crips on a plane  
High high high up on a crane  
Way below in a submarine  
Submarine  
Submarine

Crips crips on a train  
With your sisters we have lain  
Caught our hair up in the drain  
Now you have our DNA

Chorus x2

Paul and Aimee

Bridge

least expected  
have been detected  
Try to eject us  
We! Will! Not! Go! go go go

Beat box (not recorded yet as of feb 7 2019-will edit in after)

Chant 1 (over Chorus instrument track)

|:Behind the door

In your hair



In the shower  
We are there:|

Chant 2 at end + Paul overlay

Chant 2

When you detect us

Try to infect us

Think we're defective?

Well. So. Are. You!

Paul Overlay

Don't be trippin just be crippling

Don't be slipping

keep speaking

For what you believe in

## Chapter 5: Conflicting Access: a discursive extension of eugenics

### 5.1 Medical Discourse Control: retelling our stories with an emphasis on our bodies as the site of the problem

Disability justice scholars, Danielle Peers (2015), A.J. Withers (2012) and Jay Dolmage (2015), place disability history and politics in the Canadian context linking the production of disability to Canadian institutions that reinforce the body as a site of social control. 'Experts' in the medical or social professions guide mainstream discourse about disability, (Orsini, & Smith, 2010; eg., MS Society, 2009) centering around treatment, normalization, conforming the person or group to 'normate status'; conceptualizing disability as something to be fixed with diagnosis and treatment. (Garland-Thompson, 1997) Peers et al. (2014) argue that equating disability to diagnosis minimizes the social, political and cultural identifications and uses of the concept, rendering many of the positive and self-or community-articulated elements of disability invisible. (268, 274) Simultaneously, ableist systems of thought mean "able-body status continues to be assumed, helping to render [both embodied] differences and their [social] outcomes relatively invisible". (Chouinard, 1997, 382) People are dehumanized on the basis of disability through a process of "disqualification [where] mental and physical properties of bodies become the natural symbols of inferiority", therefore providing a logic for the naturalness/ neutrality of excluding and attempted correction of disabled people. (Siebers, 2010, 24-25) In this medical discourse, disability and diverse ways of being are often seen as deviating from the norm, or in need of intervention. (Boisvert, 2016) These social forces are based on a culture that valorizes a particular normative body and modality of cognition and are encouraged and enforced through interplay between institutional services, public discourse, and daily interactions, which often reinforce each other.<sup>9</sup> (McRuer, 2006, 1) "People with disabilities... are routinely desexualised, degendered and infan-

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<sup>9</sup> A recent illustration: at physio the other day my therapist explained the stretches she recommends in terms of reverting a bit the "deviation" that my wrists have. This (desired) control and attempt at reducing the 'deviation' offers a model discourse for speaking about undesirable social or sexual actions uses the same terminology and conceptualization of the normate status (non-deviated, the place that my wrists are imagined to have deviated *from*). (Garland-Thompson, 1997) It wasn't long ago in the Canadian context that homosexuality and queerness were illegal and labelled as sexual deviance. In a different application of the same logic, disabled people were displayed as 'deviants' in freakshows in 1700s (in England that USA) to hold up as the antithesis of 'normates', and to entertain and evoke horror/ pity and titillation. (Snyder & Mitchell, 2005; Garland-Thompson, 1997) While modern day self-solicited physio is a rather mild manifestation of this logic of deviance and correction, it stuck with me as 'treatment' terminology/ the logic of deviance informs social categories, and vice versa.

tilised. Sexual identity and even gender identity become secondary to our bodily identity.”  
(Young in Findlay, 2015)

Our current binary way of thinking about disabled or non-disabled draws directly from the eugenics movement of the mid 18th -19th centuries. Eli Clare (1999), in his historical and cultural analysis of freak shows of that era, writes that “Scientists and politicians... were re-affirming the less-than-human status of people of colour and rationalizing much for their social and political policy. Simply put, the freak show both fed upon and gave fuel to imperialism, domestic racist politics, and the cultural beliefs about ‘wild savages’ and white superiority.” (99) Further, designations based on what we call intellectual disability now, meant that “... the consolidation of human variation under an exclusively derogatory classification imposed a disastrous logic of binary thinking. ‘Normal’ and ‘feeble-minded’ (or ‘N’ and ‘F,’ as the eugenicists call the two groups) became the default categories for all human beings... By restricting the social liberties and rights of disabled people, eugenics invented the category of “disability” that grouped people with widely divergent physical and cognitive characteristics under a single heading of ‘defect’”. (Snyder & Mitchell, 2016, 113) “[Impairment] ‘is an historically specific effect of knowledge/power,’ which divides human variation into categorical types in order to render the people assigned to some of these categories susceptible to the disciplinary interventions of other people, especially people who are regarded as “experts.” (Tremain, 2006 in Peers, 2015, 185)

This social and economic nation-building project used terminology like efforts to “civilize”, which is the same kind of terminology used in colonization discourse. “The rhetoric of social rescue [prevalent in eugenic discourse] also parallels missionary efforts to deliver Christianity to ‘unenlightened’ racial populations” such as First Nations in Canada. (Snyder et al, 2016, 116) “In both cases the presumed identification of inferior individuals corresponded to a dearth of access to modern belief systems equated with Euro-American civilization.” (ibid.) Similarly, “Gilroy refers to a parallel racial practice as ‘infrahuman’ blackness reconstituted in the ‘half devil, half child’ patterns favored by older colonial mentalities.” (Gilroy, 2001, 26, in Snyder & Mitchell, 2005, 115)

Importantly, not only were “idiots”, ie: disabled people, “incapable of helping themselves but [they] also threatened the fabric of society.” (Snyder & Mitchell, 2005, 116) So, it wasn’t just that these people needed individual correction or therapy, but that their presence in society was threatening the society as a whole. These children and adults were seen as having “excessive demands,” pointing to economic motivations for this view; having a child who needed more care at home prevented at least one parent from going to work in the “industrializing labor pool.” (Snyder and Mitchell, 2005, 116) So, when institutions started opening up, they were presented

as temporary training centers, where people would be institutionalized only as long as it took for them to be trained for a “life of normalcy” (Snyder and Mitchell, 117). In Europe and North America, “institutions began to transform themselves from educational to custodial structures, and training missions quickly gave way to efforts of social erasure of ‘undesirables’.” (Rothman, 1971, in Snyder and Mitchell, 117) American psychologist and eugenicist, Henry H. Goddard said “We need to study them very seriously and very thoroughly; we need to hunt them out in every possible place and take care of them.” (Goddard in Snyder & Mitchell, 117). Essentially, what started as ‘we’re just going to take them away for a bit and fix them’ turned into them being like ‘ok, it’s not working, they’re just going to stay in here and we’re going to keep them out of society and away from the risk of corrupting other conforming/ compliant members of society.’

The logic and philosophical undergirding of colonialism seems to function in similar ways, through self and peer-policing, in addition to state-down policing. The history of attempted “rehab” of disabled individuals and communities shares a history with colonization as it stems from a similar logic of correctionalism, conformity and social threat. The mentality was similar and was applied on these diverse “abject” bodies. Histories and experiences and current realities differ immensely amongst these populations because of racial and class hierarchy, which is also a function of this conformist and racist basis of Canada. “[Racial] domination lies at the very heart of Canadian nationhood, at the core of its identity and its social, juridical, and moral order.” (Thobani in Peers, 2015, 28) Eugenics as a transnational ideology underpins “[restrictive] public policies toward people with disabilities that limited or denied their participation in public institutions and privileges, such as marriage, reproduction, the labor market, the right to live in non-segregated communities, and immigration.” (Snyder et al, 2016, 112-113)

Through time and efforts of making invisible these oppressive forces, there was “a mid-20th-century move from an “an overt racial dictatorship” to an implicitly white supremacist nation that loudly celebrates itself as a compassionate and multicultural welfare state.” (Thobani in Peers, 2015, 28) This continues with policies such as restricted immigration for disabled applicants, everyday policing through microaggressions in public space, and modern sites of the logic of eugenic ableism such as restriction and in some instances, banning of vital accessibility tools such as plastic straws. (Habel-Thurton, 2018)

## **5.2 Zero-sum access, or the logic settler colonialism**

The eugenic connections of the logic of ableism and white supremacy have been articulated by activist/ artists/ thought-leaders such as Patty Berne (2015), Mia Mingus (2018), Janine Bertram Kemp, Lydia X. Z. Brown (2012), The Harriet Tubman Collective, Sins Invalid (2017); and Schol-

ars such as Peers (2015), Snyder & Mitchell (2005), Dolmage (2017), and Siebers (2010). Sites of access conflicts or zero-sum access between disabled people, between disabled people and other populations, and disabled people and the environment are sites of policing that can present social preferences of the day. As a contemporary example of this logic of correction, below is an articulation of the straw access/ environmental conflict that arose in 2018, wherein media coverage of the environmental impact of single-use plastics gained attention, and opposition to the widespread use of plastic straws was articulated on social media. This led to a very drastic shift in the availability of plastic straws in restaurants and public spaces, including a level of public shaming when straws were requested as needed by disabled people as an accessibility tool. (Findlay, 2015; Smith, 2018)

I argue that the logic of zero-sum access acts as an extension of more overt systems of subjection, and at its most extreme interpretation, as a current expression of eugenics in colonial North America/ Canada. These tensions or conflicts, between crips and the environment, between crips of differing needs; these conflicts exaggerated by concern about the (environment's) future, occur often. In my embodiment and in the world, tensions are common between myself another disabled people and between my "movement" for disabled people and the environment or queer community (Eg., inaccessible venues where wheelchair/ ASL access is dismissed in service of budget) or artistic communities.

Below are sections of autoethnographic creative writing that explores this zero-sum conception of access, further reflecting on straw availability, the cultural narrative that disabled people are asking too much, are too much and creative articulations of my personal process of using tools that I need. I draw out elements of this process of zero-sum access, or an articulation similar to the logic of settler colonialism, which can make disabled people feel like our needs are "excessive demands" on society, each other and the environment. (Snyder & Mitchell, 2005, 116)

OK, I told myself I wouldn't get into the straw thing because it's just such a pain in my ass and it's one of those things where I don't want to validate people's stupidity with my attention, kind of like how you ignore seven-year-olds when they're acting out. It's like they know they're acting out, so if you give them attention then you're just feeding into their cycle of seeking attention through negative behavior.

I don't have kids. I think that's what it's like but...

I have to ask for straws now, and sometimes I'm met with 'sorry we don't carry those anymore' and sometimes I met with statements on menus that say: because of environmental reasons we are no longer providing straws.

That reads to me like: because we care about the environment we don't care about the needs of disabled people who require straws to drink.

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Yesterday a Facebook friend who is outspoken about disability stuff posted on their wall something along the lines of "we often hear about how disabled people are in conflict with environmentalism, we never talk about how disabled people are good for the environment. Here are some things that make me and my experience support the environment: I don't drive, so I use transit, because of dietary restrictions I hardly eat takeout, I just eat unprocessed foods"... The list went on.

\*\*\*\*

At this conference a colleague and I went to someone needed artificial lights on in order to see, those lights gave this colleague a migraine, she asked if we could turn the lights off and the other person responded, if the lights are off then she can't access the space. She hoped to find a shared solution like maybe open some of the blinds and leave some of the lights on so there would be a mix of lighting and therefore a compromise. The other person then referred to a zero sum conception of access where she said well that's OK I'll sacrifice and we can leave the lights off and the blinds open for you-I don't need to see right now anyway. It was then a unilateral decision and any collaboration or collective problem-solving was shut down. This response reiterated the idea that there are only solutions to access conflicts where one party has their needs met and the other does not: zero-sum access.

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Seeing this Facebook friend's posts make me sad. In medical, educational, employment, transit spaces disabled people in different ways, are in positions of having to justify our needs or our existences. It sounds dramatic. It feels like shit. It's not constant, and it's more prevalent for multiply-marginalized disabled people. But seeing this person on Facebook justifying and attempting to prove that they weren't bad for the environment, as though environmentalism is the new human, as though if you don't support the environment then you are cast out of the category of desirable human. (Siebers 2010; Snyder & Mitchell, 2005) And similarly, seeing this logic of what I see as settler colonialism translated into disability spaces, also saddens me and just frustrated me because what I desire in community, aside from friendship and camaraderie - maybe most of all - is the openness to doing things differently, to not replicate the system that inevitably, and at its base causes us harm.

The straw social media frenzy, happened shortly after my poem, Pounds, got accepted to be published in a book, Body Politic. (Wright & Gibbons, 2019)

### 5.3 Pounds

Yesterday, you

Drank warm tea with a straw for the first time. You

Carry straws on you now. You thought to yourself, I'm proactive, I guess. It was jasmine tea.

The cups at that restaurant were covered in images of fish: unagi, maguro, ikura, all sorts of fish.

The names were written below in Japanese. Red and orange, a sliver of blue on the fin. The fish

went all the way around the cup. Maybe it was the weight of all those fish, the seawater

they were swimming in - chasing the endless route around the cup. Maybe it was the solid

porcelain, a material you traded out for plastic a few years ago, but those fish were heavy.

So you

drank warm tea with a straw for the first time, glad that you

Carry straws on you now. Otherwise, it would have been water only. Except that

the water glass, tall and foggy, was heavy too. As though

the frost, the condensation made the cup weigh ten more pounds.

You did the increasingly automatic calculations: a million crip pounds.

You may come to revel at how beautifully light the straw is as it submerges in expectation,

actuating ripples; You may be tickled by the power of surprising waiters and passers by.

But yesterday, in the restaurant, the straw outed you. It

Screamed, She is Thirsty! for all people and unblinking ceramic fish to hear.

But, you wanted to have tea, and you decided that you will

practice.

And this is not going to be the straw that breaks you.

This poem had nothing to do with the environment and everything to do with congratulating myself for finally being OK drinking from straws for warm drinks in public. I don't have a huge conclusion to this concern of zero-sum access and access conflict, however, it informs the way I went forward with my research and autoethnographic analysis of my interview process.

## Chapter 6: Methodological reflections from the process of recruitment and film-based research-creation

### 6.1 Who is entitled to position whom?

“Take a picture” she said to herself as she confirmed the gawking gaze of some teenagers on the bench near her. The teenagers gawking at her with open mouths reminded her to turn on her camera. “I should try to catch them starting as the train comes in - what a nice shot that would be.” The metro was hot and she had her thick, bird jacket on. Her armour.

She had decided to take transit over uber because she couldn't stomach the prospect of making small talk with a smelly stranger for the 40 min drive. It was a beautiful fall day and at least on transit she could blast Gaga and be alone - in public. Plus, she was so beyond the point of not affording uber every trip outside of wheeling distance at this point. (Field Notes Oct 27, 2017)

In Winnipeg in 2017 at Performing Embodied Oralities in the Americas II, Peter Kulchyski stated that the “logic of spectacle breeds docile bodies.” (Personal correspondence, Aug 5, 2017) Spectacle. I've been at the lens end of image production: photographed, measured, traced, childhood footprints padded along a roll of lined flip chart paper, to document my arches, toe placement and who knows what, occupational therapy masked and wrapped up in a game that, while being kind attempts by parents and therapists, wasn't really fun. Decades later, journalists set up shots of my partner's scooter in a story about transit discrimination that centers on me using a walker. These journalists don't know or don't care about the difference between these mobility tools, they just need images that will represent di

Sa

Bili

Ty

To all their

Viewers

Viewers

This experience took place in 2014-2015, when I experienced a lot of bus-access refusal due to broken ramps and lack of training of drivers in the STM in Montreal. This is when I began using more mobility aids and so needed ramp access. Certain experiences were so dramatically discriminatory that I felt compelled to contact the media, thinking that exposing this blatant dis-



crimination – new to me as it was – would lead to a change in transit policy or at least a shift in public perception of accessibility. Because as it was, often, when I was refused access to the buses, ambulatory passengers cut in front of me, or just avoided eye-contact, or performed annoyance that I was stalling their trip. So I thought, this issue needs to be exposed and blown open in the news media.

The above instance occurred in 2015, when I was using a walker and the bus driver didn't know how to lower the ramp at the front of the bus and refused access. It was icy and slippery outside so already I was on edge. It was also the first day of a new job that I didn't want to be late for, and unfortunately never made it to. When it was clear that the ramp was not going to be lowered I asked the driver to assist me to lift my Walker up and she didn't. She was aggressive and I got defensive and hostile back. A passenger assisted me in lifting my Walker up so I did end up getting on the bus, however the whole trip ended up with me staging like a one woman sit in on the bus at the last stop. How absurd and yet mundane and institutionalized this ableism was that I could not get across the city using public transport.

Outraged, I contacted all English news media I could in Montreal and some key French-language outlets as well. From this experience I gave a number of interviews to Global Television, CBC TV and CTV. One particular outlet and journalist stays in my mind as a pivotal moment in my realization that exposure of an issue in this fashion also led to exposure of myself in way that involved a lot of personal risk and opened up the possibility of more ableism than less.

As mentioned in the above poem, an interview with CTV occurred in my home and Julien was there, and the television host asked us to move his scooter in order to have it in the shot, but the story was contingent on the fact that I was using a walker, I wasn't using a scooter. This adjacent representation, hinting at the issue of mobility, and yet completely misrepresenting the important detail that I was refused ramp access because I was on foot and using a walker - and at the time the STM policy was ramp access for wheelchair and scooters only. I felt frustrated and after clarity of analysis I realize this was a type of policing of my image by 'professionals' that have power of representation and much less knowledge about the embodied experience they were producing a story about. Further, when corrected, they continued this adjacent representation. For them, the symbolism of mobility aids or disability was more important than accurate portrayal of the story.

An interview with Baptiste Zapirain from the Journal de Montreal began with him repeatedly asking what my disability was, and there was a moment where I decidedly refused that question because it didn't have to do with the story of discrimination. (Zapirain, 2015) He was insistent, and tried to negotiate with me saying like, if I didn't say what it was, readers wouldn't

have the context they needed to understand the story. This reiterates the trope of medicalization and problematization of people's bodies, rather than the institutions, practices, and physical structures that disable us in context. (UPIAS, 1976) Zapirain was so insistent that following the interview he repeatedly called me, sometimes at work, sometimes in the evening. I repeatedly reiterated why I did not want to share this personal information with him. Here, on top of the micro-aggression based trauma of being discriminated against by the transit authority, this disrespect of boundaries and consent on the part of this journalist caused further ableist harm and microaggression-based trauma.

This type of image/ discourse misrepresentation and policing has come from other sites as well, besides journalists. It has also come from peers. (See Peers, 2015 chapter 9). One such instance of peer policing of image and representation and expression occurred in 2016, when a colleague from a former workplace proposed a collaboration on a video that she was going to air on CBC arts show, *Exhibitionists*, a web-based platform, which features outspoken artists and their work. She pitched it to me as a way to showcase my writing and activism. At first I was extremely excited by this opportunity to increase my exposure as an artist, particularly as a writer, as she had based her pitch on my concept of *Underwater City*, elaborated in my 2014 publication. (Louw, 2014) The aesthetic that she pitched for the piece was drawn directly from the aesthetic of my poem, *Underwater City*.

As discussions between us took place I found out that she had already pitched and had the pitch conditionally accepted by producers at this show prior to speaking with me. I found out that she had pitched a short video documenting "a day in the life of Aimee Louw, a mobility impaired writer and activist." She envisioned, as an animator, that she would design certain aspects of the day in my life and then show some just live footage of a day in my life. In her pitch she proposed that I would go and do activism, then go to my South African Gospel choir rehearsal and then come home at the end of the day where I felt more comfortable than out in the world in Montreal's inaccessible infrastructure. (Personal correspondence, Sep 29, 2016) Several things began to unsettle me about this pitch, particularly the fact that she hadn't asked me prior to pitching to CBC Arts. Beyond that the way that she described a day in my life, was really more like a concentrated week; I felt misrepresented and did not want to have this piece place me in the trope of 'supercrip' activist who is highly productive. (Peers, 2015, 14, 230) This, I felt, would do a disservice to the crip time that I live within and that I try to encourage through my writing. Most importantly, as I questioned and suggested different approaches and focuses, it became clear that it actually wasn't going to be a collaboration in the way that I think of collaboration. I felt pressured to agree to her terms, that I had little say in, and felt frustrated and un-

comfortable that she, as the film-maker, animator, and director, would receive all the professional credits, while I would be subjected and peer-policed into an inaccurate representation of myself.

Danielle Peers (2015) states that power is not strictly top-down and, in a liberal democratic context, some of the most effective mechanisms of power and control come from our peers and ourselves. (208) This instance could be pointed to as an example of that peer policing and control. This filmmaker desired to expose intimate parts of my life with little input or direction from me as the subject. This experience was pivotal for me in reaffirming my desire to self-represent through media production in a strict way, controlling my own story and ideas and art output, and collaborating with people I trust and who I feel respect consent.

After these and other experiences I became frustrated and largely uninterested in being interviewed by/ collaborating with people from whom I felt a level of exploitation (usually not-intentional but present nonetheless). As Peers et al. (2014) write, “their questions and resulting publications often felt like misrepresentations, if not complete betrayals.” (4)

## **6.2 A story of running**

Mine began to be

A story of running

Away

Every time someone pissed me off

Everytime fucked off away from my personal code; my expectations. It happened quickly, practically instantly. You're

A friend, all good

And then

You did this

I'm out. And

I'm out and

I'm out. It happened

Slowly, quietly - I'm there

I'm there and then

I'm out.

Not thinking about visibility or

Representation

Or

The table or  
A seat at it; I usually bring my own seat anyways.

But dismissal is not a strategy  
Not something worthy of a  
Roundtable or  
Panel or  
Speaker's fee. It comes  
Free. (Field notes Jun 28, 2017)

### **6.3 Dismissal/ engagement**

Dismissal was an effective strategy of harm reduction - a prevention based on instinct, a way to protect myself from further exposure as I dealt with ongoing effects and ongoing microaggression-based trauma. And since those media experiences in 2015-2016, I had been actively working on consciously deciding when to engage and in what ways, moving past simply withdrawing from these instances and dynamics towards engaging in less committed or safer ways. So when journalist, Nicolas Pham, from Radio Canada contacted me in spring, 2018, and invited me to be involved in a web piece about sexual assistance in Quebec, I decided to engage to see what could come of it. I was the point of analysis of my thesis interviews. And at this time, I was developing my portfolio as a journalist and broadcaster, specifically focusing on accessibility and stories involving disability in Canada. (Louw, 2018) I saw this as a potential opportunity to shift my public persona from activist to journalist.

Mr. Pham contacted me by phone, and shortly into our conversation he began asking extremely personal questions about my sex life, which felt presumptuous. (Personal correspondence, April 20, 2018) Not feeling in the mood to just dismiss, I turned the questions that he posed of me, back to him, asking about his dating and sex life. When he immediately got uncomfortable, I explained that that is how I feel as well, and just because I have written in particular contexts about sexuality and dating doesn't mean that I'm interested in discussing in any context. I did not feel he respected my boundaries in asking me intimate questions about sex.

I told him there are a lot more issues than state funded sexual assistance affecting dating for people with diverse experiences and bodies and embodiments. I suggested why not focus on ableism? That would allow for a broad range of topics, including if it comes up from interviewees, sexual assistance. I stated that I was available to co-produce and/ or contribute as a journalist. From there he said he would get back in touch after talking to his producer.

A series of email correspondence between us followed. He acknowledged the role I played in expanding the focus of his story, "I've done a bunch of reading. And I better get what you meant when we had a chat. And what I would like to do now, as one content in a series on accessibility, is five interviews with different persons with disabilities - about ableism." However, after I reiterated that I was not available for interview, he wrote, "I did read your own published articles and found them interesting, but they will not be cited." This showed me that he wanted an interview subject to expose personal details about her life and that he was not interested in collaborating as peers. Another media producer looking for a subject. (Personal correspondence, May 8, 2018)

"[The] hallmarks of neoliberalism are co-optation and incorporations, meaning that the words and ideas of resistance movements are frequently recast to produce results that disserve the initial purposes for which they were deployed" (Spade, 2011, in Peers, 2015, 223).

This experience was an instance where a media producer was looking for a subject, and another where I turned down the opportunity to be subjected. I felt frustrated because he did not value my knowledge. I felt proud that I respected my own boundaries and 'no' to an interview. I feel our correspondence was the site of peer-led attempted discourse and representation control that became hostile when I acted as an active agent rather than a docile body on which he attempted to enact his own interests. (Foucault, 1975; Peers, 2015) This instance showed me, among other things, the importance of mutual benefit when engaging an interviewee, especially about topics of marginalization and oppression. It also demonstrated how bad it feels when your expertise isn't valued or recognized.

In the above experiences to varying degrees, there were elements of ingroup/outgroup dynamics. All the media producers self-identified as non-disabled explicitly, and through their way of asking questions of me, as though seeking out 'the' disabled experience. I was recruited by non-disabled people, asked to expose personal details and experiences. And there was a tangible pressure in these experiences to self-define in hegemonic terms - for example, in medicalized terms, locating the source of the problem of discrimination in my body not in the (social) infrastructures that surround us. Like the other experiences described above, this experience greatly informed the ways that I approach media production, interviewing and involving and holding other people's stories in my thesis. In my thesis I was the producer, director and leader. I was to use creative and crip methods to intervene into normative fields of representation. I would power-share and take leadership in terms of location, focus and tone from participants. I did not want to reproduce the dynamics of disrespect and attempted subjection that I had experienced

with media producers. I would do my best to rest communication and relationship-building on the basis of consent and respect.

#### **6.4 Problematizing my research question and recruitment**

“I need more data” I said to the girl I was dating as she embraced me in all my grumpy, mid-writing hostility in the cafe we meet at every week.

“What kind of data?”

“Interviews.” I felt I needed to interview more Indigenous disabled participants, as so far only 1/ 5 identified as such.

I’d put off pursuing disabled Indigenous participants for a year. I’d done some half-assed recruitment, attempted some snowballing from white participants who have worked with Indigenous crips. But mostly, I’d put it off. It feels wrong to hunt people down. To pursue them hard. It has felt pushy when I’ve been the “participant” in interviews, as described above, exposable to the degree desired by the ‘producer’ and ultimately, disposable if not performing to their agenda or tastes. I felt that now I was the ‘outgroup’ media producer seeking participants of a social group that I was not a part of. Previous experiences as an interviewee had made me conscious and nervous of this dynamic of exploitation, and I was now feeling uncomfortable as the “re-searcher” at the idea of searching for participants in communities in which I wasn’t already embedded or invited. Yet, the other side of this: leaving those perspectives least close to you out of research because they are hard to access is also a risk of having bias or exclusionary research: something Dot Tuer said at *Performing Embodied Oralities in the Americas II* resonated, “Absences speak.” (Personal correspondence, Aug 5, 2017) Now it was spring, 2018, and I felt at a bit of a standstill.

Around this time I had also been developing in collaboration with INDI Master’s Candidate, Katie Jung, a concept to hold the question of what do we make public, or present as popular education elements of our work, versus what are the private or intra-group discussions we want to have without the prying questions and need for explanation to the larger community and communities. “For us, micro-protections are a practical application of accessibility politics; prevention and responses to felt, tangible and non-metaphorical experiences of inaccessibility and feelings of being unwelcome.” (Jung & Louw in Acton et al., 2019) Anonymity had become a precious and hard to come by element in my activism and thinking. Why, then, was I asking people to expose their embodied knowledge in a similar way to what I had recently questioned, and in many instances, rejected? My desire to self-represent through media production, control-

ling my own story and ideas and art output, had recently been affirmed and I had committed myself to only collaborating with people I trust and who I feel respect consent. How then could I invite people who I did not (yet) have a foundation of trust and consent with to expose themselves and share their stories? It felt hypocritical. I felt stalled in my project and didn't want to force my way forward reproducing the dynamics of exploitation that I had been exposed to as an interviewee.

## **6.5 Interviewing/ listening**

These questions of power, consent and comfort in the interviewing process have been addressed through innovations in community-based research, and research action and research creation methodologies. My initial proposed and followed-through methodology was motivated by research-creation, autoethnography and embodied knowledge as a starting point. In recent decades, scholars have expanded the traditional question-answer interview to move towards “power-sharing”. Recognizing the inherent power imbalance in the researcher-participant relationship, wherein the interviewer gets to set the agenda. They have developed methods such as the semi-structured interview, where participants can add, redirect and reject any questions. Petra Kupperts' (2013) shared experiments in cross-community poetic exchanges, as method, provided guidance to me in the proposal and initial interviewing stages of my thesis process in 2016-2017. As did Ashlee Cunsolo Willox et al.'s (2012) “community-driven methodological strategy.” (1) And oral history scholars have shown in the last 3 decades that storytelling moves beyond the linear question-answer power structure of interviewing. Inviting stories and holding space for storytelling had seemed like a good place to start experimenting with ‘unsettling research.’ Yet this methodology can still require prompting, often in the form of questions, which to me feel like loose interviews with less curation or involvement from the researcher.

The semi-structured interview style that I proposed, and went into the interview phase(s) with, involved offering witnessing and space for interviewees to share aspects of their embodied experiences and micro-assertions in accessing public sites.<sup>10</sup> (Woo & Gallagher, 2011, 400) I saw this in contrast to a purely social science approach, where I would have sought specific responses to questions, to support a hypothesis as I outlined (Louw, 2018) This was an experiment in trying to do “unsettling research.” (Tuhiwai-Smith, 1999)

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<sup>10</sup> Woo & Gallagher, 2011 use the term ‘micro-assertions’ in the context of citizens’ use of the courts, which they argue is “necessary for the realization of equal citizenship” in the democratization of modern day China. (400) I extend this term to include the micro-practices taken by individuals and communities to assert their belonging in a space, and their ‘right’ or sense of calls for access.

From the time I read, synthesized, took this information in, wrote and defended my thesis proposal and did other episodic work, I struggled with how to do my version of 'unsettling research'. (Tuhiwai-Smith's, 1999) The actions I said I would take to try to 'unsettle' in my proposal included:

being transparent about the focus area of my research and my research-creation objective of future "cross-community solidarity", as well as the academic and professional benefits I will gain from the outcome of this project (MA, potential publications). (Miles et al., 2017) I will provide written questions ahead of time, and will mention that any questions that seem irrelevant or uncomfortable, we will omit. During conversation, I will prompt with those questions with the aim of sparking ideas/ stories/ experiences for the interviewee to then direct and determine. I will ask, where seems appropriate how the person is feeling on time, location and subject matter, providing a break from what could be difficult emotional communication, and also, offering an opportunity to shift toward being more comfortable. (Louw, 2017, 13)

In the interviews I had conducted to this point, these actions really just seemed like good harm-reduction approaches to interviewing - which may be helpful, but were they 'unsettled methodologies?'

Could the truth that an interviewee might bring with them or that might emerge, be minimized in service of my own research agenda? Indigenous people have been subjected to a long-standing process of pressure to re-define in colonial state terms, (to advocate in settler institutions/ systems eg court, policy, schools) and more recently, facilitate leftists/ environmental allyship in settler terms. (Snyder & Mitchell, 2005; Gehl, Personal correspondence, 2018) Even if I was loose with questions or not forceful with my agenda or purpose, the way that I approach disability and Indigeneity is steeped in my own cultural perspective and affects the concepts I use to think about disability and land, and shapes the questions I ask. (Tuhiwai-Smith, 1999) At this point in my research, I felt I needed the perspectives of Indigenous people with disabilities but also felt uncomfortable seeking them out without prior existence of a relationship.

Tuhiwai-Smith's (1999) methodological notion of 'unsettling research' and the interview process, calls for actively resisting academic traditions and practices which extract knowledge from Indigenous communities and people for outsider settler researchers' benefit. She calls for Maori-led research, emphasizing the importance not only of shared power, but of her communities setting the agenda, designing the research, embodying the the roles of researcher from beginning to end of a research project. (Tuhiwai-Smith's, 1999) "Seemingly dominant and powerful normalizing forces are... 'fed by innumerable and often conflicting individual aims'" (McWhorter,



1999) Through our roles and actions we can subject people without directly aiming to. (Ibid) I had experienced peer representation policing and withdrew from further recruitment as a way to prevent activating that dynamic now as a media producer and researcher.

When it came time, it seemed, to seek out the least accessible participants to me - Indigenous disabled people, I realized that I had put off chasing disabled Indigenous 'participants' to be interviewed to answer the question, 'is there an irony to seeking more access on stolen land' because I already know there is; any justice movement on stolen land has an element of hypocrisy and exclusion if not centering the foundational struggle of the First Peoples who have been displaced and subjected to attempted genocide. (Berne, 2015; Mingus, 2018; Bertram Kemp, 2018; Brown, 2012) Those people who found out about my project and wanted to or were available to participate, did. Because of the secondary research, interviews, autoethnographic writing and video work I had done I had some understanding of the historical and present day social disadvantages and social privileges that people experience based on settler colonialism, racism, classism; as filtered through my lens of experience as a white Canadian. I reflected on how I participate in, and benefit from, the colonization of the Americas and subsequent resource extraction and profit from the displacement of First Nations to benefit the nation state and settlers and all complying 'Canadians'. As Lee Maracle said, decolonizing is a Canadian problem not an Indigenous problem. (2018) It is easier to be told by people marginalized in different ways than myself how to address the problem, but what if instead of seeking answers in a digestible format I undertook undoing and unlearning the invisible and embedded entitlement of white supremacy on my own rather than relying on the labour of Indigenous people to help me understand? (Thanks to Katie Jung for helping me understand and articulate this)

While it is important to recognize the importance of "[considering] the conditions in which we do research as much as the questions that we ask," it is also worth interrogating our roles as researchers. (Kivits, 2005) Deconstructing the subtexts in questions asked, implications of directorial/editorial decisions such as angles shot of video in video production, interactions between people in public spaces "[reveal] more about the able-bodied culture doing the asking than the bodies being interrogated." (McRuer, 9) When considering the reinforcement or critique of cultural hegemony, "repetition" is used to "maintain heterosexual hegemony." (Butler, J, in McRuer, 2006, 9) This could extend to me recruiting and interviewing for this project. Based on a literature review and prior research and experience, I created questions and framed my research project; my research question was defined in my terms, which are hegemonic in racial terms, and racial bodymind terms, meaning, my understanding of disability comes from my embodied experience.

rience as a white, raised middle-class disabled cis queer woman who has the privilege of a lot of access to crip community.

McRuer (2006) shows part of the work of liberation as exposing the “passing” of heterosexuality or “able-bodiedness” as the “natural order of things.” (12) Drawing on Tuhiwai-Smith (1999), I could draw a parallel and argue that part of the work of chipping away at white supremacist racism is exposing the “passing” of the white researcher setting the agenda as the “natural order of things.” (12) McRuer (2006) draws on Jonathan Ned Katz quoting “the coming out of the homo, provoked the coming out of the het.”<sup>11</sup> (12) By extension, I could come out as white and have come to question my role as researcher in this field of bringing into conversation Crip Theory, Indigenous Studies and Mobility Studies. (Sainte-Marie, 2017; Lamm, 2015; Berne, 2015; Moore, 2018)

### **6.6 Wheeling interviews as reappropriation of prior subjection**

At the same time that I was reevaluating my position and interview methods, I was reflecting on the wheeling interviews and filming I had done to date, spring, 2018. (Parent, 2016) Part of my process of reappropriation prior experiences of attempted subjection by other media producers described above, for me, was to resist orthodox media production norms by self-producing in my own way, using mobile media tools. This was to be my own version of crippling video and research. I thought it would feel amazing to show the world the view from my wheelchair arm. I thought it would be a way to have my mobility be understood. (K.J. Personal correspondence, July 27, 2018)

Wheeling with some interviewees (Amanda and Q) felt fun and brought camaraderie between myself and participants, particularly Q. But reappropriating tools (such as the camera) that have been used against my best interest didn't always feel empowering like I thought it would. In many ways it felt foreign, not embodied to me, the appendage of GoPro clamp felt alien to me -

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<sup>11</sup>McRuer's linking of two broad groups can provide insights into modelling in this research project as well. A major question that emerges in relation to borrowing theories written specifically about one group superimposing them onto theories or a developing theory of crimpness, is what are the politics and risks involved? For example, drawing non-disabled scholars as theoretical framework or bases for disability studies theory, but on the other hand also see the appeal, because in some ways those marginalised identities can really inform a crip understanding of identity. using a theory as a framework or underlying assumption of this theory, an understanding of “ethic of incommensurability” would be useful so as to not to blur the lines of different between these diverse identities. (Tuck & Yang, 2012, 36) Incommensurability would be a useful term to build around in order to avoid the really unhelpful and potentially further marginalising trend of applying on theory onto another group of people, who are themselves quite diverse, under that umbrella.

conspicuous. It got in the way of me getting up and out of my chair. I ended up shooting people's stomachs and crotches. At that time, video felt dissociated. Jason Spinney's (2011) assertion that traditional methods of inquiry are "too distant from the embodied practice of cycling [which Parent, 2016, expands to 'wheeling']", relying at best on verbalised accounts of practice divorced from the context of doing that is so fundamental to the creation of meaning in mobile practices" seemed contrary to my experience. (163) For me, writing at that time felt much more embodied, closer to my felt reality than filming while wheeling. This thesis was a pilot project - with the aim of experimenting and creating a 'proof of concept' and I realize that although mobile filming does capture mobility shots and gives perspective on sidewalk texture, the presence of barriers in my path as I wheel along my research sites, I feel that for my driving aim of showing the closest thing to my embodied reality that is possible in a mediated world. It felt at times like it was not making the mediated version closer to my reality, but pushing me and my reality further away. At times I felt that self-producing, directing, doing all the camera work and sound recording was difficult and isolating. For me, the conversation was the most interesting and important part.

## Chapter 7: Articulations in crip poetics - poetic engagement with interviewees' words

“All that you touch  
You Change. All that you Change  
Changes you. The only lasting truth  
is Change. God is change.”  
(Butler, O. E., 2000)

### 7.1 Poetic engagement

At this point in my research-creation process, I chose to stop recruitment because it felt ethically sketchy. I listened to my gut and teachings from past experience and discussed with my peer, Katie Jung, who encouraged me to explore the methodological findings and questions instead of chasing an answer to the questions I desired to ask disabled Indigenous people. (Personal correspondence, August 20, 2018) Inspired by the poetry project, Sonnet's Shakespeare, I shifted my focus from documenting interview moments in video form, to engaging with ideas/ expressions/ questions in the interviews I'd done so far, by writing found poetry using key lines from interviews. (L'Abbé, 2018) I felt this would honour the participants' contributions. It felt like a more embodied medium for me as a writer, and would allow for multiplicities of interpretations. “Los Intersticios” refers to “the space between the worlds... (Anzaldúa, as a lesbian of colour) inhabits.” (1987, 20) This term and description of inhabiting multiple worlds and not fitting into them, into any of them specifically, is a helpful concept when thinking about cross-community dialogue and exchange across differences.

### 7.2 Why poetics

Poetry is my primary partner

Poetry helps me express my emotions, frustrations, desires

Poetry is a safe space for me to channel or tunnel the excessive observations I have of others, myself, interactions, tiny elements of our environment; the things that are none of my business.

Poetry is who I tell the shameful or hard parts of my day to, first;  
the exciting, silly, naughty, unacceptable parts of my days and mind to.

Poetry listens, holds my experiences so I don't have to

Poetry is a space where I can come back to examine these emotions and observations and experiences so that I can, increasingly, catch my own shit.

Poetry is a way of dialoguing with myself, when there are multiple ways of seeing a thing, which is always.

Poetry is my primary partner, and is increasingly calling my attention to past mistakes, spaces to grow,

Ways to apologize?

Poetry is a way to engage with contentious stories, highly politicized lives and scorned communities, a way to celebrate the unexalted.

Poetry, she calms me, makes me feel closer to whole, welcomes - demands - honesty.

Poetry is a gentle but relentless coach, lover, personal benchmark and record for growth, shifting beliefs, practices, emotions, pitfalls, steps back, steps around, stillness.

She is always available by phone.

She invites others' poetry to be in dialogue, in love with me.

She is where disagreements and difference of experience and perception come to explore, touch, play.

She believes in every imagined future I secretly agit; a perfect accomplice.

She holds me, encouraging me to be brazen in my vision, faithfully consistent in reminding me not to be a know-it-all.

Poetry has been my research partner, through every stage from scribbled note in the margin to central creation, exploring the previously unworded.

She is an antidote to the "poverty of language" that Virginia Woolf lamented over a century ago in her call for increased attention to illness as an experience of so many, and a literary focus of so few.<sup>12</sup>

We are dancing together towards a scattering of the "hierarchy of... passions."<sup>13</sup>

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<sup>12</sup> Woolf, 2012

<sup>13</sup> *ibid*

For all the love and faith she has given and continues to give me, I pray, try to articulate the truth that  
now is her time.

### **7.3 Crip Poetics**

Whereas Parent's (2016, 2014b) methods engage with mobility and geography and Dokumaci's (2018, 2017, 2014) methods intervene with performance studies into DS and vice versa, I draw on the above scholars in addition to Eli Clare (1999), Gloria Anzaldúa (1987), Tobin Siebers (2010), Danielle Peers (2015, 2014) to experiment with, and articulate a crip poetics. Existing in multiple communities, identities and spaces is something that these scholars all touch on. As do themes of borders and spaces between and spaces of connection and dissonance between genders, other cultures and other peoples, different genders and sexualities and the human and natural worlds. (Anzaldúa, 1987) At the core of crip poetics are these themes and multiple different sites explored through poetics and combinations of prose, storytelling, poetry, and interweaving of words from multiple artists. In this section I will show in part, crip poetics' capacity for holding multiple sites of an issue and experiences of it in the same publication, and the intellectual promise of this hybrid form of writing that my thesis draws on and experiments with. This section is a reflection on my manifestation of my version of crip poetics, which has been made possible in large part due to what these writers have made way for. This evolution of crip poetics is not about representation of disability, but asks how disability can crip the thesis form, and the written transmission of knowledge and questioning where mediums flow together, where writing and filmmaking are more a "processes of transformation". (ibid.)

### **7.4 Elements of Crip poetics**

Crip poetics is multimodal. It combines languages, voices, prose and poetry, historical and cultural analysis with creative articulations that hold space for and share the emotionality of the repercussions of historical phenomena. For example, in *Exile and Pride*, Clare's historical inquiry centers around themes such as the word and concept "freak". (1999) Clare applies what I think of as a crip poetic to this historical inquiry, essentially crippling the discipline of history in a way by incorporating poetic writing and analyzing as if history were a text in and of itself. Clare writes to people in history, such as William, the "dean of freaks", blurring timelines and eras speaking

directly to a person in history. (12) This illustrates an emotional side to historical inquiry and adds layers of meaning besides just intellectual ones. In *Homeland*, Anzaldúa (1987) incorporates prose historical writing her own poetry which is written in English and Spanish and quotes from other writers as well as quotations from her mother and other people who are important to the story she is telling (Eg., p 8) Placing historical writing in conversation with personal life storytelling is part of Anzaldúa expression of a crip poetics. For example, she goes from writing about the history of Anglo vigilante groups in southern US during the conflict over south Texas in 1915, and the next paragraph is starts with a quotation from her mother telling her stories from her own lineage. (Anzaldúa, 1987, 60) Anzaldúa and Clare both express their stories in a multi-modal writing style emphasizing certain quotations in indented sections. Their interweaving of poetry and prose, personal alongside social history offers a touchstone for the evolution of my crip poetics.

Scholars' life-story writing and/or auto-ethnographic storytelling is an important part of crip poetics. Crip poetics uses imagery and memory to evoke a strong sense of these social phenomena inked with personal experiences. In this regard, Clare's (1999) auto-ethnographic and poetic writing style call on his memories from childhood and point to present observations on word-choice around disability. Dokumaci uses the hybrid writing-video medium, and Anzaldúa (1987) uses characters in written prose. For example, the character of the "shadow-beast" appears multiple times in *Borderlands* as a way to describe and create a sense of what it symbolizes: the unacceptable parts of "lesbian of colour." The use of this character or monster is part of her crip aesthetic, using the imaginative and grotesque imagery and monstrosity to make plain what is considered monstrous in heteronormative culture.

Autethnography is also important to crip poetics because it shows the positionality and the personal trajectory that a person took to get to where their thinking and creative work is now. This is especially significant because a lot of people congenital/ early age crips experience similar things in their earlier years such as isolation, self-misunderstandings, questions about their future, because they might have been the only disabled person in their environments. (Clare, 1999; Mingus, 2011) And because of this, a lot of those stories from childhood aren't told at the time; telling these stories becomes a sort of excavation, a process of self-discovery, critique of the world around them at the time, and sharing this writing becomes a community-building exercise. These stories become sites of mutual understanding, shared experience and solidarity. Placing them alongside social history, such as Clare does when discussing the ADAPT and disability rights movement in the US and his own personal journey as the first disabled child in a

non-disabled school in his area shows the personal and embodied realities of these social times and movements. (1999, 101-108)

There is a significant tradition in crip writing, art, and research-creation that “seeks to render visible what remains locked up within the boundaries of [one’s] skin.” (Dokumaci, 2015) This is one of Dokumaci’s articulations/ manifestations of crip Poetics: a hybrid of written storytelling of vignettes of lived experiences and visual art, aiming to show embodied experiences that are otherwise unknown to outsiders. (Dokumaci, 2015) In film, the interweaving of captions is an important part of crip poetics. Peers (2014) incorporates captions into their films, which serve an important functional role, while adding to the tapestry and hybrid style of the aesthetic of their films. This is something that Siebers (2010) highlights as an important and creatively interesting contribution of disability aesthetics- that disability brings layers of creativity to a work, and is not something to be solely accommodated or integrated.

Crip poetics offers mediums which hold space for what Anzaldúa called, *la facultad*, The presence of deeper meanings below surface articulations. A poem for example might be about love between two women, but within that story contained in the poem could be a critique of the chauvinistic, male dominated power structure in Chicano culture. Clare exposes deeper meanings within the text of history as he explores his own personal history and discomfort with the word ‘freak’ and sets out to “unravel freak, to pull on the thread called history.” Scholars’ use of history as one possible thread or line of analysis is indicative of the multi-modal style of crip poetics, where personal embodied experience might be one thread, etymology might be another, literature is another, history is another and so on. Quotations from other writers are combined or woven seamlessly in a sort of patchwork hybrid writing style. This encourages me to incorporate prose, poetry and quotations from other writers and my interviewees, (I experiment with this in my *I Have Heard Poem* series, below). A queer crip poetic draws on multiple lines of thinking and creativity to create an assemblage or kaleidoscope of knowledge sources, disseminating multiple sources of knowledge within the same piece of writing and multi-modal work, with the aim of de-prioritizing hierarchies of knowledge.

I had one more interview booked, with Anishinaabe scholar and thought leader, Lynn Gehl, who has a vision disability. I had interviewed her in 2015 for a radio program, and had kept in touch peripherally over Facebook. Given the shift in my focus from asking questions purely to answer the thesis question I developed, to platform-giving and exploring themes together while prioritizing work already completed, I based our interview on her book, *Claiming Anishinaabe*. (2017) In it, Gehl lays out theoretically her articulations of Traditional Anishinaabe knowledge as well as her personal journey towards claiming her nation. (2017) I wanted to value her time, and



didn't want to ask her questions she may have already addressed in her book or other writing. I prioritized talking about her work and then drew links and connections where I felt appropriate, to my interest in addressing colonialism in settler-dominated disability communities. This felt like a good conversation, and we reached new ground about embodied knowledge in terms that neither of us had thought of before. The themes I drew from our conversation are: embodied knowledge (EK), relationship to land/territory, disability as gifts, and access tensions (negotiating different needs).

### **7.5 Embodied knowledge [EK]**

The most meaningful part of my interview with Lynn, for me, was our description of what embodied knowledge (EK) means to each of us in our distinct cultural worldviews. Gehl writes about EK in chapter 14 of *Claiming Anishinaabe* where she writes, "As part of [the return to Indigenous knowledge that she advocates for] we need to value that our bodies are intelligent; our bodies remember. Knowledge comes to us through the practices of our bodies, and exits that way too." (2017, 111) In conversation, we realized that for each of us, the source of EK was very different. For Gehl, it comes from the community, it comes from the people that are close around you. Anishinaabe "cultural teachings [are] inscribed in landscape in very conscious and intentional way." (Personal correspondence, May 9, 2018) She explains this in claiming I'm a national bae when she writes "corporeal knowledge is the jurisdiction of families and communities, not nation states such as Canada." (Gehl, 2017, 112) For me, when I think of embodied knowledge it means the thing that comes from the core of your own self and your own self understanding. EK represents, for me, an internal knowledge that might not be immediately conscious but that my body knows. Whereas her understanding comes from the community from the outside-in words to one's body, my understanding of it comes from the inside and then is transmitted outwards to one's surroundings and community. (Louw in Personal correspondence, May 9, 2018)

In our exchange, the issues that I was preoccupied with were mostly related to translating or explaining my embodied needs and moving through the world to people outside of my experience. "[That's] like one of the issues with, when like, dealing with other people, you have to, because of the structure that we live in, we have to, we're in a position where we have to explain it." (Louw in Personal correspondence, May 9, 2018) Lynn recognized that type of knowledge by sharing experiments with light, "my relationship with light is that I didn't really like it, especially in the morning, and I didn't have a conscious understanding of it, nobody taught me that embodied knowledge, it was something I was born with, and I only really started to understand it when I was reading the literature for two years on my vision, and embodied knowledge you're born with,

and you don't really have a conscious understanding of it." (Personal correspondence, May 9, 2018) We had a moment where Lynn pointed out that she had distinguished between our different understandings of embodied knowledge:

"it's interesting because I think I just distinguished in talking to you, I just distinguished between two kinds of embodied knowledge, and I'm sure there's a lot more, but, you know, for culture, to understand, such as the Anishinaabe people, and to value that embodied knowledge is really important to inscribe in the mindscapes... while babies are young, while children are young, and to have cultural teachings and practices to do that is quite, you know, phenomenal." (Personal correspondence, May 9, 2018)

Coming to this distinction of embodied knowledge was meaningful and important for my study because it helped parse out the difference between external and internal elements of experience. When considering the site of ableism and disablement, the strict divide between the social and the medical understandings of disability is a helpful starting point. Currently, scholars, artists and disability justice practitioners are certainly moving beyond this Dichotomy. (eg., Piepzna-Samarasinha, 2018) Rosemarie Garland-Thomson's feminist-materialist theory of disability highlights the structural, economic and materialist elements of disability oppression while also recognizing felt experiences of certain disabilities whatever they may be. (2011) However, being introduced to the Anishinaabe worldview of embodied knowledge brought from the community instill in children and Foster in children is interesting shift for me as a EuroCanadian, in understanding how culture also plays a huge role in our embodied experiences, and how that can be very conscious and thoroughly planned project.

The theme of fostering and encouraging children to follow types of activities that they are skilled and gifted at, emerged from this part of our discussion.

"[The] Anishinaabe worldview... and the clan system of governance is that we, we pay attention to people's subjectivity and their gifts, and we nurture that subjectivity and gifts... That would mean that if a child didn't have the gifts of good vision, like me, and so they were sloppy when they were chopping wood, for example, then that wouldn't be a task that I would be doing. If a child's subjectivity was more geared towards dance and oral tradition, then that's the gifts that would be nurtured. The Anishinaabe tradition does both, they consciously embody reverence in children, but then they also consciously look for and nurture gifts that the children, that the child has. So that's again another respect for embodied knowledge..." (Personal correspondence, May 9, 2018)

My interview with Q also brought up discussions of embodied knowledge and how crip knowledge is shared. Q seemed to have the same conception of EK as me. It is outlined in this lyric exchange, which is comprised of found text from my interview with Q.

### **7.6 And then some people write it down**

um, people that I've interacted with that kind of have the disability justice language under their belts just from even just from experience, not even reading anything

Yeah... Well, it's one of those cool fields where it's like, it comes from like, embodied experience first...

and then some people write it down...

Totally, yeah

at least that's my perception of it

(dog barking)

yeah, it's always, you have your own language first, and your own lived experience, and then after that, like, yeah, like you said, some people write it down, and it's kind of, it's kind of cool when people write it down, because, like, you can compare and contrast and be like, oh yeah I understand this one, or no, like, this one doesn't make sense to me, I haven't lived this one...

they're all interesting, they're all different ways of getting through the world, um, yeah  
(dogs barking and yipping) (laughs)

pupper (laughs)

The above poem consists entirely of found lines from my conversation with Q, and as an experiment pointing to the shared knowledge that exists between us in exchange, I removed our names related to corresponding spoken line. I will ask them if they are comfortable with this and include or edit or change as relates to their preference.

(Q, Personal correspondence, May 30, 2017)

What Crip poetics can do

Crip poetics subverts. When I was younger and less comfortable with myself, poetry allowed me to express things that I was not comfortable stating explicitly. It was the way to express the hidden or shameful parts of my observations in reality in a safe way. I feel that in some ways, poetry and poetic can be a language between marginalized or oppressed people, or in less constrict-

ing circumstances, can offer recognition of certain shared embodied experiences or desires or observations that the average reader wouldn't pick up on but that someone with a similar experience to the writer might. Solidarity and inside jokes are an important part of crip poetics for me. "There is a magic aspect in abnormality and so-called deformity, named mad and sexually different people were believed to possess supernatural powers by primal cultures - at the end of cultures, magico-religious thinking. For them, abnormalities was a price a person had to pay for her or his in-born extraordinary gift." (Anzaldúa, 1987, 19)

Subversion happens in the most mundane of spaces, gestures, actions, ways of doing and being. While acknowledging that habitus is difficult to investigate because it involves the unconscious phenomena of daily life, Dokumaci (2014) flips the idea that people mis-perform and that there's something "the matter" with them by pointing to the usefulness and expository potential of those phenomena by disabled people, in this case, people with chronic pain. Dokumaci's exposure of "[the] ignorant occupation of space... as 'the habitus of ableism'" exposes the performative nature of all people, and de-exoticizes disabled people's actions. (2018) This performance studies optic informs crip poetics, in that it shows the generative and transformative (though not always chosen and rarely celebrated) result of disabled people living out daily life (and I extend to creative endeavours), in relation to an outside world not designed for them/ us. "While its experience is highly unpleasant, an opportunity emerges at the same time to reflect on the choreographies of everyday: why we move in the ways we do and whether we could have done things differently." Here, transformations of the material world come from experiences of a person misfitting and, through exchange with materiality, transforming it. (2018, 2014)

### **7.7 Embodied knowledge: Spatial**

Another conception of EK emerged through discussion with Q: Spatial EK. For me, spatial and body knowledge is unconscious or semi conscious way that we move through the world as marginalized/ abject bodied people. The knowledge of sidewalk texture for me, or proximity to parked cars for Lynn would be examples. This type of embodied knowledge also points to the shared observations and shared knowledge that crips and people marginalized in public space have amongst ourselves at times, where we don't have to explain, but rather just move together. (Mingus, 2011a) I experienced this on my wheeling interview with Q as I felt we had a good rapport together even though we had just met. I illustrate this through the following poem, which consists of text entirely transcribed by my attendant, of my interview with Q. (Personal correspondence, May 29, 2017)

## 7.8 Space

(sounds of Q and A getting up and moving)

(Q laughs)

(A says something indecipherable)

(sound of zipper)

(both laugh)

So, there's a really big pole –

Oof, found it! (laughs)

Do you want me to guide you?

Sure

Yeah

Cool, there we go

I'll just come back to my chair

Yeah (laughs) okay

hopefully no dog pees on my chair

(laughs) that would be unfortunate

(both laugh)

Yeah, okay, I'll be right back

(laughs) yeah, rescue your chair

(bird sounds, voices, dogs barking, the sound of Aimee approaching in her chair)

(Q, Personal correspondence, May 29, 2017)

Crip poetics could be a gathering point

What scholars such as Clare's and Anzaldúa's styles and interventions into the written form offer, in addition to a form that is guided by the most appropriate match of the topic and content to the form, is the potential for dialogue through poetics between different movements, artists, and individuals who experience different marginalizations, in same piece of writing or multi-modal piece. When poetics is used as a gathering point, a generative dialogue/ conversation, and experimentation through play and exchange can occur. New meanings, interpretations and relations emerge when multiple perspectives, embodiments, experiences, voices are together, as themselves, in proximity to one another. Coming at discussions of public space and landscape and entitlement/ title from the optic of poetics could allow for the revealing of shared experiences and emotions, while also providing space for individuality, divergence and substantial differences between collaborators or writers or artists who are placed in conversation with each other.

Crip poetics is transformative. Anzaldúa (1987) explains writing makes her self examine and that leads to a shift in her reality. (70) This is what I see and experience as the transformative process of creating something that examines, critiques the environment in which a writer is, and goes beyond critique to generating something new, articulating desires of how that person wants things to be. A personal example would be my poem, I am magic, (above) which represents a transformation in thinking about the days when I am in bed from seeing that as wasted time, to seeing it as dreamlike and a time and temporal space where imagination thrives and the reality of the next day or week is shaped.

### **7.9 I have heard poem series**

I carried these conceptions of EK with me as I continued to explore landscape, my relationship to it and other people in Vancouver, paying attention to access tensions, my subjectivity as a settler using a mobility aid, and the voices of the people I'd interviewed. I came to experience different connections to EK. The following poem series illustrates some different connections I have to EK. The series incorporates quotations from my conversation with former Sam Sullivan, former mayor and current MLA, and first (openly) disabled Mayor of Vancouver. I engage with his words poetically as a way to dialogue with him after our communication ended, to engage with affective meanings/ interpretations of what he said, and to engage beyond identity and political affiliation.

I offer two poems exploring mainstream framings of dichotomies between accessibility and nature, visibility, intimacy, and auditory connections to mobility. The poems are entitled, "I have heard", and "Wheelchair love ballad."

1

I have heard  
skytrain and rebel cry: not  
angry, but catalytic  
bees purposely landing on ragged small edged  
leaves, while a human power washes or power vacs a machine or home  
(I have heard) Smells entering my nose as I  
breathe deep and twigs are bent under me – the cli-click of my joystick  
engaging as I consider moving, staying still;  
mechanical and natural blending.

rolling over? Caressing  
masking? A way in

2

scraping  
beeping  
sound renders me visible  
witnessed, without my express consent

“disabled people are very visible by our presence and by our  
absence.”<sup>14</sup>

sound renders me visible  
a selection of observations and questions  
Is there a way to be present  
without being witnessed?

3

Steps and crunching of browned and  
yellowed leaves;  
the attention of buzzing, furry, hurried  
bees is not  
drawn to bent twigs or  
beeping or occasional humming  
of seat angle adjustment

4

(1)

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<sup>14</sup> Sam Sullivan, Personal correspondence, May 25, 2017

To be  
present without  
being witnessed? (2)  
to be present without  
being an object of attention  
(3) to invite witnessing by those  
I choose (4) unspectacularly belonging  
(5) To be present, welcomed and move alongside with  
negative, positive, ambiguous, uncertain space accounted for and  
filled with warmth. To want to be included, to desire unspectacular belonging;

Not contradictory, they are complimentary; ah that they could become counted on.

To be present  
without being witnessed,  
unspectacular belonging; these are the blessings of bees and moss. We called it  
being in nature unmediated<sup>15</sup>.

The cli-click of my joystick engages.  
Attention of intelligent, thirsty bees  
remains on task and petal at hand.  
Mechanical and natural blend,  
finesse a way in.

\*\*\*

“[When] I got this wheelchair it was like a duck suddenly in the water, and I was zooming everywhere, I could do anything I wanted you know, and it was such a liberation, so, ya, we are, as disabled people, we live on the very fringe of life in a way, we live in an area where the issues are much more clear and we have to make decisions, most people can just go through their life sort of winging it and not really every making that decision, you know? Whereas we have to actually make a decision if we want to be independent, or do

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<sup>15</sup> Discussion with writer, Warren Cariou, June 21st, 2018, Winnipeg, Manitoba



we want to be... uh, live a full life, you know (chuckles). So there's a lot of, lot of thinking should be done." (Sam Sullivan, Personal correspondence, May 25, 2017)

4

Moving in chair feels  
different than moving through air  
To dance in wheelchair  
a larger radius,  
mass moving through  
space, less assemblage  
of body parts,  
More entirety.

To dance in a field with  
strangers is  
like shopping for shampoo;  
More decisive if standing,  
more connected to products, air through the grass.

move with more  
certainty,  
out and up and  
out.

park  
or beach,  
connected to the landscape  
if  
on foot or ground.

what difference does it make?

the weight of other people's' gaze?

A craving of monotony  
uniform mobility,  
equal footing?

medium, mode  
determines  
the shape that my current  
body can take

medium  
determines the mode  
my mind's in?

energetic messages,  
blocked  
by the metal and cushion  
of my chair

We called it being in nature unmediated<sup>16</sup>

if you have these trail riders more available uh, they would help people to access these beautiful parts of our country<sup>17</sup>

the cli-click of my joystick  
engaging as I consider moving, staying still;  
mechanical and natural blending.  
rolling over? Caressing  
masking? A way in

Crip poetics allows for multiple definitions, subjects, subjectivities, with the aim of undoing/ subverting normalized and anticipated subjections such as pitiable crip (Clare, 1999), racial-

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<sup>16</sup> W.C., Personal communication, June 21, 2018, Winnipeg, Manitoba

<sup>17</sup> Sam Sullivan, Personal correspondence, May 25, 2017

ized woman as less than (Anzaldú, 1987), or disabled as unable (Dokumaci, 2014). Crip poetics can be a space where crip ways of doing things, and moving through the world and perceiving the world are not framed in normative terms, but in one's own terms, or could aid in the process of discovering one's own way of being. Moving beyond the post-structural goal of self-representation to a self articulation and transformation in crip poetics could be a research-creation method to level hierarchies of knowledge production, and facilitate collaborative world-building exercises in questions where multiple and multiply-marginalized people share space in post-colonial contexts.

### **7.10 Wheelchair love ballad**

I want to take it as far as it will go

Wheels

Freedom after

Weeks of

Counted steps

Rationed steps

Rationalized bets

Gambling on minutes out and minutes back

Minutes, days,

Getting places in old, tired ways

Take it to one bar

Fully charged

Wheels

Freedom;

A reminder

After cursing her boxiness

the way she separates me from the air

thankful for her constance when everything I pass by and place myself within, is changing.

Take her and let her take you  
a woman talking  
To herself while headphones amplify mandolin-tickled folk music and mask self reflection  
asking myself what I think  
nothing to be masked by white headphones and speed.  
I took her and allowed her to carry me  
Carry me  
As far as I wanted to go: no further no shorter

A bridge  
An oceanside Park  
Another one  
Another one  
Pass by the pool  
The bus  
Benches - not one did I use as she held me in her supportive nest  
her hands on my back, wrapped around upper thighs and ass

Today, not scanning ledges, steps, concrete separators between bike path and walking area, for  
a place to rest, hoping to be held by unknown or familiar surfaces,  
my wheels and I went far. No further no shorter  
And then she had enough for me to place heavy groceries on her back, adding a bottle of wine,  
hair dye, two types of tofu, and still she did not complain. Her constance is my freedom  
And for that I  
Cherish her  
today  
she  
Carried me.<sup>18</sup>

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<sup>18</sup> Sept 2 2018

### 7.11 Like Everyone Else

When analyzing the interviews I did for this thesis project, I noticed a phrase that two of the people that I interviewed said that had drastically different meanings, contexts and connotations: like everyone else. It stuck in my mind like a little nugget, dense in its implications. I thought I would write a poem based on the concept, as I found that I had a strong reaction to those parts of my conversations with interviewees, I had my own interpretation of the sense of belonging, conformity, desire that it evoked in my mind, and wanted to reflect on it more, through writing. The little phrase had other plans for how it wanted to live; in the end it's reflection came out as a lyric essay. Something Lee Maracle said in a writing workshop I attended was that, for her, the format or genre of a piece of writing fits the content and vice versa. (Maracle, 2018) This rings true for me as well. Below is the essay, Like Everyone Else, which contains my reflections, self-questioning, and engagement with Caroline's and Amanda's words on the phrase.

Bringing different perspectives on like everyone else illustrates / hints at different valuations of conformity, shared desires, conceptions of empathy and isolation in experiences of disability and intersecting marginalizations. What comes to mind first when I think of the phrase is how I often hear disabled people say it when talking about how they want to be treated. This can be in response to interviewers asking them questions in the news media. Or in the context of some expose on discrimination, where they are trying to do the difficult task of humanizing themselves in the public eye. Sometimes, I hear people say they want to be treated Like Everyone Else in moments of frustration or when they are being underestimated in terms of their desires and hopes for their lives, relationships, mobility, work, what they can do and could do given the opportunity.

I place myself and my biases first, for transparency. My initial and pre-existing interpretation of like everyone else involves my opposition and personal ethic of non-conformity. I generally bristle when I hear people say the phrase in an aspirational way. My commitment to non-conformity is informed by my childhood as an outcast, finding community and friendship with other weirdos, and manifestations of queerness. (Don't tell my childhood friends that I refer to them in this way - I call us weirdos lovingly and affirmingly.) My bristling also comes from my visceral opposition to what I see as capitalist-informed, heteronormative life goal driven ambitions to seek and achieve performance of 9-5 jobs and what the 'accommodations' model of disability calls 'integration', where disabled people have material equipment and 'adapted' workplaces, which bolster them to the perceived level of productivity and performance of normalcy (normate status). (Garland-Thompson, 1997) In my culture, white settler crip culture, the imperative seems to be independence or individual navigation, connected to what Alfred calls the 'settler

fantasy.’ (2009) In a way, like everyone else seems like the site or process of pursuing the colonial settler dream of upward social mobility and living an “exalted” life, by gaining access. (Peers, 2015)

As I write this, I recognize that my opposition has been cultivated through time; to be like everyone else has been for me, at moments, a desired yet unattainable goal. For example, even with adapted equipment, I am still a tired person. This is not removed with a footstool and external keyboard. Like everyone else has been, in a way, the site of this realization. It has been the site of judgment of other people’s desires to conform, tinged with jealousy that some people can and do succeed in reaching the rank of normate status. (Ibid) These relations to like everyone else were mostly centered around the belief that everyone else existed and that conformity or membership in that group was desirable. That it was an option, just not for me.

As I began to engage in news media as described above in 2014-2015, calling for accessibility and social transformation in terms of viewing disabled people as not inherently wrong or in need of correction, I became especially observant and sensitive to other calls in the media regarding disability and accessibility. (See section 6.1 of thesis). For example, the 2014 Marche des 10%, which was the second annual march to gain attention for issues related to disability, organized by activist Richard Guilmette (of Mouvement Citoyen Handicap-Québec) was a moment where I recall stating to a journalist, “Montreal needs more empathy.” (Personal correspondence, Sept 1, 2014) As my relationship to disability shifted, so did my relationship to like everyone else. I saw like everyone else as a site of critique. I began to see my unwillingness or inability to conform in certain ways as a gift. It became, is becoming, an opportunity and perhaps an inevitable embodied form of critique of heteronormative-capitalist-nuclear family norms and social expectations. I was pushing for less division and fear of others, with attention to disability but more than that: general contact and breaking of walls between strangers in public, communities, etc. I saw like everyone else, which other vocal crips who got attention in the news, called upon as an argument for humanization, as a call for fairness parallel to mine. Whereas I called on the need for respect and comfort with difference, I saw this parallel call as harkening on our universality - something I was less convinced of. Their argument: we’re like everyone else. If you think of me as just like you, then you won’t treat me badly, or you won’t uphold social and physical structures that exclude me. This logic runs deep in Eurocanadian Christian based cultures, it’s the ‘do unto others’ logic. In struggles for rights, where a foundational tenet is that everyone is born equal, it makes sense to argue that if we are all born equal then we disabled people grow equal and live equal after we are born, just like everyone else, and therefore should not be excluded or devalued as people.

However, we're not like everyone else. Whether 'we' is disabled people, queers or other people who diverge from prevalent and visible social norms. I felt at the time that this like everyone else minimized differences, calling on a unity argument that whitewashed divergent experience, identity and perspective. This argument of sameness, I thought, think, was predicated on conformity. My discomfort with like everyone else in this context, was based on my disbelief in universality, and my belief that we shouldn't have to be like everyone else in order to be treated decently and to be able to live our best lives. And what if a person doesn't conform and fit into everyone else status, what if someone like me who has divergent preferences and life choices and desires, doesn't appear to prefer the goals set out by like everyone else - would she still qualify for the equality that these parallel interviews and co-humanizers articulate and advocate for? (Siebers, 2010)

In the world that I know (primarily cities in Canada), the divide between disabled and not disabled exists and is upheld by the social project of disqualification, which succeeds in keeping disabled people marginalized. This disqualification is determined by the ways that we fail to conform to what might be the myth of like everyone else. (Siebers, 2010) Further, the structures that undermine our power and impede us from flourishing, operate to undermine so many people marginalized by the structures that shape Canadian society, and these things intersect to multiply marginalize for example, racism, cisnormativity, heteronormativity, poverty, chauvinism, etc. So, does everyone else actually exist, and second, is it a desirable goal? I saw like everyone else as the goal of reaching the ranks of the most powerful, and part of my critique became, becomes, about the reproduction of harm by marginalized people who seek power and then in doing so, participate in harming others in some ways. (Mingus, 2018; Katie Jung, Personal correspondence, July 27, 2018)

The conversations I had for my thesis offered different perspectives. This prompted a lot of reflection and personal growth for me. One articulation of like everyone else that I hadn't considered in the same way came from my conversation with Caroline. My interpretation of the phrase had been, in the ways outlined above, clouded and determined by my preoccupation with conformity and my hang-up on universality. Caroline runs Beautynight, "a charity she started... sixteen and a half years ago... [which provides] programming to build self-esteem and change lives for women and youth living in poverty, and in the last couple of years [they've] been adding services with men, in addition to the work [they] do with women, where we go different shelters, transition homes, group homes, hospitals, correctional facilities, and offer wellness and beauty services, as a way to reintroduce touch to victims of violence." (Personal correspondence, May 31, 2017) Caroline's primary clientele is women who live in Vancouver's down town east side

(DTES), who deal with homelessness and poverty - she hinted that her clients may feel like outcasts and may be dehumanized based on their living conditions, which impact their appearance and self-image. So part of the version of like everyone else that she articulated has to do with making clients feel better about their appearances, providing services that they can't afford in order to encourage them to feel worthy of support. This emotional articulation encompasses the emotional desire "to be treated with dignity and respect". (Personal correspondence, May 31, 2017)

Caroline explained her observation of service provision in the DTES, that "one [thing] that's missing is... self-esteem and feeling ok;... feeling like it's okay for me to ask for resources I deserve." She believes that "once people are treated with dignity and respect... both through our medical system where they can talk to their doctors freely, where it's not that sing-songy voice they have actual conversations to find solutions... they don't feel shameful about something that's going on." She brought like everyone else up when discussing the ways that people's struggles and needs come out - and their requests for help followed - when they feel comfortable and respected by hairdressers or Beautynight volunteers. In this conception, feeling like everyone else refers to a level of humanization where a person feels heard and safe. She gave examples of once clients feel safe and supported they might be more open to expressing things like "I need a shelter bed,' and 'I'm having difficulty walking,' [or] 'I'm having a problem with my wheelchair.'" Through this project she works on "creating those conversations and those areas where people are okay to talk about things" as a precursor to seeking out and accessing needed resources. This articulation of like everyone else seems less about conforming to a certain ideal of exalted Canadian, as was my original interpretation, and more about a sense of personal worth, positive self-image, and being heard, to empower people to pursue accessing the things they need for daily living. (Personal correspondence, May 31, 2017; Peers, 2015) Beautynight is approaching the empowerment of women to feel better and up to the level of self-esteem to ask for what they need and are entitled to within the social network, and like everyone else is a sentiment, an affective expression.

Another articulation of like everyone else is the desire to have one's own struggles and desires understood by those who don't experience them. Amanda brought this up in the context of responding to my question "what kind of practices and goals [she has] as part of cultural education [work]." Amanda went on to call on the notion that her people, Squamish and Nisga'a are "people just like everyone else here" in Canada, in lower mainland BC, and Vancouver, suggesting that people of Euro-Canadian and other backgrounds do not deserve space more than Indigenous people. She said this phrase after explaining that she "grew up you know, before this



era of truth and reconciliation where people weren't talking about the Indian Act, First Nation's right to title, residential schools and the impacts have and how they affect our people." In this way, Amanda's articulation of like everyone else addresses impacts of colonialism by pushing back against the Canadian idea that Indigenous peoples are less than and not entitled to their own lands and cultures. Amanda spoke about this in terms of her "language [being] on the brink of extinction" and the current felt effects of colonial policies such as language extermination enacted by the banning of mother languages in Residential Schools. "[This] ban existed in every residential school that existed in Canada."<sup>19</sup> (Personal correspondence, May 30, 2017; Ing, 1990)

"The desire to create an understanding that we are people just like everyone else here" in Amanda's usage of the phrase portrayed to me the desire to not be viewed and legislated and treated as less-than. She explained her work as a cultural educator as "[educating] people in the government to do cross-cultural training about who we are and where we come from, breaking the stereotypes that people look at us as drunk lazy Indians." She said "that's the most comfortable term they have for us... not knowing that we're suffering with complex trauma from residential schools... from not having the love of our parents." Here, Amanda's articulation of like everyone else is anything but assimilationist, as my original interpretation of the phrase made me think. Here, Amanda articulated, it is about assuming the rightful place of entitlement to land and language and cultural flourishing that her people deserve. It is about stating that no one else belongs in that territory more than the traditional stewards of the land and waters in and around Vancouver, the Musqueam, Squamish, Tsleil-Waututh nations and that part of that is accessing "funding for our language programs... and teachers to teach those programs... administration to run those programs. In order to do that we need to be healthy, we need to be educated, we need to be fluent in our language." She said "we're, we're getting there, you know, like, but it's a slow, gradual process." Amanda said "I am so brave to say that I feel we more entitlement to feeling comfortable, um, to be successful in our own communities." (Personal correspondence, May 30, 2017)

This phrase-centered analysis is an opportunity for me to recognize my bias and pre-existing interpretation of the phrase, and then to expand this interpretation or take space from it to exchange with two interviewees' conceptions of it. Words and language in common, used by people interested in different approaches to landscape, community and their work, has been an opening, a fissure into dialogue. (Brown, 2001) These interviewees brought up considerations of

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<sup>19</sup> "10 fluent speakers out of 4000 people in our nation" (Personal correspondence, May 30, 2017)

similarity/ difference, unique/ universal experiences and desires in the contexts of their work, which allowed me to analyze their perspectives on their own work and their relationship to social transformation. There are opportunities for multiple relationships to, and desires surrounding, social norms, conformity and universality in a crisp ethic of non-sameness between collaborators, and within the same person, depending on the moment.

### **7.12 FILM SCRIPT: [Who's City? Seeking Access on Stolen Land]**

Key segments of the following exchanges are part of the film script for *Who's City? Seeking Access on Stolen Land*

Sam – I used to enjoy hiking and going into the wilderness so when I became quadriplegic it was very difficult to do that, so I had uh, an engineer come and we worked together on an idea that could get me out in the bush again, out in the sticks, which is a Chinook word, um, so, you know, I drew out what I thought I needed, and he went and he found some old parts and, basically an old lounge chair, wheelbarrow wheel and some handles and made a device, and I was able to go out in the forest, so that's now uh, been formalized and we now have manufacturing, I think we sold around 200 of these all over the world.

Aimee – Right on. What does it mean to you to experience different landscapes?

Sam – Hmm, well, I mean, this is, this is a philosophical issue about accessibility - should we just pave you know, roads through the forest, or should we find ways for us to conform to the forest, without doing so much damage... So uh, we, you know, there are different options of maybe taking one, one small natural area and then doing some pavement which is a valid one as well, but then this trailrider enables us to get all sorts of places that uh, helps make the argument that you don't actually need to pave everything, you know that if you have these trail riders more available uh, they would help people to access these beautiful parts of our country

Aimee – Mhmm. And um, so, from my experience when I'm using like, a power chair versus when I'm using a manual and someone's giving me a push it's a different- experience-

Sam – Mhmm

Aimee - ...um, so how, how does that play into that whole discussion about you know, nature, preserving nature or, using pavement-

Sam – Ya, ya, ya

Aimee – ...or other options?

Sam – Well, I'm probably the most fanatical, saying I want to be in control, you know, the other program I started was a disabled sailing association, and there's some really good groups in Montreal, in fact our boats are manufactured in Montreal. These are boats that were designed here, you know, using a lot of my own basic uh, mandates, that uh, it's the person with the disability that's in control, and if there's an able-bodied person coming they have to sit behind, where they can't reach the controls, if they do want to reach the controls they have to be very uncomfortable, and that was one of my goals, is that we want to keep that able-bodied, keep their sticky-fingers away from the controls-

(Aimee laughs)

Sam – ...if we go uh, sailing, I'm taking you for a sail-

Aimee – Mhmm

Sam – ...you're not taking me for a sail, so, you know, I have that general philosophy, and, and it was a worry for me that I would feel like I'm just cargo being carted around, but I've never felt like that you know when the person in the trail-rider is an active, you know first of all you know, you've got your handles but you need to quickly get hand off when you're bouncing into trees and thing, because you could really hurt your, your hand of, you also have to watch you know, for branches that are going on you, and uh, there's always a risk, it's a one-wheeled vehicle, and you're on the edge of cliffs, you know, and there's always a chance you're going to go over so you have to be strapped in and you have to be ready for it and you know, to take protective action if you do start to go over, so um, I find I'm just so usually terrified the whole time, I don't really think about the fact that somebody's carting me around (laughs)

Aimee – (laughs) That's the good type of fear, the exhilarating one (laughs)

Sam – we used to have races for the uh, called Access Challenge ...and I always reminded the, the able-bodied people if they don't return with the quadriplegic they lose points... I wrote myself in for value." (Sullivan interview transcript, 12 - 14)

When I asked Amanda Nahanee her thoughts on the paved trails tension this was our exchange:

Amanda – a lot of our people like you look at our communities, you look at the people who live here in cities like this, the mountains are way over there, that's where all the nice trails are... that's where all the freshwater is, that's where our hospital is – traditionally, we used to say mountains, like that was our hospital, that was our, that was our Save on Foods, that was our, that was our schools, our post-secondaries, our Harvards... that's where we went to get strength, that's where we went to go take care of ourselves. There's a saying in our culture, go fix yourself, and what that meant was you go to the river and you pray, and you ask for the life giver, take away my pain... take away all these worries that I have. And then you ask, give me back some strength, give me back some beauty, give me back some nourishing, I need that right now, right, and we used to do that. And now a lot of us you know, who live here in the city don't have a car, they can't go there at six in the morning (laughs). You know, and, um, I really feel like that, really, it takes away from our spirit-

Aimee – Mhmm

Amanda – ...you know, it takes away, you know, the ability to love ourselves and take care of ourselves-

Aimee – Right

Amanda – ...the way the society is developed and, and put together, it's meant to keep us individual and self-sustaining... which is rewarding in this kind of society, but we, we worked out in communities, we lived in longhouses, you know, our great-grandmothers, our grandmothers, our mothers, our children, our grandchildren, we all lived together, and we all had roles and responsibilities... to the house, to the home, to the community, everybody had a job to do, everyone had something to contribute. We had our special gifts that were nourish and that were brought

up in, and everybody, we were a functioning society you know, and now we're so displaced from our responsibility to community, we're displaced from our responsibility to our culture...

### **7.13 Trails I: mansions**

Three of my interviewees responded directly to questions of shared access and access conflicts posed by My Shoreline. When I asked Lynn about paved trails as an illustration of contradiction she said she recognized the tension I was getting at. She said, "there's a difference between a contradiction and a hypocrisy... I just see that as a contradiction... you may love the natural world and have reverence for the natural world, but at the same time you need a flat surface to, for your wheels to roll on right?" (Personal correspondence, May 9, 2018) When I asked what a hypocrisy would be in this instance for her she responded, "a great big huge house [or] a lot of material items." Her response pointed out the element of consumerism and waste rather than access to nature for mobility purposes. She also said that she couldn't fully answer that question because "[her's] is not really a physical disability, it's more of a vision disability." (ibid.) What I took away from this part of our conversation, and I may be reading too far into her response here, was there's going to be contradictions between people's needs and their ways of being in the world. And Canada is a place that English and French-descended people have tried to colonize, so it's not without its tensions inherent in its existence as a state. That's a state of being that we're in, currently. Lynn's take on the contradiction laid out in My Shoreline was based around the choices a person makes, given the current socioeconomic context. The way she responded, and didn't dwell on the presence of access tensions in shared space, made me think that maybe it's more interesting to focus on the way those tensions are treated, rather than solely on their existence. (Field Notes, May 11, 2018, 4) Shaping a future that embraces marginalized people requires us to explore and sit with the tensions that exist when one's needs rub up against another's.

### **7.14 Trails II: everything should be fixed, AKA Reminders on transit of Euro Canadian logics of correctionalism**

Q had a personal experience that, when they described it to me, made them reflect on Euro Canadian perceptions that disability is in need of correction. They describe it way funnier than I could in summarizing it:

since 2017 started I can think of 10 clear times that that's happened, um, where people have literally put their hands on me and prayed over me, and I'm just like, maybe don't.

Um, it happens a lot at, like, Skytrain stations and stuff, when I'm waiting for someone, um, or if I'm on the bus and I'm sitting there

They went on to say "that summarizes most of my experience with white people and the way that disability is held in their minds." For Q, this plays into their own process of unlearning Euro Canadian ideals about disability and ableism, "as a white person because, it's not something that [they] know innately, it's not something [they've] experienced." It was interesting for me to witness Q's discussing their take on white perceptions of disability, hinting at the links and some common roots of body-problematizing and correctionalist tendencies, which are at the root of other forms of marginalization, that for some, intersect with disability. Q said "I think that also, oddly enough [it] kind of relates back to the way disability is medicalized in Western, like, Europeanized cultures. [It's]... this idea that like, everything should be fixed, and if it can't be fixed, then it's a tragedy, um, and it's this weird kind of... weird colonial idea, I guess." I felt a lot of camaraderie with Q. We're in the same general age group and we were both working to unlearn racist understandings of disability, from our perspectives as white queers. For Q, "it's still something that [they're] trying to put into words [themselves], about how, how... European ideals have overlapped into the medical models of disability." (Q, Personal correspondence, May 30, 2017)

This logic of correctionalism intertwined with anti-Indigenous racism is something that Amanda illustrated with a story of her days in elementary school. She was placed "in all the special programs [because] they told [her she] wasn't able to learn." She said that "after [she] dropped out of high-school [she] went to the library a lot to read a lot... that was [her] safe haven, so, when [she] got to taking [an equivalency] test [her] comprehension level was really high, it was university level." (17-18) She had essentially been assigned a diagnosis that was not her reality, assuming she had a learning disability because of racist ideas about who an ideal, exalted white student was. (Personal correspondence, May 30, 2017)

### **7.15 Roses**

They let us fall through the cracks, actually, pushed us in the cracks

There you go

You know

One of those roses that was

in the cracks

Saying noooooo! I'm coming through!

Breaking free

There you go

I'm going to bloom whether you like it or not  
I'm going to bloom whether you like it or not  
And I smell fabulous, by the way.

The above poem consists entirely of found lines from my conversation with Amanda, and as an experiment pointing to the shared knowledge that exists between us in exchange, I removed our names related to corresponding spoken line. I will ask her if she is comfortable with this and include or edit or change as relates to her preference. (Personal correspondence, May 30, 2017)  
As Lynn and Q offered their perspectives on access conflicts and tensions, so did Amanda. While discussing the process of inter-community understanding, she said warmly, “[it’s] getting there. We’re still not like, at the point where we understand like, enough about each other (laughs).” (Amanda Nahanee, Personal correspondence, May 30, 2017)

## Chapter 8: Methodological contributions to the field of ally-ship research

In this research-creation process, when I asked what would a less colonial access politic look like, part of that thinking occurred through experiments in video production, wheeling interviews, and related methodological reflections and personal growth. (Parent, 2016) Below are some of those methodological reflections and findings of what a less colonial interview politic acts like, feels like in interviewing, recruitment, engagement of interview content, media production. In this lyric essay, I reflect on the roles I assigned myself in this research-creation process, informed by key experiences articulated above as a white crip media maker, and reflections and directions for my future in this field.

### **8.1 'angry crip', 'humiliated crip,' 'sassy, I don't give a rip crip'**

This thesis has become a pilot project in going beyond "shared power" to an examination of intellectual labour. (Katie Jung, Personal correspondence, July 27, 2018) During this thesis I was dealing with the effects of micro aggression trauma. (Eales, 2018) The roles I felt squeezed into by journalists and media producers who wanted me to fill; role of 'angry crip', 'humiliated crip,' 'sassy, I don't give a rip crip' etc., felt narrow and exploitative. At the same time, I felt a certain responsibility and desire to expose the instances of ableism that they wanted to cover, as I felt silence represented a level of complicity or acceptance, and would lead to reiterations of this ableism foo myself and others. For example, I thought 'if I don't join the chorus of crips exposing STM inaccessibility, it won't improve for future crips.' But as articulated above in section 6.1, this type of outsider-defined image curation was another cite of ableism and in some cases, compounding trauma. I came to realize:

You don't owe your trauma to anyone

You are not your experiences (Field notes, April 22, 2018)

It became exceedingly important for me to enact this not only for myself, but also in relation to the participants and potential participants in my thesis. I haven't really used the word 'ally' in this thesis because I find the word can be used without any connection to a community or with no accountability. It's almost a statement that suggests arrival, allows for staticity, removing the imperative to learn from people with different experiences and realities than me. In a social sciences and humanities context in 2019, in which community-based, allyship research is promoted as an ethical practice, growing in popularity and disciplinary importance. I feel that reflections on



methodology that I offer in this lyric essay could have implications for what is generally called allyship in social justice-based research.

The notion of including the people in the research that a researcher is doing emerged from critiques of anthropological practices of entering a community in order to study it, often with little context or awareness, with research driven by harmful, racist and imperialist beliefs. This shift occurred as post-colonial scholars critiqued anthropology and advocated community involvement. Similar to the notion behind the disability justice slogan, 'nothing about us without us' these scholars pushed for a huge shift in the objectifying trend of academic research. This is a huge and important -an ongoing- shift led by researchers of colour, third world researchers. involvement is crucial in knowledge production of marginalized people/s and communities.

From the time I designed my research with intentions of involving disabled Indigenous people in exploring less colonial access politic, in 2016 to the point where I was in line to recruit Indigenous disabled people to be interviewed, a major shift happened in my thinking. Simply put, it didn't feel like allyship with other people if I'm asking them to labour for me, to answer my question, to explain things in terms I'd understand, to do the work of cultural translation - rearticulating things in 'mainstream' or settler conceptions in order to get their embodied experiences and knowledge across. Critiquing and developing further the area of knowledge production of marginalized peoples, in the context of research about the Maori, Tuhiwai-Smith (1999) writes about negotiating new relationships with non-Indigenous researchers. She points out important questions to ask in cross-cultural research such as "[who] defined the research problem... For whom is the study worthy and relevant?... What knowledge will the community [/] researcher gain from this study?... To whom is the researcher accountable?" While I had been exposed to these questions and had considered them in the development of my research proposal, being in the act and interpersonal role of researcher and recruiter made visceral these considerations. Importantly, Tuhiwai-Smith argues that researchers should also question the belief that they "have an inherent right to knowledge and truth." (173)

As Alejandra Gaviria put in while discussing the Colombian memorial; museum work she did, "when someone else sets the format, this [influences] strongly, what stories do you tell?" (G., A., Personal correspondence, 2017) I came to recognize the importance of de-privileging my research question and goals at this point in my learning. Marginalized people should not have to take the lead in ways that those from outside their/ our communities define.

I came to realize a more appropriate use of everyone's time and energy and expertise would involve me doing the labour of intellectual grunt work. To pick at the system of settler colonialism from my position, and then systematically prioritize giving people a platform to talk

about their work. This would touch on and supersede my framing of the contradictions of seeking access on someone else's territory, with openness to collaboration, seeking new, relevant questions and truths. I hope that this could lead, where appropriate, to future collaborations that are mutually imagined, designed and created. After all, "[if] you are white, and you're not explicitly challenging white supremacy in your daily practice of living, then you're not doing disability justice." (Lamm, 2015)

A PhD student participant during Warren Cariou's presentation at *Performing Embodied Oralities in the Americas II* (2017), said that she thinks of herself as a "learner not an expert."

"Let yourself  
let it go  
The urge to have  
the need to know"  
(Gaelynn Lea, 2015)

The methodology that evolved, stalled, and ultimately became my contribution, involves demonstrating my approach to the intellectual grunt work needed to increase conversations about settler colonialism and 'model citizens' in settler-dominated accessibility / disability spaces, especially among white people, the beneficiaries of white settler supremacy. This methodology came from desire for interviews that I haven't been afforded, and a desire to not do more harm by imposing the same interview structures that have harmed me, or wasted my time, in the name of social justice research. It was a "desire born of absence" (Kafer, 2013) that I will build on as a methodology for the future. As I continue making media and writing, I will have this methodology with me, reminding me to do the research and personal work of unlearning, as much as amplifying voices that are different from mine and that carry different concerns.

As Peter Kulchyski states the "logic of spectacle breeds docile bodies" but as that a "logic of care invites care." (K. P., Personal correspondence, 2017) I don't have to reproduce the instrumentalizing, objectification or edge-of-consensual interviewer-interviewee relationship. I aim to approaching future work from a logic of care, a logic of reverse benefit/ privilege by providing a platform for people's work or stories as the starting point, where appropriate, instead of my research question as the starting point, or from a focus decided upon with collaborators.

In the end, answering my initial guiding question 'what could a less colonial access politic look like?' was less about asking Indigenous disabled people about their relationships to disability and Indigenous identity and experiences, and more about practicing different ways of relating

to participants, collaborators and research itself. While blockages in my recruitment and interviewing process were related to the development of my version of episodic crip production, they also revealed the discomfort I had with reproduction of instrumentalization that I was at times subjected to by researchers and journalists. (Eales, 2018) The method of my interrogation was an answer to my research question.

“[Modern] racism is not really about nonwhites; modern racism is really all about white people.” (McWhorter, 2009, in Peers, 2015, 238)

## 8.2 Crip ancestors II

Selfishly searching for crip ancestors

For connection to this land that I'm temporarily and hungrily and unbeknownst to la RAMQ calling home

The settler project of I belong

I belong here too

Searching for connection to ancestors connected by curb cuts and chirping lights and paved trails - not gravel trails - paved trails. Gravel trails are bullshit

and I am vulgar; like my dad.

Gravel trails are bullshit, unless I'm on foot and then they're nicer, like moss if it's small gravel. Moss is best.

if I have my wheels, then paved is best.

Searching for ancestors in specks of asphalt and ribbing of new curb cuts

and sittingshoulder height light buttons,

and trails, paved for the wheeling iteration of myself, so that I can feel connection

beyond enjoyment,

to this place.

Jessica Johns, said as a Nehiyaw from Sucker Creek First Nation in treaty 8 Territory, she was training herself to be ok in the water here

- looking for connection.<sup>20</sup>

I have no problem with the water, I can feel it's love for me.

at home in it this summer,

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<sup>20</sup> After-word, 2018

my feet then my legs then my undergarmented self then my undergarmented self and a  
love, ebbing and swelling into each other;  
the ocean wanted us  
welcomed us, held us together.

It's the land I'm looking for connection to -  
with?

The pained and abject body project of I belong  
I belong here, too

how do I move forward without knowing connection to the past?  
fuck, it's been over three years, have I come any closer to touching that connection to the past? I  
told you I was vulgar; like my dad.

Looking for lineage beyond the activists that have  
moved on to better things:

“What’s happened over the decades is, you know, we used to have strong advocacy  
groups, full of angry disabled people who couldn’t get on with their life because society  
was not dealing with their issues well enough, and when society did finally loosen up and  
deal with the issues all the disabled leaders left and went off and lived their lives and did  
what they wanted to do... disability organizations, advocacy and service, very few are  
run by disabled people... in a way it’s a great tragedy, and in a way it’s a great success,  
people with disabilities don’t have to be advocates, it’s all being done, or much of it has  
been done” (Sam Sullivan Personal correspondence, May 25, 2017)

Maybe he hasn’t been to Quebec or a poor neighbourhood or been unemployed in a while

it's my dad's 50 anniversary of coming to Canada this year. The south African woman in our  
rental has

never gone back, why would they - everyone's moved on and where she grew up in Jo-  
hannesburg, where my boyfriend now husband would step over the cute little stone wall,

has now been replaced by ugly barbed wire fence. No, why go back, coming to Canada was the best thing they've ever done.

Does her description of Johannesburg turning ugly and falling apart means she regrets the fall of apartheid?

Her comments, milky and blurred, racist or not?

How to clarify I'm not in on the secret,

on her team?

dispose of her or not?

I hear her accent every shared elevator ride.

And then she asks if I want help opening the door and I mumble something about the door opener never really having worked and she opens the door and she stops to chat with another neighbour and we wave and I head off towards the Skytrain. I'm vulgar, like my dad, and I fucking love the Skytrain and I still don't know who made it so accessible. J probably knows. He's on the Translink<sup>21</sup> accessibility committee. I considered joining but it was at the same time as my writing group and guess which one I chose?

Sam said it wasn't him who made the city accessible when he was the mayor:

“when I was mayor people would come to the office and say, ah! This makes sense why Vancouver is so accessible, because it has a disabled mayor, and I would say, mm, actually it's the opposite, Vancouver has a disabled mayor because it's so accessible... but once I was mayor, I mean, it was not even uh, something anybody would do is bring an inaccessible project to me, you know, I didn't even have to say anything they just took a look at me and say, mm, I think we're going to go back and redraw this thing you know (laughs).” (Sam Sullivan, Personal correspondence, May 25, 2017)

Searching for ancestors in the words of an earlier generation of People With Disabilities,  
on waves actuated by water taxi  
towards my interview with Sam Sullivan,

The 1.5 generation project of I belong  
I belong here too

---

<sup>21</sup> Metro Vancouver transit system

Selfishly searching for crip ancestors

It began feeling a bit like searching for connection in other people's ancestors.

So I'm turning inwards and gonna look at my own.

## Chapter 9: Possible ways forward

### 9.1 Coming home to witnessing

After my process of shifting and updating my methods to include found poetry, and reflection on interviewing, I attended a few events in a short period of time that came at the right moment for me. These were a roundtable about DeafBIPOC stories, hosted by Jessica Leung and Ashanti Monts-Treviska. This was a sacred space for invited DeafBIPOC to share stories, and those of us attending to witness and hold space for that as an educational experience. Another was a writing workshop with Lee Maracle, Stolo author, storyteller and Order of Canada recipient, who told stories about writing and encouraged us to write from our perspectives. Another was a performance called *Unsettled*, which told first-hand stories of disabled people: a woman who was abandoned as a baby, another person learning Indigenous sign language in addition to ASL and LSQ and English. The last in this cultural education was the film *Paint it Red*. (Cohen, 2017) Each share some of the struggles to support Chinatown, Vancouver, as gentrification threatens and resistance against land 'developers' has kept them at bay to date. This is close to where we live in Vancouver. I go to Chinatown for lots of things, and after this screening I saw buildings and places that I pass by often, in a different light. The older Chinese-Canadian presenter said the newcomers to the neighbourhood look at us sideways, not straight at us. She thanked the ancestors who built Chinatown and thanked/ acknowledged the Squamish and Tsleil Waututh.

Through these events that took place as part of the Heart of the City Festival and close to date to that, I was in a mentored role instead of the role that I “felt” in as a researcher or activist. In these instances before, I was one of or the only “out” disabled people in spaces like classrooms, workplaces, community organization settings, and was looked to as the expert. I positioned myself as such in order to incite change, market the knowledge I have and feel seen or understood and share knowledge with younger generations of crips. But in that position it doesn't leave so much space for growth. It is not an elastic way of being/ relating. I'm learning that rather than interview with research question from my head, I can witness art, discussions, films etc. and connect on the terms these mediums and artists offer. From there, if appropriate, I could offer what I have and can contribute where I feel called, where contributions are welcome. Embodied knowledge is something everyone has, and it is desirable to create spaces to exchange. These events encouraged me to take lots of steps back and witness.

I am getting back to witnessing. Coming home to witnessing. Listening as method. (Carrou, 2017) Witnessing asks of me, invites me, to take something and sit with it and have it communicate with my beliefs and biases and experiences and regularly adjust and expand. It brings

with it opportunities to look at the resistance that is internal. Not public and not in relation to systems or institutions. The resistance that I'm least comfortable with: resistance against the things that make me feel frustrated against myself. The shame I feel around being slow being sick and tired. The things that make me crinkle my nose when I go through Chinatown and by the open-air shops - the smells that an interviewee in Paint it Red said smell like him growing up. (Cohen, 2017) The ways I think about and wonder about Indigenous disabled people that I talk with - or hypothetical Indigenous disabled people that I imagine giving me the answer to what's the difference between you and I. When the conversation could be and is becoming something entirely different and more fun and interesting. (W.A., Personal correspondence, Sept 9, 2018)

“Build up and beyond”

(Sainte Marie, 2018)

Next steps for me based on this research creation process will hopefully allow me to contribute to a network or interrelated web of people's, stories, creations, projects, conversations, political or community actions where needed while producing art and writing from my specific position. In resisting what is contained in my original understanding of like everyone else, or simply, not fitting and thereby resisting, we embody non-sameness. Fostering and celebrating and using this ethic of crip non-sameness as a methodology for relating could certainly be a framework within which to mobilize in the coming years amongst different groups and peoples and environments.

An example of a possible way forward could be co-editing an anthology or special issue containing multiple writers' and artists' takes on the theme, “Accessing Colonial Canada” or something along those lines. The idea of having writing by different people in their own voices, theme based rather than research question based would be an interesting approach for me. We would be ‘bound together’ by the spine of a book, but encouraged to offer different perspectives based on our embodied knowledge. (K.J., Personal correspondence, July, 24, 2018)

## **9.2 Collaborative world building II**

Collaborative world building

Takes closeness

Takes love

Being able and comfortable enough to disagree

Space to f up and not ruin everything

Note to self -

Build on this



### 9.3 Looking for home

Not feeling at home in Alberta

Sometimes in my body

Do I need pathetic fallacy?

accessibility translates as a way of explaining feeling of not feeling at home

Searching for it in the history of concrete

More than just being there / getting in - it's intimacy, love, feeling seen and accepted with all parts of myself known, equal parts moving the legged-chair in anticipation for my being there and bringing it back the second I get up from my wheelchair, knowing I don't want to stay in it

Home is bed

Home is you

Home is us

Home is where?

Home is breath

Home is ribs

Home is your hand on my leg

Home is quiet

Home is space

Home is being surrounded by strangers

Home was Wednesday night dinners in my apartment because no place else is accessible and comfortable

Home is friends

Home is private

Home is defaulting to the you sitting upright my legs draped over you position

And you

And you

And

You

I look to the distance and see a rainbow flag

That's nice that the science world wants to signal a welcoming to rainbow people

Home isn't in a rainbow flag

I sit on a pillow from our rental apartment in a community garden,  
building fan blows stale air towards flourishing echinacea, fuschia flowers

Home isn't this pillow

I take sips of Starbucks misto, seeking the excitement I felt two hours earlier, post gym,  
Is home in caffeinated energy - a feeling of aliveness?

I touched down

Vancouver bound, from a province over, and tension exited my ribs - less cage more flowing  
cloths, dancing and freeing, breathed air with every shift in the wind.

Is home in this place? Or is it in the places that I have built independence - looking more and  
more like connection, interdependence?

Will it translate to Montreal when I go back or will the ribs close in, my heart, caged?

Home is your hand on my leg

Home is quiet

Home is space

Home is friends

And you

And you

## Chapter 10: Conclusion

### 10.1 Conclusion

“Alien consciousness” is the rising in the borderlands, According to Anzaldúa. (1987) What is tumultuous and seen by the dominating Eurocentric culture as threatening or broken, becomes the site of a new consciousness. (see Chapter 7)

I set out with the initial guiding question ‘what could a less colonial access politic look like?’ Through hosted conversations with six people of diverse cultural backgrounds, who are disabled/ Indigenous/ personally invested, and drawing on Parent’s (2016) “Wheeling Interview” method, I explored this and related topics such as embodied knowledge, conformity, queer expressions of self, intergenerational effects of colonialism and residential schools, mobility, crip ancestors, self-expression through art and storytelling and generational disability movement concerns. Reflections on the recruitment process in communities that I am not part of or had not been invited into (such as disabled Indigenous groups), informed by my personal experiences as an interviewee, led to methodological findings about positionality, the nuances of recruitment and consent in recruitment of allyship research, and ultimately, the importance of collaborative knowledge production. Drawing on Tuhiwai-Smith (1999), I was influenced to prioritize secondary research based on research and writing by Indigenous disabled/ Indigenous scholars, and witnessing over seeking answers defined by myself as an outsider researcher by ‘in-group’ participants. Simultaneously, experimentation and articulation through poetry and creative non-fiction throughout my research process led to the development of my practice of poetic exploration.

Drawing on crip research creation scholars, my hybrid form combining short videos in conversation with poetry and auto ethnographic, creative non-fiction containing key moments from my interviews, desires for accessibility, and interaction with the landscape offer my intellectual contribution to the fields of Critical Disability Studies and Media Studies. This could be seen as an extension of Laurel Richardson’s writing as a method of inquiry, because it is a method of inquiry but also a practice which reveals different ways of relating between individuals and communities; a crip poetics. By presenting writing and videos in a non-linear way and providing space for and attributing value to embodied, emotional, and relational elements of inquiry - relations with self, other people, and the environment and physical surroundings - I have drawn on research-creation scholars to develop a space where multiple realities can co-exist in a non-linear or asymmetrical or non-coherent way. By articulating this in writing I seek to manifest it in

the wide array of research creation literature, and through the process of writing it I deepened my understanding of this desire.

Including my poetry and version of crip poetics in the body of my thesis I invite other scholars, artists into conversation with my embodied, emotional experiences and articulation in a way that prose doesn't through the 'fissures' in linear thought, pauses, breaks and multiplicity of voices included and styles expressed. (Brown, 2001) This provides a methodological provocation and a way of exploring privilege and marginalization based on intersecting social phenomena like settler colonialism, homophobia, racism, chauvinism and classism within disability movements, and relationships both creative and interpersonal. Crip poetics does not rely on one single logic and has possibilities for multiple logics or world-views to be in dialogue with each other in the same written/ creative space. This is a creative and poetic space where critique can coincide with generative contributions and imaginative visions and possible futures that go beyond what it is considered possible in current paradigms. Perhaps if placed together in the same written space, then these realities and perspectives could thrive together in the world outside the page as well. I hope that this research may spark a conversation and future collaborations, which recognize, engage and challenge our respective privileges, oppressions, complicity, friendship, and evoke possibilities for a more equitable way of pursuing/ enacting accessibility. In a present that doesn't have space for all embodiments and ways of being, I hope that this research and future articulations of crip poetics contribute to inviting futures that do.

## **10.2 Possibility**

Tentative lips come toward, pull away  
Eyes unafraid  
She bows her head

Unexamined  
Soft hands express what words have avoided  
Verbal failings,  
Accept  
The long-awaited spring

Possibility:  
The future, an idea now  
Not just paper carried on the wind

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