THIS AREA IS RECOMMENDED FOR

WALKING THROUGH A WAVERING WITH-ITNESS: AN EXPLORATION INTO
DISABILITY PRIDE AND SHAME

by

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A thesis submitted in conformity with the requirements
for the degree of Master’s of Arts

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This is a thesis about disability pride and shame. I explore how these two characters appear in theoretical texts, personal stories and my experience of disability on the streets as an identity which connects me to others and the world as an interpretative being. This project begins by demonstrating how the popular imagination of disability pride describes the prideful person as one who relates to their embodiment with constant satisfaction. I trouble this version of pride, a version that requires one to turn away from shame, for being exclusive of disabled people who, like me, experience their disability through a wavering bodily relation. I conclude by crafting out a pride that remains with us in troubling times rather than in the abandonment of shame. This pride is accessible to us all and the never-steady stories of disability we tell.
Acknowledgments

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I wrote this thesis as part of a community of disability and equity scholars and activists. I thank this community for their commitment to doing disability differently, together. I am very humbled by being part of a community who has a dedicated passion for changing the way we relate to each other and to difference in scholarship and everyday lives. I thank Katie Aubrecht for our many conversations about orienting to one’s embodied identity with pride and shame. Katie’s support of my scholarship and her loyal friendship are truly extraordinary. Thank you to Anne McGuire for ‘mentoring’ me throughout my first year in the department — sharing books, and engaging my just-started work with creative suggestions for proceeding. Thank you also to Anne for being such a passionate presence in our department. Thank you to Sarah Snyder for many insightful conversations throughout the day, sharing resources and letting me talk through my always-shifting way of proceeding with my daily work. I also thank Sarah for her many, many hours of invaluable editing.

I am very proud to be part of such an inspiring, supportive, and genius community that is bounded together by disability and disability matters.
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Introduction

This is a thesis written through, with and for sidewalks and the stories they tell. I move through streets, on sidewalks, as a “walkie” (Clare, 1999a): feet to ground; alone; sailing through rivers of moving others, careful not to brush shoulders keeping our togetherness a shared, never spoken, secret; strategic turns down quieter streets lined with big homes, old enough to spark shifting and repeating fantasies of other lives. Feet to ground; sometimes stumbling, always holding the possibility—this is how I get around.

This is a thesis written through, with and for disability, my Cerebral Palsy (CP), and the stories it tells. How, for what, and why the “matter” of my disabled embodiment “means” (Butler 1993) is intimately bound to my “being-in-the-world” (Sartre, 1958, p. 328) on the streets. My teachers, peers, friends, and families who make up my cripped scholarly, activist, and artistic communities have made it matter that disability is constituted in the midst of others and the world, as an indication of our togetherness (Michalko, 2002, Titchkosky, 2007, McGuire, 2009). The “normates” (Garland-Thomson, 1997) I meet and move with on the streets may sometimes recognize me only as “the containment of difference”, a simplistic exchange of my otherness for the constitution of their subjectivity (Bhabha, 2006, p. 72). But I know that this is not the end of these sidewalk stories. It is the “disturbing distance in-between” that constitutes the other in relation to the impossible object (Bhabha, 2006, p. 72). I do not only and always

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1 Garland-Thomson defines normate as: “Usefully designating the social figure through which people can represent themselves as definitive human beings. Normate, then, is the constructed identity of those who, by way of the bodily configurations and cultural capital they assume, can step into a position of authority and wield the power it grants them” (1997, p. 8). Following Erving Goffman’s work (1963), Garland-Thomson tells us that “normate” describes only a minority of actual people (2007, p. 8). I follow Garland-Thomson and use “normate” not to refer to a person but rather a performance one enacts when they encounter difference and use their perceived normalcy to position themselves in privileged opposition to noticed difference. As such, I do not use normate as a synonym for non-disabled people, or even a non-disabled person who meets the elusive criteria for normalcy.
encounter normates as I move through space, but these are the engagements that orient me to the troubling terrains between us where the meaning of disability emerges indicating that these stories of bodies on the streets are never mine or another’s, but always constituted by the entanglement that is our togetherness.

Understanding that disability is constituted in the midst of others also means knowing that disability appears in the midst of conflict. This was a hard lesson to learn. I came into disability studies in my early twenties and began to identify as disabled rather than avoiding disability at all costs in disembodied activities, as I had previously done. Almost immediately, I was drawn to sidewalks as sites of interpretation to take back my embodiment from the stares and gazes which claimed disability as their own, slipping it away from me. I approached Toronto streets with my background, performance art, emboldened with the power and the possibility to create an imagination of disability in congruence with the experience of my embodiment. Though quickly, my emboldened sense of power that I could interpret disability in the public sphere turned to discouragement, as it appeared that my performances would not create the waves of social change I had hoped for. And here is that story.

My series of street performances were born out of my challenge to watch myself walk down the street. Pervious to this demanded engagement, I would notice to avoid my walking reflection in windows and the like. However carefully and consistently I turned away from myself, I was reminded—sometimes with every step—that I was disabled. The noticeable reactions of the moving-others I passed on the street told me that they recognized me as disabled. Eventually I decided that it was time to watch myself as others did. This two-part project began simply enough. I would set up a video camera on
the street and walk towards it. Then I would sit and watch the tape play back, which was perhaps the most difficult part. Watching these street performances was the first time I realized that my right foot dragged a little in its step; I saw that my right hand stiffly hid behind my body or lingered a pace or two behind me. I also noticed that my head would snap back raising my chin up when I passed by a moving-other. I knew how all of these bodily characteristics felt, but had no idea how they visually manifested. It was through watching these videos that I first received a sense of how my body moves through public space, and took in what others notice.

I continued recording my walking and watching the recordings. My walks changed from time to time, from street to street. Once I moved to Toronto, I came up with the idea of walking down the busy and fashionable Queen Street West in a costume that exaggerated my disability and my sexuality. Through this performance called Catwalk, I intended to confront the stereotypes that disabled people are asexual and undesirable. I dressed up in a black dress, a back coat, a white hat, a red feather boa and yellow high heel shoes, which noticeably affected my shaky gate. This performance followed the same format as the others. I set up my camera on this busy street and walked towards it and then back away from it a couple of times.

After I was finished the performance and was packing up, a woman approached my friend who had come with me to make sure my equipment was not damaged or stolen during the performance. The woman asked my friend if she could take a picture of me, adding that she understood why my friend had chosen me as her model. In a quick look, I told my friend to let this interaction happen in front of the recording camera. While she was photographing me, the woman did not address me directly; all requests for me to
move my body into more aesthetically pleasing poses were given to my friend. Standing right beside me, no closer to the photographer than I was, my friend would repeat what the woman had just told her: “she wants you to face the sun”.

My experience tells me that sidewalks are sites of interpretation; sidewalks are where disability, my CP, becomes significant with meaning. I wanted to gain control over the signification of my disabled body. However, here, on the sidewalk, in the moment I was attempting to assert my autonomy, I was recognized as a passive object of art rather than its producer. I was dissuaded by the woman’s reaction— a striking indication of so many I had received before — which so poignantly demonstrated that the link between my intention for the performance and the intelligibility I provoke was not guaranteed. It was clear that I could not replace her story of disability with my own. And so, instead of lingering a little in the discomfort of our conflict together to discover what new meanings of disability might grow in the space between us, I decided that this project developed through, with and for disability was meaningless, and I did not want to continue.

But I did continue, eventually, not to arrive at a solution, but to dwell in the midst of conflict, consensus, and all of the in betweens inevitable in our togetherness. Here is part of that continuation.
In an interlude to *Reading and writing disability differently: The textured life of embodiment*, Tanya Titchkosky writes,

Through my experiences of disability as always already a problem… I think that the search for solutions, a common practice, should be slowed until we develop some understanding of the problems for which we find ourselves seeking solutions. The search for solution itself needs to be opened up to reveal the conception of the problem that the solution makes manifest (2007, p. 43).

Drawing on Titchkosky’s words, as will be explicated in Chapter One, my work is not driven by a desire to search for conclusive solutions to established research problems; rather, I strive to trip up in complications and to dwell at home in an uncertainty inspired by my with-itness of CP. For here, in the cracks, I sense there is possibility for new meanings to grow. My intent is not to convince my reader that disability is not experienced as a problem, since my own experience of CP rubs up against the story of disability as a living problem. Even if I did experience disability as always and only desirable, it would be irresponsible of me to offer this story as representative of all disabled people, or propose it as a benchmark for yet another standard of normalcy towards which all disabled people should strive.

This thesis about pride and shame suggests that when unwavering satisfaction with our embodiment is constituted as a prerequisite for coming into disability with pride, we constitute disabled people as “excludable types” (Titchkosky, 2007, pp. 149- 150). In this thesis, I am not working with a definitive articulation of “disability pride”, disability pride can arise differently in different bodies and at different times. At this time, and in
this body, I understand disability pride to be that through which we can interact with the world with a sense of being-at-home (Ahmed, 2007, p. 9) in our disabled minds, bodies, senses, and emotions (Titchkosky, 2007). Part of being at home in these never-still embodiments is opening up to and engaging with the “trouble” (Michalko, 2002, 2007, pp. 401-416) our corporeality might cause us sometimes, or all the time, and the resulting shame we may experience. Disability pride may also lead us to recognize our disability as an identity that binds us to others and to the world, rather than as an individual problem experienced in isolation. With such a prideful recognition, we are able to form “crip communities” (Clare, 1999b, pp. 127-135) of disabled people and our allies, where we can share with pride the stories of the trouble we experience. Stories like these sidewalk stories of disability as it appears on the street. I believe disability pride should be accessible to all disabled people because this pride can provide the opportunity to imagine disability differently through moving into community and away from self-hatred (Titchkosky, 2007). Therefore, my thesis offers an articulation of pride and shame existing in togetherness.

In Chapter One: A place to start, I begin my exploration of pride and shame with a discussion of how I have selected sidewalk cracks and the trips they may provoke as both my methods of inquiry and my site of interpretation. Here, I follow a tradition that requires scholars to explicate how their position in the world is bound up in the ways they

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2 Chapter 5 offers an exploration of crip communities. This chapter discusses how crip communities can open up to, and be cemented with pride and shame.

3 I use the phraseology “disabled people” to describe a personhood rather than a marginalized, disconnected population, following the work of Clare (1999), Linton (1998), Garland Thompson (1997), Michalko (1992, 1999, 2001), Titchkosky (2000, 2007) and others. My decision to use this language is explicated in Chapter 1 and Chapter 2. Here, I am not suggesting that disability pride should only be available to people who identify as “disabled people”. I believe disability pride should be accessible to anyone and everyone.
interpret and produce knowledge (Haraway, 1991, Harding, 1987, Hill Collins, 2006, Smith 1999). I articulate my “point of view” (Merleau Ponty, 1956) as a “with-itness of CP”, which describes both my physical body and relation to this body as shaky and tremoring. This chapter presents my “orientation” (Ahmed, 2007) to disability, pride and shame through understanding that the meaning of matter is never restful; is always on the move.

To explicate how I have come to understand pride and shame as interactions that attach us to the world, Chapter Two: Interactions of pride and shame reviews some of the literature where pride and shame appear. The first part of this chapter discusses how disability pride appears in popular texts. In this textual analysis (Titchkosky, 2007, pp. 11-40), I am particularly attentive to how life narratives often articulate coming into disability with pride as a turn away from shame. I reveal this popular structure for telling the story of disability pride as being potentially exclusive to those whose satisfaction with their disabled body wavers—waverings that my with-itness of CP tell me is often a reality. Using Ahmed’s (2007) articulation of “stickiness”, the second part of Chapter Two explores how shame can swell up under our skin and “stick” us to the world. In my exploration of shame, I also think about how epitaphs, such as a “retard” or “negro” called out to us on the street holds the potential to lurch us out of our sense of being-in-the-world, bringing us into Bhabha’s “Third Space”; the space which all interpretations occupy.

Chapter Three: Orienting towards a temporality of disability pride, unpacks how pride and shame first emerged in my body. I did not always think about pride in close relation to shame; for a long time I assumed that the shame of disability living inside of
my bones excluded me from identifying as disabled, let alone doing so with pride. The first part of this chapter will describe the lived experience through which I came to know disability pride and became troubled by my relation to its articulation of a prideful person as someone who claims complete and unwavering satisfaction with their embodiment. I explore my disability pride through unpacking a street performance dedicated to speaking this pride publicly. The later half of my chapter is devoted to explaining how I propose to make a disability pride “materialize” (Butler, 1993) that is accessible to us all regardless of our current or ever-lasting relation to our embodiment. With this proposal, my task is not to replace this version of pride with another, rather I desire to create another pride to new to inspire many and multiple radicalized identifications with disability.

Chapter Four: Sidewalk stories and the troubling task of disabled identification
thinks through the inter-relational processes through which one comes into identification as disabled. In this chapter, I dwell in sidewalk stories to think about the processes of coming into disability as a radicalized identity and wonder: If we refuse to constitute shame as the pre-given ground from which pride rises up as an actor and instead, think of a muddlement of these two characters, what new possibilities for political alignment and an inclusive crip politic might be ignited? My thesis closes with Chapter Five: Final notes. This chapter does not offer any conclusions or summarizing answers; rather, I take from the exploration of pride and shame laid out in this thesis to think about how such an entanglement of these two characters can provoke and be sustained by crip communities.
Chapter One: A place to start

This chapter about pride and shame suggests that the “matter” of the disabled body becomes significant with “meaning” in the moment it “materializes” (Butler, 1993), a moment which occurs during interactions between the self and another, and the self and the world. In our togetherness, we come to mean in relation to each other. In this work, a togetherness of disability is situated in the realm of “the street,” as is told through sidewalk stories.

To begin telling these stories, it is necessary for me to think about my “point of view” (Merleau Ponty, 1956) as an embodied interpretive being-in-the-world. To begin such thinking, I turn to Sartre, who tells us that: “The body is our means of existing in the world, and the body as we exist in it is the means by which the world comes into being for us” (1956, p. 259). From Sartre, I understand that I come into the world full of recognition and the potential to be recognized through my body; I can know and be known by the world in no other way. In this chapter, I articulate my embodied perspective through which all knowledges enter and pass through as a with-itness of CP. I use “with-itness” to describe CP as something I live in, with, and through rather than an embodied attachment typically inferred by a “with”. I am always enraptured by CP in my being-in-the-world, and through this with-itness I interpret and make sense of the world as it interprets and makes sense of me. My with-itness describes a wavering embodied relation as much as a wavering sense of the world. And in these wavers, in these cracks, the “meaning of matter” (Butler, 1993) is never restful.
In his book *The Two-in-One: Walking with Smokie, Walking with Blindness*, Rod Michalko tells the story of his developing relationship with his dog guide Smokie, and with his own embodiment of blindness. Oriented to blindness through his relationship with Smokie, Michalko (1999) unpacks cultural conceptions of blindness taking us through different times and places of their time “alone-together”. In the final chapter, “The Two-in-One”, Michalko explains that through his analysis of blindness he has made a distinction between “living with blindness and living in blindness” (1999, p. 174); a distinction necessary for me to think through as I am distinguishing between living with CP and living through a *with-itness* of CP.

Michalko makes clear that language *does* something for the constitution of identities; the articulated distinction between living *with* blindness and living *in* blindness or living *with* CP or living through a *with-itness* of CP is not meaningless. The way we come to know ourselves through language is full of meaning for how we relate to our embodiments and the world. Therefore, a discussion of methods of inquiry must open the reader up to the meaning of our words and the imaginations they bring and operate within. Michalko’s writing provokes me to think through how my words imagine disability. According to Michalko, how we relate to our disabilities depend on our conceptions of them (Michalko, 1999). For example, when blindness is conceived of as a negative condition imposed upon an individual, for example, we relate to blindness as an embodied attachment rather than an integral part of our identity and being-in-the-world. Such a relation that dismisses the possibility of organizing around disability as a politicalized identity inspiring community, friendship, love, and pride.
The *with* in living *with* blindness does work similar to the *with* in the popular nomenclature ‘people *with* disabilities;’ a phrase bureaucratic talk, political correctness, and polite conversation demand. The motivation behind this language is to claim, lest we forget, that we are “people first”, suggesting that disability discourages—even potentially forecloses—the opportunity to embody a personhood. Therefore, the way to achieve personhood is to regard disability as an embodied attachment, and certainly not something integral to our being. People-first language achieves what Michalko refers to as the “person/body split” (1999, p. 177). This language decides that we are people who happen to be disabled; we are people despite embodying the antithesis of humanness. This language reminds us that things could always be otherwise. For, as Titchkosky (2001, 2003) writes, only certain bodies have to claim that they are, in fact, *people*.

Michalko also tells us that: “Living *in* blindness, however, requires a different understanding, one that goes beyond coping with and adjusting to blindness” (1999, p. 181). It requires keeping blindness alive in one’s self (Michalko, 1999). This shift, from “living *with*” to ‘living in”, dwelling in disability to pay close attention to how it both mediates my interpretations and textures others’ interpretations of me, is what my methods of inquiry seeks to achieve. To regard CP as a with-itness, a CP that has lessons to teach, requires an unsettling of disability from its “discursive roots” (Butler, 1993) as always and only a medicalized problem located in the individual, at best overcome and at worst coped with. This is the story of disability that I have lived with for so long; a story of embodied attachment which seeped into my bones, effectually rendering how I orient to my disability—understood as a problem. And at times, I do experience my disability just this sort as problem.
My task here is not to write over this story with another, to write over my story of disability shame with crip pride. Rather, dwelling in CP as a site of interpretation with a method of with-itness as a way of proceeding, is to be open to the reality of my corporeality, the ways of the worlds of the streets, and the interpretation that arises. Shakes in my right hand when reaching for an object in the midst of others may be shameful, shakes in my methods when reaching for meanings may be productive for trying to orient anew. But never is it an either/or situation. Living through a with-itness of CP is to orient differently to the ways that pride, shame, and everything in between shakes my body. And so, I proceed “living in” CP through a with-itness, paying attention to the ways I exist and am interpreted in the world.

Of his sense of “being-in-the-world”, Sartre explains that the body also exists according to “particulars” (1958). He writes:

My birth…my race…my class… my nationality…my physiological structure… my character… my past, all this in so far as I surpass it in the synthetic unity of my being-in-the-world is my body as the necessary condition of the existence of a world as the contingent realization of this condition (1957, p. 328).

From such a positioning of the body and “its particulars”, we come to understand how our embodiment, our absolute point of view is inescapable. As such, it is the only way that we can exist in the world as interpretive beings. Through this positioning of the body, we come to recognize that the ground from which we receive, interpret, and produce knowledge is never neutral. Rather, our ‘being-in-the-world’ is always already biased and positioned. Dorothy Smith (1999) asks us to remember our embodied
subjectivities as researchers and producers of knowledges, for our standpoint always mediates how we come to “know what we know” (Snyder, 2009, unpublished). How and why I know what I know is inextricably bound to my body; a movable, shaky character. This character is an uneasy one. Therefore my methodology must explicate how my bodily relation—my with-itness of CP—effects and shapes these presented knowledges. An exploration of my embodied view—thought of here as my “home-in body” on the streets— must be enacted to lay a ground providing openness from where one can know the “particulars” through which this work is created.

These presented (sidewalk) knowledges bring new sense and sensibility to the meaning of disability as an indication of our togetherness, and these knowledges are bound to my body and bind me to the world. Sara Ahmed tells us: “Orientations are about how we begin; how we proceed from ‘here’ which effects how what is ‘there’ appears, how it presents itself” (2006, p. 8). She continues: “The starting point for orientation is the point from which the world unfolds: the ‘here’ of the body and the ‘where’ of its dwelling” (2006, p. 8). My body is “here” in a “with-itness” in CP. It dwells in CP as I orient to the world and to disability studies. As much as my body—never steady, always tremoring— can only be described as and through a with-itness of CP, this wavering with-itness is also what brings me to the world full of interpretive understanding.

I experience the street only and always through a with-itness of CP: the streetscape appears to me in shaky view, bouncing before and towards me as I move with my unsteady gate. I walk with the ever-present possibility of being lurched out of, or into, my sense of being, provoked by a trip, a stumble, or a fall, which could come to me at any and every moment. The moving-others I walk amongst notice me, notice CP, even
when it is only noticed and named as shaky… a moving body out-of-control. I walk with wavering looks interpreting my body, looks shifting between ambivalence, curiosity, confirmation, admiration, annoyance, and back to ambivalence. On the streets, a with-itness of CP is not only my own. While walking together with someone demands, perhaps, that they adopt a slower pace as my walking pace insists. Walking with another who I am guiding, with my elbow, hand or shoulder, we enter into an unsteady dance together as my rhythm demands, guiding us both. Alone or together, I do not know the streets without a within-ness of CP.

In the same way that I come to the streets, I come into disability studies through a with-itness of CP. By this I do not mean that I have an inherent and always-intimate knowledge of disability and disability studies simply because I am an emboider of a disability. Disability studies can be known by any “bodied being” through a dedicated curiosity and commitment to its scholarship and the ways of words and worlds it binds us to (Titchkosky, 2007). As this is my “here” and “where” of dwelling in the world, I approach disability studies as a wavering scholar. Disability in mind, body, senses, and emotions does not guarantee our fate as “natural scholars”, however I think—or maybe I know—that we cannot approach disability studies as disembodied scholars. Disability, CP, provides the “texture of my embodiment” (Titchkosky, 2007, p. 9). I must turn to more than my experience of disability as I approach disability studies (DS). I must also turn my attention to how this study leaks into my being, as my being leaks into my work firmly situated in this developing DS scholarship. To think more intimately about the relationship between skin and scholarship, I turn to Eli Clare’s work. He writes:
I want to write about the body, not as metaphor, symbol, or representation, but simply as the body. To write about my body, our bodies, in all their messy, complicated realities. I want words shaped by my slurring tongue, shaky hands, almost steady breath; words shaped by the fact that I am a walkie—someone for whom a flight of stairs without an accompanying elevator poses no problem—and by the reality that many of the people I encounter in my daily life assume I am ‘mentally retarded.’ Words shaped by how my body—and I certainly mean to include the mind as a part of the body—moves through the world (2001, p. 359).

By returning to the bones of my body to dwell in disability and disability studies, as Clare suggests we do, I am made strikingly aware that “we are never alone in our bodies” (Titchkosky, 2007, p. 5). I am never alone in my body; I am always conscious of my experience of “being a bodied being” (Titchkosky, 2005, p. 219). My CP does not let me forget that I am always in my body. In my quietist moments lying in bed just before full recognition that I have woken up, I am aware that I am in my body in its twitches and tingles. I am never without the awareness that it is the corporeal connecting me to being in my reality; my embodiment will not let me forget bodiedness when thinking about, with, and through disability. Thus, a with-itness.

To think about disability pride and shame through my being-in-the-world, I dwell in sidewalks and the stories which emerge from my body on the streets. I dwell in sidewalks as my site of interpretation as well as my method for interpretation. For here, in the in between, the meaning of matter is never restful, is always on the move. I have chosen sidewalks as the site for my inquiry into the meaning of disability in relation to pride and shame for a couple of reasons. Firstly, sidewalks are uneasy terrains which we
occupy when we engage the task of getting there. My thesis work also occupies a liminal space, as it will never arrive at a conclusive ending. Secondly, my lived experience tells me that on the streets my pride and shame are most often tumbled into one another, for here disability is never my own. For its interactive character, there is always the possibility that my disability will be apprehended from me. Yes, on the streets is where I need to be with a troubled pride the most.

With Ahmed (2005), I think about my dwelling in the streets as inhabiting a bodied “home” that is neither tethered to a sense of departure nor arrival. Instead, my home is occupied with a sense of disability as a perpetual state of getting-there. Ahmed suggests: “Home is here, not a particular place that one inhabits, but more than one place: there are too many homes to allow place to secure roots or routes of one’s destination” (2000, p. 77). Such articulation of the liminality of homes informs my work and informs my method of inquiry. Through it I come into a methodology of cracks, cracks in the sidewalks which trip me up causing me to crash down to the ground of disability, to dwell in my being-in-the-world. This methodology locates cracks as sites of interpretation asking us to dwell, to “be at home”, in the in between. To be at home in my never-restful body is to be open to a way of interpreting the world that embraces wavering meanings.

In her work, Not-Yet-Time: The paradox of disability in bureaucratized university life, Titchkosky tells us that in relation to new legislation in particular, the Access for Ontarioan’s with Disability Act [AODA], “disability remains imagined as, configured as, a not yet” (June 2009). Titchkosky’s (June 2009) work tells us that in the wake of legal and bureaucratic change intended to make Ontario accessible and more universally
inclusive, disability remains a “not-yet”, excluded from conceptions of the “all”. When we move in the streets it may seem that it is “not-yet-time” for disability: stairs can prevent us from going; loud noises can unsettle our nerves; unclear directions can confuse us; strange looks can unnerve us; cracks can trip us up. That it is not-yet-time for disability in the streets (and in other realms) in 2009 is startlingly common and blatantly discriminatory to bodies we all will enter “if we live long enough” (Garland-Thomson, 1997, p. 14). But what if we linger “with wonder” in the not-yet, being-at-home in this world of possibilities (Titchkosky, 2009)?

My work suggests that inhabiting the space of “getting there,” existing in a perpetual state of not-yet, allows us to rest in academic unease, never arriving at an end full of understanding. It is “not-yet” time for me to depart from my body full of unwavering satisfaction for my being-in-the world to arrive at any full understanding of disability’s being-in-the-world. It is not yet time to be completely content with scholarly and activist projects through, with, and for disability and disability studies—where is the fun in such restfulness? My work, my body-at-home-on-the-streets, like Ahmed’s, is constituted as and by the journey of always and never getting “there”. The “there” of my work is always “here” in the dwellings. It is time to dwell in the not-yet-time-ness of unsettled meaning of matter— in this thesis, the meanings of the matter of pride and shame. “Here” in the dwelling of the journey new meaning emerges and also shifts. The only thing I hope to arrive at in the end of this work is the imperative to continue chasing the never-still meaning of pride and shame—and revel in these uneasy times.

My method of inquiry continually lingers in these cracks as disruptions to getting here/there, for this is where I am most “comfortable and familiar” (Ahmed, 2000, p. 89).
Ahmed suggests that when we identify home as “stasis, boundaries, identity and fixity, as a purified place of belonging, the subject may become too comfortable to question the limits or borders of her or his experience” (2000, p. 87). When home is constructed as “too comfortable”, “too familiar”, then the subject-at-home’s experience is known as the “absence of desire” and “the absence of engagement with others through which desire engenders movements across borders” (2000, 87). Instead of constructing home as a place of rest that only accompanies one’s arrival at a final destination, Ahmed asks “How does being at home already encounter strangeness” (2000: 88)?

My being-at-home- on the streets through a with-itness of CP, articulated in this thesis through sidewalk stories, always “encounters strangeness”, always gestures towards the boundaries of comfort. I enjoy them quite a bit, but the streets are never restful places for me: trips on cracks, ruptures provoked by uncomfortable stares/stairs, moving carefully up and slipping slowly back down icy inclines, reveal the streets as never-steady ground. Ahmed also tells us that: “homes can be ‘giddy’ places where things are not always held in place, and homes can move, as we do” (2007, p. 9). In my home, in this shaky body, the meanings are never “held in place” and I sense productivity and creative potentiality in the unsettledness of my wavering. Although I can do it in no other way, I desire to approach disability and disability studies through a with-ness of CP, for this ruptured climate is needed to unsettle the roots of matter, allowing new meanings to grow.

Like the streets and the disability scholarly realm, I am oriented toward my corporeal by my with-ness of CP. This “here” is the starting point of my bodily relations. My wavering body, and thus wavering relation to it, needs a windy pride, one
that blows between pride and shame and at the same time is always—necessarily—
captured between these two characters. Given this, how might my “being at home” in
CP orient me towards disability? Put differently, how do my twitches and tingles and
never steady breath, and living in a perpetual state of “not yet there/time” (Michalko,
2009; Titchkosky, 2009), orient me toward disability as a wavering relation, making it
possible for me to utter: ‘My bodily relation is never steady; my pride cannot be steady
either?’ With these questions in mind, body, senses, and emotions, I proceed.
Chapter Two: Interactions of Pride and Shame

As I demonstrated in Chapter One, I know disability as an interrelational phenomenon. I think about pride and shame not as individual, emotional, or affective fates experienced in solitude. Rather this chapter takes from my own experience of a with-itness of CP, thinks through pride and shame holding onto this with-itness, and imagines disability pride and shame as emerging out of interactions in which we recognize and are recognized as disabled. For disability is thus a response or indicator of our bodily relations. Through such a configuration of pride and shame, I pay close attention to the temporal beat of these characters to suggest that they do not live in isolation in the others’ exclusion. Instead they arise in a muddlement that cannot be untangled for individual consideration.

In this chapter I think carefully about how pride and shame appear articulated by others and remember Titchkosky, following Smith (1999), who writes: “Text gives us a starting place where we can organize an encounter between our embodied selves reading in time and space, and the time of the text with the space it delineates, as all of this orders our consciousness” (2007, p. 15). By starting here, in these texts, I inquire into the meaning of pride and shame as it has already materialized through others’ work to discover how my developing work relates to, and finds a place in this discourse.
Disability pride

When crafting out a new disability pride for myself and in the disability community, I do not propose that we do away with the popular conception of disability pride; the idea that disability is not something to be ashamed of is undoubtedly powerful, and is key to inspiring alliances with disability as an identity rather than as a problem to be solved. However, we must build upon the version of pride that emerged in conjunction with the North American disability rights movement, captured in the description below. I analyze this articulation of pride not simply to critique it but to productively trouble the ground from which I suggest we emerge creating pride anew.

According to the website *Disabled and Proud*:

Fundamentally, Disability Pride represents a rejection of the notion that our difference from the non-disabled community is wrong or bad in any way and is a statement of our self-acceptance, dignity and pride. It signifies that we are coming out of the closet and are claiming our legitimate identity. It's a public expression of our belief that our disability and identity are normal, healthy and right for us and is a validation of our experience\(^4\) (Triano, 2009).

This description of disability pride is powerful and promising. Disability is an embodied experience that appears in our popular imagination as shameful, regrettable, and problematic. Resisting the idea that the “difference disability makes” is simply “wrong or bad” is a necessary starting point, which this declaration of disability pride provides (Michalko, 2001). However, such an articulation of “self-acceptance” and the desire for the recognition of our “disability and identity [as] normal” are not necessarily reflective

\(^4\) I recognize that this is only one of many articulations of disability pride that are widely disseminated. However, this thesis is not dedicated to deconstructing all popular articulations of disability pride, and so I’ve selected this quote as indicative of a sentiment that is widely expressed.
of the myriad of goals of an entire disabled personhood. People, like me, whose relationship with their disabled embodiment wavers, are excluded from pride when the prideful disabled person is only and always imagined as those holding an unwavering satisfaction with their embodiment.

Titchkosky posits: “Texts never just get it right or wrong insofar as they are also a ‘doing’—right or wrong, texts are always oriented social actions producing meaning” (2007, p. 21). Because the meaning of matter—here pride and shame—are made between us, it is necessary for me to become familiar with how other disabled people orient themselves to pride and shame as a starting point for thinking through my own embodied relations. While my textual analysis of these two stories problematize the ways in which disabled pride appears, I do not mean to judge the way that the authors’ articulate their relations to their embodiment as “right or wrong”. Rather, I read these narratives to locate room for pride to move beyond how it has already materialized in texts to create a pride that is open to diverse bodily relations.

The version of disability pride that appears in the text on the website, Disabled and Proud, is an indication of the popular way we often tell the stories which describe how we can relate to our disabled embodiments differently—with pride. And these stories often articulate what I refer to here as ‘a turn’—a definitive turn away from shame to arrive at the destination ‘pride’ without the possibility of a return. The journey from shame to pride, as it is often described, follows a one-way, disappearing path. When one arrives at their destination, they never return from where they departed. They never get tripped up in ‘getting there,’ dwelling at home in the in-betweenness of the journey (Ahmed, 2007). Such a version of the story of disability pride may be useful; certainly
turning away from self-hatred and hatred of other disabled people is a necessary move. However, when we constitute a normative standard for coming into disability with pride as always and only articulating the requisite move of turning away from shame, we foreclose the opportunity to tell the other stories of bodily relations. In this move, we turn away from the possibility that stories of disability pride can live beneath our bones in countless ways, inspiring stories describing wavering and windy prides that are not constrained to a structure of departure and arrival. Might we be less prescriptive and more open to different ways of prideful beings-in-the-world when we embrace the possibility that prides can exist in the time and place of the journey of never getting there, as Ahmed (2007, p. 9, 10) and my with-itness of CP suggest? I move now to textual analyses of two texts which describe the experience of coming into disability pride as being determined by a turn away from shame to wonder about how we might orient to pride otherwise.

In the introductory chapter to her book, *Pride Against Prejudice*, disability activist Jenny Morris tells the reader that she came into disability later in life, as a result of an accident causing a spinal cord injury that paralyzed her lower body (1991, p. 2). Upon being diagnosed and recognized as disabled, Morris was confronted with the assumption and articulation of her new corporeality as “tragic” by doctors and others around her (1991, p. 3). “In subtle and not so subtle ways”, Morris tells us, “a number of people conveyed to me that they felt my life was no longer worth living” (1991, p. 3). Morris writes that she felt “outraged” at the assumption that her life had taken a tragic turn. While it seemed unfair that all she had worked so hard to achieve—personally and professionally—might have been jeopardized by her accident, she did not think of her
disability as tragic (1991, p. 3). As she quickly resolved that the structure of her life would remain unchanged, she decided that all that would have to change was that she would now be doing things from a sitting position (1991, p. 3).

Nevertheless, soon after her accident, however, Morris realized that things could not continue as “usual” from “a sitting position” because being disabled made her fundamentally different from, and set apart from, the non-disabled world (1991, p. 3). Moreover, coming together with other disabled people bound by their disability in community was perceived by nondisabled people as pitiable rather that prideful (1991, p. 170). Of this discovery Morris writes:

Many of us find that joining together with other disabled people brings a feeling of strength. However, when we take collective action together, or organize our own cultural event, we have to fight against the negative connotations of just being together in a group of disabled people. To overcome [the attitude that a group of disabled people are a subject of pity, fascinated repulsion and, sometimes, fear], however, is to feel empowered by joining together (1991, pp. 170-171).

Throughout the book, Morris articulates that her pride materializes in the politicalized act of joining together in disabled communities. By demonstrating that it is an identity around which to organize friendship and political action, Morris and her disabled community combat social and systemic discrimination upheld by the assumption that disability is “personal tragedy” (1991, p. 2).

This way in which pride materializes is further emphasized in the book’s final chapter, Pride, which does not even mention the word, but for its title. Instead, this
chapter tells the story of the day that Morris and other disabled people came together at their local BBC television station to protest the charitable event, “Children in Need” which raises money for “disadvantaged children” each year (1991, p. 190). Organized by the Campaign to Stop Patronage, this protest opposed:

The way that the charity system uses negative images of disabled people to raise money for things we should receive as a right, instead of beg, conform and show gratitude to patronizing organizations over which we have no control (1991, p. 190).

Of this event, Morris tells the reader that others were surprised to see disabled people protesting an event that was meant to “benefit” them. So surprised, in fact, the “nondisabled people” (her description) who were donating related to the protestors in a way that indicated they assumed she and her disabled comrades had shown up to express thanks, even as they were positioned behind picket placards (1991, p. 191). But it was not thanks they had to offer. Instead, this group of disabled people had shown up to trouble to the construction of them as pitiful by this and likewise charities (1991, p. 190). Morris’ pride is inspired by her community, answering her question: “How can we take pride in what we are, when disability provokes such negative feelings among non-disabled people” (1991, p. 15)?

Morris’ pride is defined oppositionally and as a rejection of the assumption that “we feel ugly, inadequate and ashamed of our disability” (1991, p. 18). As such, her pride is constituted by what it is not—shame as its other— and therefore, it seems, dwelling in shame becomes an impossibility for a prideful being. Morris’ proclamation of pride requires us to become other than the ashamed subject culture expects us to be. This
definitive turn from shame may require us to forge—or at least articulate—a relationship with our embodiment which may be other than how we experience our corporeality… in troubling time.

Together, through pride, Morris and her crip community organize politically and advocate for change. I have stories, many of them, in which my disability materialized only as prideful, in complete abandonment of any trace of shame. Through my crip community⁵ and dwelling incripped spaces, together we “do disability differently” (Titchkosky, 2007) and “provoke new imaginations of disability in congruence with how we experience our embodiments” (Chandler, 2008). Being-at-home in these spaces orients me to being with disability other than a difference which need not make a difference (Michalko, 2002). And within this community, sometimes pride overcomes shame. Sometimes on the sidewalk my pride is steady even when I am wielded as a shameful subject by another’s look. And here is one of those stories:

There I was, moving down the sidewalk, College Street in Toronto, situated in the journey of getting there. I was walking toward a meeting with my supervisors, Rod and Tanya, to discuss mounting a disability arts exhibit at the Ontario Institute for Studies in Education (OISE). This walk was motivated by my destination for I feared I was late and was excited to get there. I was hardly dwelling in the in-between, my mind was “already there”. I moved swiftly down the sidewalk, weaving carefully between and around moving-others. This walk was different than most. I was wearing a dress without pockets. I usually carry a purse on my left shoulder so that the bag hangs down by my right hand. Such positioning disguises the disabled character of this hand, as it appears that its

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⁵ For an exploration of crip communities andcripped spaces, please see Chapter 5.
stiffness is caused by its proximity to the bag. But on this morning I carried my bag on my right shoulder—my left one was sore, probably from over use. My right arm was unattached to do what it may. I pass a woman, my right hand curled up into my stomach, comfortably. I hear her laugh, and then, I hear her say, “Well, well, look at her”.

Here, I turned too. Turned away from the robust potential for embarrassment, to be “stuck” back to shame, resisting its temptation, which did not even materialize as a tempt. I did not think to force my right hand down, hiding it behind my body. Here, shame did not swell and I sailed on with steady pride. Still focused on the destination, knowing that at the end of this walk I would land into an unwavering crip community, and here, in the midst of laughter at me, my pride did not waver either. During this potentially embarrassing interaction between myself and another, shame did not swell. This was a prideful walk; the in-betweeness of this walk constituted by the character of the destination.

And this is the truth of this story, but this is not always the case. Not acknowledging these stories, these truths, would be to neglect the powerful persuasion of my crip community that stay with me, even when I feel alone on the streets. However, to treat these stories of unwavering unwavering bodily satisfaction as the only stories of pride would be to deny my stories and others.

To continue my path of wondering about being in the in-between, dwelling in the cracks, I move to another story with another turn away from pride. This is a story from *Mouth*, a bi-monthly magazine dedicated to disability rights and discrimination issues. This story, *Escape from shame* by Tammy S. Thompson, makes materialize a pride constituted by a ‘turn’ away from shame. Thompson begins her story in the fashion that is
usually called up for articulating pride, lingering over the details of the pain and loneliness she experienced when living in shame of her blindness. When I read Thompson’s words, I could relate. She states: “I’ve spent many years on a mission to cancel out my disability by frantically stacking up achievements, hoping that someday I would find that final, magic accomplishment which would absolve me of the sin of being disabled” (1997, p. 56), I felt her frenzy of trying to make up for the deficit of my disability by accomplishing more, by doing more. Her words describing the isolation and sadness provoked by the “stigma” of her disability reaches a memory that lives in my bones, a memory never to be erased by my current and also shifting bodily relation (Goffman, 1963). There was a time when I hated my body too; my relation to these memories of this time remind me that living in complete shame of my disability is, indeed, also to occupy a place to which one may never wish to return.

I continue reading her words of loneliness and half way through the story, I’m hit with a “then”. This “then” reminds me of the inevitable turn away from shame required of us when we arrive at a pride and full satisfaction with our embodied way of being-in-the-world. “Then”, Thompson tells us, she stumbled upon the idea of disability pride on a street that she traveled along by bus. Like me, disability pride first appeared an “oxymoron” (Thompson, 1997, p. 56), a strangely unthinkable concept. This pride was “sticky”. It attached itself to her in a relentless way and, as Thompson writes, “I had to find out more” (Thompson, 1997, p. 56). She joined the Disability Rights Movement

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6 Encouraged by examples of other civil rights movements, the Disability Rights Movement aims to provide equity for disabled people through providing access to built environments, implementing polices aims at equitable rights for disabled people, and confronting negative attitudes about and representations of disabled people. For more information about this movement, please see: Longmore, P. and L. Umansky. (2001). New Disability History: American Perspectives. New York: New York University Press and
and turned. Then her ways of being in the world were “liberated” and the “disability warriors”—her comrades in the movement—taught her “a new way to live” that freed her from her past (1997). The statement: “Today my friends in the movement are teaching me how to accept my disability and carry myself with pride” (1997, p. 57), provides the emancipatory ending to this narrative of pride which rose up from, and lives in abandonment of shame.

When we choose to tell our stories of pride as only living in the shadow of shame, who are we excluding? Moreover, when the path from pride to shame is imagined as swift and disappearing, which of our experiences are we neglecting tell? Are we, the wavering, disqualified from disability pride and all the possibilities it holds? Is this the end of the story? My analysis of this version of pride and my lived experience prompts me to wonder how I, along with other disability scholars and activists, might imagine disability pride in new ways. Disability studies offers a critical paradigm that asks us to be unsatisfied with the constitution of a norm, and challenges us to rethink the meaning of bodies deemed ‘abnormal’. Might disability studies also invite us to trouble the conceptualization of a “normal” prideful disabled person, and come up with more versions of disability? In this project of making a pride materialize anew we must hold close the popular imagination of disability pride, to wonder how we can establish new meanings, new possibilities, that seeks not to normalize disability, but to trouble pride.

Shame

I turn back to Ahmed to think about the interactional character of shame to imagine how such an interaction holds the power to lurch me out of my sense of being-in-the-world, my “body-at-home” on the streets. In her book *The Cultural Politics of Emotion*, Ahmed suggests, the transference of emotions are “sticky” (2004, pp. 89-92) and the “agency of emotions is not to be found in one place, within the self, or within the social” (2004, p. 89). She continues,

Stickiness then is what objects do to other objects—it involves a transference of affect—but it is a relation of “doing” in which there is not a distinction between passive or active, even though the stickiness of one object might come before the stickiness of the other, so that the other seems to cling to it (Ahmed 2004, p. 91).

Working with Ahmed’s words, cultural theorist Sally Munt suggests we consider how much the epithet “queer” is sticky in multiple senses: “A sticky wicket for some to negotiate intellectually or politically, recalling the dual significance of ‘tacky’ as in gummy and cheap, and even the accusation/appellation ‘Queer!’ sticks…” (2004, p. 12).

Trips on the sidewalk are not only caused by shaky bodies and feet that drag over the cracks, but can be caused by others as well. The epithet “retard” sticks to my bones to lurch me out of my sense of being. And this effects how I move. “You retard” shouted out by another can excite uncontrollable swelling of blood underneath my bones; a swelling which reminds me that bones are thin sticks, my skin thin sheets, that do little to separate my body from my world. Ahmed tells us that, “Some forms of stickiness are about holding things together while others are about blockages or stopping things moving” (2004, p. 91). Following Ahmed, I suggest that the word “retard” sticks in a
way that stops meaning from moving. For me, retard will always be stuck to teases and taunts leaked into my body during a time when I was without pride, instilling loneliness, self-hatred, and shame within me. Unlike other words, such as “crip”, retard can never be claimed because of its stickiness. I can claim crip as my own word through which I name my disabled identity and refer to my community. Not again, but for the first time, for crip has never been hurled at me, carelessly or recklessly, like “retard” has. Crip has no stickiness for me. However, it is difficult for me— in this body with its attachments to history stuck to memories that will never leave my bones— to hear “retard” without being brought back to a time when disability lived in me as an uninvited guest. “Retard” sticks me back to a time when this word gained its stickiness and stuck me to shame and silence; a time when these binds were not easily unstuck.

My with-itness of CP does not allow me to endure the experience of being called back into times when shame exclusively occupied my body, mind, senses, and emotions, without becoming noticeably jolted. When my body hears “retard,” my head snaps back quickly and my right hand retreats to my chest where it is most comfortable. I even make a small noise. These bodily reactions do not indicate that I am ashamed in myself and by myself. My shame only and always swells in the midst of others. By this I do not mean that we necessarily need another to feel shame, for we are always with others, in our memories and in our thoughts even when we are alone. Such as this is, we always have the possibility of swelling with shame in solitude. Ahmed tells us: “Insofar as shame is about appearances, shame is about how the subject appears to and for others” (2004, p. 105). My shame requires the witness of another, whose normalizing gaze transmogrifies me into the “containment of difference”. Such an apprehension by another renders me the
“difference to be different from” for another to achieve their subjectivity of sameness (Bhabha, 2007). In this moment, I am ashamed of the version of my body that appears for others: nothing more or less than a failure of the normative standard of corporeality. This swelling of shame does not necessarily indicate that I regard my embodied self as failure, for I do not share these normalizing ideals with this normative other.

I now turn to Sally Munt’s book *Queer Attachments: The Cultural Politics of Shame*. Here, I think more about how shame is experienced in engagement with others. In her introductory description of the embodiment of shame, Munt draws upon Charles Darwin’s articulation of the appearance of shame in the moment of recognition—precisely in the interactional moment of being “stunned into [our] own recognition” as living difference (Patterson and Hughes, 1999, p. 603). Munt draws on Darwin to assert that the noticeable manifestation of shame—blushing—only appears in the midst of others, pointing to its integral togetherness. As Darwin suggests: “It is not the simple act of reflecting on our appearance, but the thinking what others think of us, which excites a blush” (In Munt 2007, p. 6). Moreover, Darwin claims, blushing most often occurs as written on the noticeably disabled body when it meets its (medicalized) gaze, as described in an encounter between Darwin and a married woman “suffering” epilepsy. Of this interaction, Darwin writes, “the moment that he approached, she blushed deeply over her cheeks and temples, and the blush spread quickly to her ears” (2007, p. 6). In this description, shame is written upon the noticeably different body. This body emerges as a manifestation of one’s own public presence achieved in the moment of recognition shared perhaps between the two characters in this interaction. Shame comes into being within
the subject because of self-attention, induced by another, in this case the ‘something’ being apprehended (2007, p. 8).

I do not think that shame is written on the body always and only through a blush, as Darwin suggests. I also disagree with Darwin’s presupposition that a shame sparked by an interaction is located strictly in the shamed individual—the one with the marked body—and not shared between the two parts necessary to ignite recognition. However, I do agree with his claim that shame is made manifest in the midst of others. Situations provoked by my disability that annoy or frustrate me when I am alone become shameful when witnessed by another. For example, a trip on an empty sidewalk is regarded only for the pain it causes me, as in no pain, no problem. Shame may swell when I think of how this trip may appear for another. A trip in the midst of others—even helping others or friendly-familiar others—may always be experienced as shameful. Others make the significant difference between pain and shame. Even though sidewalks are moving spaces, shifting between spaces shared with others and spaces of my own, the stories they provoke always hold the potential for being ashamed, being lurched out of my sense of being into an uncomfortable home.

To think further about how my recognition as Other by moving-others causes me to swell up with, or be jolted into shame, I relate my experience of being apprehended by an epitaph on the street to a similar experience described by Franz Fanon. In his chapter ‘The Lived Experience of Man’ in the book Black Skin, White Masks, Fanon tells the reader of a similar apprehension by others whereby through the “liberating gaze” of others, he is taken out of the world and put back into the world (2008, p. 89). For here, in this world, “not only must the black man be black, he must also be black in relation to the
white man” (2008, p. 90). Fanon describes an interaction with others in which he is brought into the world through recognition called out as “negro”. Fanon’s story of this interaction is as follows:

“Look! A Negro!” It was a passing sting. I attempted a smile.

“Look! A Negro!” Absolutely. I was beginning to enjoy myself.

“Look! A Negro!” The circle was gradually getting smaller. I was really enjoying myself.

“Maman, look, a Negro; I’m scared!” Scared! Scared! Scared! Now they were beginning to be scared of me. I wanted to kill myself with laughter, but laughter had become out of the question. (2005, p. 95)

Fanon becomes apprehended, jolted out of, or into, his sense of being in the world by an epitaph. His “Look! A Negro!” uttered by a white child to his white mother (2008, p. 91), seems similar to my “retard”. My recognition swells me into the world with shame whereas Fanon’s recognition as dangerous-other swells up in him with the desire to laugh—laughter which for him, had become out of the question. These words calling him into recognition as ‘negro’ transform Fanon into a trope of dangerous difference, “sticking” him to a blackness defined by cannibalism, backwardness, fetishism, racial stigmas, slave traders; a blackness that he describes overthrows his “ethnic features” (2008, p. 92). These conceptions cannot be disrupted by his lived reality, even if this version of blackness does not define him. These words, these conceptions, as they make up part of the world he encounters, will always be a part of Fanon’s being-in-the-world, even if they do not describe his path and his experience of it.
Fanon also describes wanting to “be a man and nothing but a man” (2008, p. 92), just like I desire to be a woman unstuck from the past hurt that lives in my bones, that swells me into the world with shame by a call, a trip, or a stare. Through his recognition as ‘negro’, Fanon is also stuck to the past, stuck to his ancestors, “enslaved and lynched” (2008, p. 92). It is through the stickiness of the interaction that Fanon is brought into, and exists, in the world.

**Pride and shame:**

Disability is not mine to hold or another’s to claim. Rather, disability is made meaningful in the midst of others. Being on sidewalks and in other public spheres means that there is always the possibility of being apprehended. In the moment where I am recognized and called out as “retard” on the streets, the with-itness meaning of my CP is taken away from my shaky grasp and changed into another character. In this moment, my CP is stuck to limited imagination. I appear for others as a convenient trope, wherein I materialize as a living problem, my sidewalk-shakes indicating nothing more than failure. Through this captivating move by another, the meaning of my bodily matter is taken from me. Here, I stand on the street in a shamefully stolen body. Because I will always be with others, even when I am alone, the possibility of swelling with shame will always be with me. However, this shame is never definitive of the whole story of my bodily relations—and it certainly not the end of the story. I may be stunned into recognition of otherness by another. And this shame, as Ahmed (2004) reminds, may stop things moving—in this case my body. In this moment of standing still but still standing, pride has not left my body. Through it, I can eventually keep moving down the sidewalk. These interactions of
pride and shame, and myself and others, remind me of the temporal beat of pride and shame. For these characters move, shift, mix up, and float away. These characters stick me to the world never in the abandonment of one another.

The lessons disability studies teach demonstrates that the meaning of matter is never held in place once and for all. We can, and we must activate this matter, establish new intelligibility, new meanings, and new ways of proceeding. Holding close the matter of disability pride as it has already materialized—as explicated in the texts and stories above—I wonder: how might disability pride materialize differently in ways that seeks not to normalize disability, but rather to trouble pride. To make the meaning of pride materialize in new ways that allow for the appearance of my wavering and messy relationship to my disabled embodiment, I turn to Butler. She writes:

To be material means to materialize, where the principle of that materialization is precisely what ‘matters’ about that body, it’s very intelligibility. In this sense, to know the significance of something is to know how and why it matters, where ‘to matter’ means at once to ‘materialize’ and ‘to mean’ (1998, p. 29).

That disability pride is already matter—a matter and meaning not to be done away with—indicates that it has already materialized to mean. And it can again. With the characters of pride and shame stuck to me, I proceed.
Chapter 3: Orienting towards a temporality of disability pride

To arrive as a self-defined people, disabled people, like other marginalized people, need a strong sense of identity. We need to know our history, come to understand which pieces of that history we want to make our own and develop a self-image full of pride (Clare, 1999a, p. 90)

We live in a culture that commonly interprets disability as a “problem in need of solution” (Mitchell, 2000, p. iv). This forms the grounds from which ‘disability pride’ can emerge, offering the possibility of alterities in which one is no longer forced to live in shame of their disabled embodiment. The possibility of developing a bodily relation full of pride may appear as a strangely unthinkable concept when the seemingly embodied contradiction of disability pride is stumbled upon for the first time. However, my experience tells me that the more time one spends with this conceptual possibility, the more likely disability pride is to transform from something unthinkable to always thinkable. Through disability pride we can come together in communities, develop cultures, work out subversive and reclamation languages, and establish a personhood of ‘disabled people’ as an alternative to a disconnected population of ‘people with disabilities’. For the hopeful and transformative ways of being-in-the-world it inspires, believe disability pride should be accessible to all disabled people. For this, I wonder how, together, we might think through the concept of disability pride in its current manifestation to make a new pride materialize which does not elide those of us who hold our disabled embodiments with a shaky grasp from the imagination of the prideful person.
In her book *Bodies That Matter*, Butler activates bodies as matter that can materialize to form new meaning (1993, p. 28). I borrow from this work to suggest that just as we—disabled people, our allies, disability studies scholars, and activists—work to constitute new meaning of the disabled body, we can also make the matter of pride as it relates to the experiences of these bodies materialize in new ways. “To problematize the matter of bodies”, Butler writes, “may entail an initial loss of political certainty, but a loss of certainty is not the same as political nihilism” (1993, p. 30).

Butler’s words tell us that the meaning of matter is not secured. She tells us that there is always potential for shifts in the ways matter is constituted. Putting Butler’s theory of materiality together with my methodology of cracks performed through a wavering with-itness to the world, I sense productive space. Here, I can take pride as it has already materialized and hold it up like a mirror to my lived experience of disability, at times both prideful and shameful. This reflective looking reveals that my prideful experience is inconsistent with the version of pride that we are most often oriented towards, as explicated in Chapter 2. Such a crack— and the connectedness cracks depend on to be cracks—between meaning and matter, as I experience it, prompts me to wonder how pride might appear anew, informed by and speaking back to my bodily relation, thought of here as a with-itness of CP.

**Disability pride: My introduction**

I was introduced to disability studies in a basement classroom of the University of Toronto when I was 23 years old. I had not heard of “disability studies” before, only the “study of disability” in which my body was an object to be medically assessed by a
doctor pursuing a solution for the problem that was my embodiment. This experience was uncomfortable and objectifying, as these doctors only viewed my body was viewed for its abnormal physicality. Therefore, I planned to stay as far away from the study of disability as possible. In fact, I planned to stay as far away from disability as possible, aside from the inevitable fact that it was my embodiment. But a course called “Disability and Social Change” caught my attention.

In this class, we were oriented toward disability studies through disability arts; cultures and communities; dance; life narratives; “models” such as the medical model, the social model, and the cultural model; social theory; and poetics. I was caught by the described ‘disability communities’, bound by the very ties that had previously cut me off from holding any sense of belonging. Particularly, I remember meeting Eli Clare’s work through his writing *Gaping, gawking, staring*. Not typically an outwardly emotional person, I remember wiping away tears before I read past the first few sentences… here they are:

Gawking, gaping, staring: I can’t say when it first happened. When first a pair of eyes caught me, held me in their vise grip, tore skin from muscle, muscle from bone. Those eyes always shouted, “Freak, retard, cripple,” demanding an answer for tremoring hands, a tomboy’s bold and unsteady gait I never grew out of. It started young, anywhere I encountered humans. Gawking, gaping, staring seeped into my bones, became the marrow. I spent thirty years shutting it out, slamming

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the door (2003, p. 257).

While reading this, I was struck by how Clare dwelled in disability and thought carefully about the ways in which it connected him to the world and to others. This was a way of being in the world that I had not before appeared to me as a possibility. All at once, within these words on the page, emerged a CP that was other than the version I had been introduced to and recognized within myself for so many years. My hands tremored along with Clare’s as I read this stranger’s words, words that so eloquently described my own body and relation to my embodiment. But it was not a version of unshakable pride that captured my eyes, breath, and heart, for Clare’s words did not skip over the details describing how appearing as disabled for another can be an unbearable experience. He reflected back to me the way that I feel ‘caught’ when my body is constructed as the “containment of difference”, the difference needed to be different from in order to make one a ‘normal’ subject (Bhabha, 2007, p. 63). When reading Clare’s description of his corporeality in troubling times, I understood for the first time that I did not have to be ashamed of the shame I experience. And in this relatable shame, disability first appeared to me as a connection, as a bind to a person, a people, a pride.

In the words, and worlds, presented in the texts we read in the class, persons with disabilities—a minority population of embodied problems amidst a population of non-disabled people—transformed into a personhood of disabled people; a community of which I could finally be a part. As disabled people, I learned, we were bound together by our experiences of embodying disability and could flaunt our disabled embodiments with pride, a concept I understood and was excited by, in theory.
Butler suggests:

If the political task is to show that theory is never merely *theoria*, in the sense of disengaged contemplation, and to insist that it is fully political (phronesis, or even praxis), then why not simply call this operation *politics*, or some permutation of it (1991, p. 14-15)?

At this time, I was uncomfortably aware that I was not engaged in a praxis of the politics of disability studies. Rather, I was in a place of “disengaged contemplation” (Butler, 1991, pp. 14-15). Disability studies theory failed to penetrate, and remained distinct from, my everyday life.

While I embraced the messages of disability articulating that my corporeal reality as a legitimate embodiment through which to negotiate the world, these teachings seemed to escape me on the streets and in my trips, where I most need to be with pride. Although inspired by the messages of pride and community, I continued to hide any noticeable signs of my difference for fear of embarrassment. When visiting cafes, for example, I pretended to not want coffee rather than bring the mug of hot liquid to the table and risk spilling it all over myself. Likewise, I paused before reaching out to grab something with my right hand with hesitant muscles to see if anyone was watching me. I did not want to be publicly perceived as a shaky body out-of-control, a fulfillment of the expectation for disability as nothing more than a problem. Within the disability pride that I found in disability studies texts, like the version found on the *Disabled and Proud* website quoted on page 18, I could only find room to imagine CP anew beyond and in spite of my shakes.

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8 By this articulation of “theory” and “my everyday life”, I am not suggesting that these are two distinct entities. Rather, I am speaking of the separation I experienced at this time.
and tremors and the discomfort they caused. And so rather than turning away from my reality, I continued to live with CP as an attachment… disconnected. I did not yet know a with-itness of CP and I was not aware of the teachings of my shaky body.

Disability pride: An artistic engagement

I was not-yet ready to give up on this elusive pride, and wanted to find its home in my body. I have always been struck by how my disabled body shifts with interpretation on the streets, for I have felt myself materialize anew through the recognition of others. It is not as though my recognition as disabled jolts me back into a sense of disability, my corporeality as real because this is where I am always at home. However, the shifts my disabled body passes through in the midst of others makes me startlingly aware that, as Arendt puts it: “I am not only for others but for myself, and in this later case, I clearly am not just one. A difference is inserted into my Oneness” (Arendt, 1958, p. 183). The streets remind me that my disability is not only my own though I live at home in it. I materialize anew out of interpretation—for others. Such interpretations of my body caused me to have a shifting sense of my being-in-the-world. Therefore, to find steady ground by claiming disability, I turned again to the streets. I continue my exploration through performance that had ended to abruptly so another sidewalk after Catwalk, the performance on the sidewalk of Queen Street West.

For Catwalk as well as for To Look Back I chose sidewalks as my performance sites because this is where the space between others and myself becomes most exaggerated. When I meet moving-others on the street, my disability comes into being by and for the characters of this interaction. I take from Garland-Thomson’s work on ‘The
gap between representation and reality’ and suggest that sometimes these interactions create “dissonance spaces between us” (1997, p.12). My noticeable difference can provoke a many-feeling reaction from others I pass on sidewalks. When I meet the “normate” on the street, “[my noticeable difference] dominates and skews [their] process of sorting out perceptions and forming a reaction” (Garland-Thomson, 1997, p. 12). The time it takes to form a reaction to disability may make for an uncomfortable pause, revealing the sometimes-troubling terrain between us. But, such terrain can also be occupied.

To Look Back was a performative attempt to occupy and activate troubling terrains, revealing myself as a speakable subject for the way meanings—my meaning—is formed. My young, white, “walkie”, physically disabled embodiment—noticeably disabled through my exaggerated gate and right hand that lingers a pace or two behind me—often attracts looks on the streets by those who perceive bodies through sight. There is power behind these looks, as mine is a body constituted as an object to be consumed. However, my publicly consumable body is complicated. As I embody both the markers of potentially desirable—young, woman—and potentially grotesque—disabled and out-of-control—my body wavers between corporeal binaries, and there are cracks in the looks my body garners. For as long as I can remember, I have been aware of my body’s ability to make people pause with wonder, disrupting their typically passive gazes. Through disability studies, I am able to locate a productive potential in the “dissonance spaces between us” for these shifting looks to disrupt the normal/abnormal binary so often used to categorize corporeal normalcy, revealing its artifice.
I engaged in a public performance, *To Look Back*, for a couple of months with the intention of addressing the shifting gazes and stares that penetrated me in places where pride had not yet reached. I knew that my body was often captured by ambiguous looks, powerful looks, as mine was an acceptable body on which to linger with curiosity. But I am a looker too. This performance was a dedication to meet the shifting looks captured by my disabled body in a way that disrupted the assumed passivity of disability, and troubled the binary of “normal” and “abnormal” as meaningful ways to categorize embodiments. Whenever I noticed such looks, I met the looking-other with a message of resistance to say:

I noticed your look, and I welcome it.

I want you to know that I am proud to be disabled.

In fact, everything I do is done with my disability, not in spite of it.

I began this performance by video recording myself reciting this message on different sidewalks around my neighbourhood. I knew that it would be too difficult to record the interactions in which I actually engaged with another, and moreover that the presence of the camera would likely effect their response to me. However, I wanted to practice this task on camera so that I could see what others would see, much the same as I did in *Catwalk*. Once I received a sense of how my body moved and sounded as I recited this message from (as much as possible) the perspective of another, I began my commitment to recite these words as a message of resistance whenever I saw, felt, sensed the stare of another upon my body.

Through this dedicated performance, I came to identify my power as an embodiment of difference. I intended my look back to assert that I was not just a problem to be stared
at, or an object to be gazed upon; I was a disabled person to engage with. The look, I
reminded my looker, was an interactional relation. My address back as the unexpected
looker who noticed the look of the other often came as a surprise. And this interaction
sparked dialogue; when our eyes met conversations often followed. We— the two
connected by the look— talked about disability and about pride, and through these
conversations I concluded that most people interpreted my message as my pride in spite
of my disability, and not as a statement declaring pride in disability.

For example, one day I was in a public computer lab rushing to print off a paper I
had to present in a class. When I rush my hands tend to become frustratingly slow. With
my stiff fingers, I was trying to quickly gather together up my papers into a neat pile to
be stapled when I noticed a woman starring at me, without a word. I felt her stare and
looked up; I knew I had to address her. I recited my verse to her and waited. Her face
erupted into a wide smile and it appeared she treated my message as an open invitation
for her to help as she took the papers away from me, binding them with a staple. I
remember repeating again the message, making sure I emphasized the final words: “Not
in spite of it.” The woman answered back, slowly, “It’s so wonderful you are in school”. I
was late and so I took the now-stapled pile of pages back from her and rushed along the
sidewalks to get to class. All the while the knowledge of how disability is interpreted
which lives beneath my bones, drawing meaning from between her words. I hoped to
provoke “new imaginations of disability” by reciting a message of disability pride in the
public sphere (Titchkosky, 2007). The messages I received back, articulating an
interpretation different than my intention, proved failure in demonstrating this elusive
disability pride.
I preformed *To Look Back* with the intention of provoking others I met on the street to think of disability in new and prideful ways. However, I think reflectively about this performance with critical art theorist Jacque Ranciere, a skeptic of critical art. Ranciere complicates this notion upon which most critical art is based, reminding us: “There is no straight line between intelligibility and forms of mobilization” (2008, p. 12). This could hold, Ranciere continues, so long as patterns of intelligibility and forms of mobilization are strong enough to sustain the artistic procedures that were meant to produce them (2008, p. 12).

Ranciere asks: “If we cannot or should not guarantee the effects and implications of artistic activism, should we dismiss art altogether as a means through which to unsettle hegemonic assumptions and provoke us to think in new ways” (2008, p. 9)? With *To Look Back*, I intended to reveal and occupy the “third space” between us to demonstrate that the act of interpretation is never simply a translation of meaning (Bhabha, 2007, pp. 36-39). I hoped to provoke discussions in which we, together, could explore the Third Space to make new meanings of pride and disability emerge between us. And in this discussion, I hoped that we could discover a disability that is not upheld by a binary structure constituted by opposing, never touching poles, of my experience and another’s expectation. Rather, expectations and experiences rub. Meaning is made in between these two posts, in the third space.

We may never know if the public will interpret our intended meaning which comes from the critical messages disseminated by public art. However, as artists we must trust that our work does linger in the imagination of our audience and hopefully provokes

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9 Ranciere is a skeptic of critical art for its presupposition of a linear relation between aim—artistic intent, means—artistic intervention or aesthetic experience, and ends—a provocation towards an awareness of a political situation leading to political mobilization (2008, p. 11).
new ways of thinking. I am motivated by Ranciere assertion that, “Breaks in relation between senses can happen anywhere but they cannot be calculated” (2008, p. 12). We — another and myself — experienced To Look Back together. And this shared experience may have altered their expectation of disability, for I made it appear with pride. “Breaks do happen”, I just may not be around to witness such breaks.

Disability pride: two stories

I now turn to the analysis of two stories to think about how pride can be simultaneously exclusionary and inclusive. In the first, pride is an actor that rises up from the ground of assumed shame. In the second, the two characters of pride and shame are curiously muddled. I tell these stories not for the “confidence game” (Mitchell & Snyder, 2007, p. 246) of critique, but rather to further explore pride through the “release” (Merleau Ponty, 1962) of stories of an uncommon pride experienced, or articulated, by others.

I begin with a story of fat pride which I garnered through a “Google search” of the words “pride” and “shame”. By offering this story of a version of ‘fat pride’, my intention is not to draw a strict correlation between fatness and disability and the pride that emerges from these bodies, but rather to learn from these “family resemblances” (Wittgenstein in Mouffe, 2007, p. 2). I located a family resemblance between fatness and the lived experience of fat pride and disability and the lived experience of disability pride. Both bodies exceed and fall short of the normative boundaries of corporeality. Disabled people, while not blamed for their out-of-control embodiment like fat people are, do share in the common experience of negotiating the world in and through a body
stigmatized for their unruly and unacceptable differences. Moreover, both the embodied experience of fatness and disability are not often interpreted as identities, thereby eliding any possibilities that they may elicit pride. I take this opportunity to explore how disability studies can be used as a paradigm through which we are able to think critically about other forms of embodied differences.

**Fat pride: First story**

This is a story by Jean Braithwaite, a self-described fat woman, and is about a bicycle ride home from her workout. Braithwaite shares, “no one moo’ed at me” when describing this particular bike ride (Braithwaite, 2009). Mooing” is presented as the always-possible interpretation of Braithwaite’s body. It is the first bit of matter, and thus meaning, the reader encounters upon entering this story. By physically exceeding the acceptable boundaries which determine a “healthy” body, fat bodies fall short of the normative standard of corporeality. Braithwaite is a type of body, a fat body, publicly (and also privately) claimed as inappropriate and grotesque, named by the indicative “moo”. The always possible commentary released upon bodies interpreted as intolerably different — “Moos” in Braithwaite’s experience—leads to the potentiality of always being lurched out of one’s sense of being. I understand, through the background of my experience, that “Moos”, the epithet “retard”, and likewise publicized interpretations encountered by the unprepared body may be startlingly shameful, perhaps even enough to be knocked off of one’s bicycle.

One might try to become very conscious of her corporeality as it’s perceived by others to guard against such disruptive acts of being lurched out of one’s sense of being-
in-the-world on the streets. Intended for protection, hyper-awareness of one’s body can take many forms—head down, quickened pace, averted eyes, clenched fists. It can also take the form of flaunting the body in prideful acts, resisting the stigma that is often attached to one’s embodiment. One might hope to deflect looks and comments interpreting their body as shameful by “claiming” one’s body as always already prideful (Linton, 1998). On this particular day, Braithwaite rides along claiming her fatness with pride, as she says: “I was proud of the way I felt and imagined myself to look, speeding exuberantly along under my own muscle power. Surely anyone could see how thoroughly at home I was in my body” (2007). Claiming “fat pride” is subversive, for it disrupts the assumption that the experience of embodying fatness is a shameful one. This disruption of the assumed contradiction of “fat” and “pride” directs my attention to other contradictions that Braithwaite’s articulations of her embodiment and its activities within the world seek to disrupt.

Braithwaite continues her narrative of fat pride citing physical activities as the experiences from which her pride grows. She tells us: “My relationship with my body was no different from any other trained athlete’s…. I felt like a walking advertisement for fat pride” (2007). Braithwaite’s fat body no longer troubles the boundaries of acceptable corporeality for, as she carefully tells us, it’s repetitive engagement in high performance sport exceeds our conceptions of fatness. In other words, when fatness transforms from its assumed dormant origins, or norms, into an active body, pride can emerge. But what happens when a fat body does not overcome its own image to measure up to a norm of healthy fat bodies, but rather continues to embody a version of fatness that we identify as common? Does pride escape the commonly fat body? Moreover, what happens when
“moos” swell shame in fat bodies living in pride? What happens when homes shift?

Again, the pride that appears in this story is one based on exclusion. For a pride that is more inclusive of unsteady bodily relations, I turn again to Clare.

Disability pride: Second story

I first found a relatable version of disability pride in the words of Clare’s book *Exile and Pride* (1999a). Clare begins his book with a narrative of climbing a tough mountain trail with a friend, and having to turn back because it was not safe for him to continue. This narrative represents how pride and shame can live together beneath one’s skin as a preface to a larger articulation of a disability and pride. Clare says:

I want to so badly but fear rumbles next to love, next to real lived physical limitations. So we decide to turn around. I cry, maybe for the first time, over something I want to do, had many reasons to believe I could, but I really can’t. I cry hard. Then get up and follow Adrianne back down the mountain (1999a, p. 5).

This is a story of how unsteady bodily relations and body knowledges can lead to the imperative to succumb to one’s corporeal reality even when one’s desire is to continue. From my own body knowledges living in and through a body who sometimes resists the messages for movements I give— sometimes to the point of full-stop— I know that ‘fear’ is scary, ‘crying hard’ maybe shameful, and wanting so badly to do something but cannot because your body will not let you, is indescribably frustrating.

These are Clare’s stories of embodying CP and when I read this passage my body responds because I know these feelings all too well. However, this story of frustration, disappointment, and regret inspired by bodily limitations is not without
There is pride in Clare’s telling of his dance of “slowly bringing both feet together, solid on one stone, before leaping into [the] next step” (1999a, p.5). When he describes the descent down from the mountain as “hard and slow”, continuing, “I use my hands and butt often and wish I could use gravity as she does to bounce from one rock to another” (1999a, p. 5). Here is pride. I understand this pride; it rumbles through my bones as well. Clare’s is a pride that contradicts—no, comforts—the shame that lives inside of me.

There is no embarrassment, frustration, or annoyance that comes from my being that does not rub up against pride. In the moment of hesitation when I reach out with an unsteady hand which may, or may not, fulfill its intended purpose, I waver; I feel ashamed and I also need to be with pride. When I trip on the street in the midst of others, I waver. I feel embarrassed and I also need to be with pride. When I think about the overwhelming shame that comes crashing down on me when I fall in the street and strangers pass without a glance (or a gaze or a stare), this is where my pride materializes. When struggling to pronounce a word that just will not leave my tongue, this is where my pride materializes. I tell a joke that gets a laugh; I make a dinner that friends enjoy; I participate in a productive class; I smile widely at a disabled comrade rolling by on the street: these are all places where my pride materializes. This wavering between pride and shame makes up the reality of my embodiment. My pride and my shame (and the cracks between them) require one another to come into existence. Therefore, I should not and cannot not be with a pride that does not embrace shame.

Clare writes: “To transfer self-hatred into pride is a fundamental act of resistance” (1999, p. 92). This transference is mine and ours, and it is our way to resist the temptation
of self-hatred as well as the hatred of others. Together, as a community of disabled people and our allies, we can take from the lessons of disability studies which tell us that the meaning of matter is never fixed, but always up for negotiation. From this we can craft out a disability pride that does not only exist in the abandonment of shame. By articulating a new disability pride that is accessible to us all, regardless of our bodily relations, we can inspire more of us to politically identify with disability as disabled people. I now return to sidewalks and their cracks to be tripped up, and to think about pride anew; pride in relation to identifying as, with, and for disability in body-at-home on the streets.
Chapter 4: Sidewalk stories and the troubling task of disabled identification

“If you step on a crack, you’ll break your mother’s back”. I remember muttering this rhyme to myself when I was a child first learning to walk. My physical therapist recommended I repeat a rhyme to help bring a smoother rhythm into my shaky gate. I liked this suggestion quite a bit, and, while it does nothing to fulfill its promise, I continue to repeat rhymes to myself, even now as I walk. This activity provides comfort and does well to keep me calm in the midst of moving-others.

“If you step on a crack, you’ll break your mother’s back”. This is hardly true, we know, but cracks can still be dangerous. Cracks in the sidewalks—weathered cracks and cracks between the paving blocks—trip me up, causing me to crash down to the ground. Painfully I fall into disability as I am introduced to and recognized as disability, again and for the first time, in the midst of others… moving-others. In this moment, the disabled body I trip into is not a comfortable one, but one with which my satisfaction wavers. This process of identification hurts. It fulfills the public’s expectancy of and for disabled bodies as stumbling… unpredictable. I fall into the public’s expectation of me as a living problem with the problem located within me. Under the social model\(^\text{10}\) between

\(^{10}\) Born out of discussions by a group of disabled people, the social model of disability first emerged in the United Kingdom in the 1980s. The social model was developed through a reaction to the understanding that disability is “a problem in need of solution, with both the problem and the solution located in the individual” (Oliver, 1996, p. 31); a pathology which dominated understandings of disability and personal and political relations with disabled people throughout the 20th century. This way of understanding disability became known as the “individual model” under the “model framework” that was derived from the development of the social model. In contrast, the social model suggests that “it is society which disables physically impaired people” (UPIAS 1976, p. 14). This understanding relies on the distinction between impaired body and disability as “something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society” (Oliver, 1996, p. 31). Oliver tells us that the social model “does not deny the problem of disability but locates it squarely within society” (1996,
me and the crack— but certainly not between me and others. The “walkie”-pedestrians who step over me when I have fallen confirm the individuality of disability (Clare 1999). These “walkies” notice me only to avoid me, much like cracks in the sidewalk. For I, living-disability, can provoke trips, causing others to dwell in disability. No, it is best to notice to avoid this liminal space.

“If you step on a crack, you’ll break your mother’s back”. This is hardly true, we know, but cracks provoke trips, that bring me face-to-face with the ground of my disability. The words: “There is still some dosa left” inspire this hurried and excited nighttime walk. Hands out of pockets, for balance, and a careful “heel-toe, heel-toe” count. I didn’t want to trip on this walk. I approached the stoplights and slowed down. I heard laughter in the doorway of the house to my left and noticed someone moving— no falling— down the stairs. “You retard, you cripple!” were shouted after him. This was not my trip but my body was recalled as the device through which his friends interpreted this fall as laughable… out-of-the-ordinary. Standing in the cast of a streetlight, I looked on at them and they looked on at me. Somewhere in the in-between of our togetherness,
the out-of-the-ordinary materialized, the unbelievable was noticed, and disability entered the mix through my body. Such recognition halted the laughter for a moment or two and then it continued, more up uproariously than before. Claims at recognition articulated as “Oh my God!” and, “Did you see her?” followed me as I walked on, humiliated and ashamed. For in that moment of recognition, disability materialized through my body as nothing more or less than a moving body out-of-control—a fulfillment of its expectation.

**My body at home**

The ways my disability materializes, much like the ways it is interpreted, vary from time to time and from site to site. My home, the house I live in, is a crippled space; trips on my stairs have soft landings, requests for help from my roommates are easily released and uncomplicated. In my home (this physical, static space) disability becomes pleasurable. Here, at home, my with-itness tells a different story than the social model tells. Under this model, disability appears to the impaired body only and always when it meets its own exclusion, oppression, or discrimination (for a further explanation of how the social model defines disability, please see footnote 6 on pages 50 and 51). My home space is without oppressive attitudes, exclusionary environmental barriers (but only because stairs pose no problem for my walkie body), discriminatory polices and yet, here, at home, I am always with disability. When my with-itness of CP is a source of pleasure both in my home and outside, I am with disability. For example, the ways my hands move to accomplish dexterous tasks in extraordinary ways brings me pleasure. The look that I use to convey to a friend the intimate and in-between knowledge that I need her to bring my coffee to our table can bring her pleasure too for the way it binds us together,
sharing with and caring for each other. Even the pains my CP causes me in my joints, muscles, lungs and skin can sometimes be experienced as pleasurable for their reliable consistency. I am so grateful for how my CP can allow me to be in the world “stuck” to (a new kind of) gracefulness, attractiveness and warmth. These stories tell me that my impaired body—CP—and my disability—my embodied way of being-in-the-world and my orientation to it—are always entangled as one. For me, in this body, disability is not a disappearing and re-appearing relation or character, as the social model describes. Rather, my disability is consistently with me in troubling times, ordinary times, and pleasurable times. My disability twitches and tingles, moves and changes, rises up in me as prideful, shameful. And never restful.

The task of identification

I turn now to one conversation to find sense in this never-still process of identifying as and for disability in relation to another and a world. My current orientation to identification was animated by a conversation which unfolded at a panel called ‘Confronting Systemic Discrimination’ at the Decolonizing Our Minds conference which featured, among others, Lee Maracle and Rod Michalko. Maracle began the panel talking about how her classes on First Nations literature are often filled with white students rather than First Nations students. Maracle did not seem to have a particular problem with white students wanting to learn in her classes, but she used this situation as an instance to call out to First Nations students to “take their place” in higher education and beyond. I interpreted Maracle’s call as a powerful insistence, and while it did not...
address my whiteness, I understood this to be an imperative of disabled people as well.

Michalko was the last panelist and built on Maracle’s (2009) call, contextualizing it
within disability, questioning: “What if your place is always already occupied with a

cultural imagination of disability?”

Michalko’s questioning of the task of “taking one’s place” arose from Linda
Alcoff’s work presented in her essay ‘Toward a Phenomenology of Racial Embodiment’
(1999). At the end of this essay, Alcoff shares a story of her past, which clearly describes
the political weight of her cultural expectation, informed by the social construction of her
racial(ized) identity. She tells of her first serious relationship, which was with a white
man (1999, p. 281). She interpreted their encounters to be “dominated by a powerful
emotional and intellectual connection” (1999, p. 281). Alcoff describes feeling
“humiliated” when discovering that her partner has “pursued [her] because [she] was
Latina (1999, p. 281). She tried to imagine how he saw her by replaying her “gestures
and actions, reflecting back even on the clothes [she] wore” in an attempt to see herself as
occupying a position already occupied, incapable of mutual interaction” (1999, p. 281).
Alcott’s story of being identified as Latina by another who apprehended her demonstrates
that we never enter into an identity or an interaction without meeting a cultural
imagination of ourselves.
The trouble with identification

Imaginative expectations occupying the space of how disability means and what it means to be disabled vary from culture to culture, and from time to time. In my culture, and in my time, as a white child born into disability of working class, married, straight parents in rural Nova Scotia, Canada in the early 80s, I was born into the expectation that disability was located in “minds, bodies, senses and emotions”, with both the problem and the desire to seek “the best possible solution” located in the individual. We may sometimes, or all the time, experience our disabilities as problems and we may seek solutions, explanations, cures, and comforts to make our lives more sustainable and enjoyable. Problems demand we move from one paving block to the next, without tripping on the crack, without going back, and never dwelling in the in-between. But there is always more to the story of disability than is made of us by the imaginative expectation of us as “living problems”, for even with solutions we can still dwell in disability and the consciousness that disability is the skin that marks our being in the world, connecting us to the streets in very “sticky” ways.

I turn again to Michalko to think more about the moments of confrontation, during the process of coming into disability as an identity, at which experience meets its expectation. When Michalko describes his experience of coming into blindness in his book *The Difference That Disability Makes* (2002), he suggests that the events of being diagnosed with a disability as an explanation for a problem, and identifying as disabled do not necessarily occur in the same temporal moment. In other words, his words, his blindness became a “what” long before it became a “who” (2002, p. 116).
I have many stories of disability, sidewalk stories and others, tucked into my body that collectively bring sense to my being-in-the-world. These stories, like sidewalks themselves, vary from time to time and from place to place. Some of these stories, delivered from doctors, tell of the vague medical details of my CP and how I came to be disabled. Other stories, told by my grade-school teachers, construct me as kind of a genius as a way, to reconcile the perceived discrepancy between my disability as deficit and my noticeable productivity in the classroom. These details are also vague and they certainly do not explain why I had trouble with math and difficulty spelling. Others still, from friends and peers, describe me as undesirable because of my disability, desirable in spite of my disability, and (my favourite) desirable because of my disability. Together, these stories make up the narrative history of how disability became meaningful to me.

As Thomas King says: “There is a part of me that will never move past these stories, a part of me that will be chained to these stories as long as I live” (2006, p. 9). My mom told me my first story of disability and in this storytelling, I was introduced to and as disability at once. My story of her story goes like this:

When I was five I went to a friend’s birthday party at the zoo. A group of girls were showing off their newly discovered skill of doing a cartwheel. As I began the dismount into this ellipse, I expected to complete it without trouble like the girls before me. Instead of gracefully spinning forward as was previously demonstrated by my friends, my wrists buckled under my weight, my legs refused to fly upwards, and I collapsed in a laughable heap on the grass in front of them. In this moment I understood my body as troubling but I did not have an idea of, and thusly did not have, a disability. Later that night, as my mom was helping me get ready for bed, I asked: “Mom, why can’t
I do a cartwheel?”, expecting she would be able to untangle the entanglement that was my experience of my embodiment. She responded with my first story of disability.

This story took me through the details of my birth, emphasizing the love and the care of the family and community into which I was born. Although she tenderly explained how special I was, my five-year-old body got hot and flushed, as the only story I heard was the story of my difference. I did not want my expectation of disability—troubling, problematic, alienating—to meet my lived experience. Although, as this thesis suggests, experience and expectancy live in an intertwined relationship with each other, young body understood these two characters as separate. As such, I felt that if I was careful not to rub up against disability through any mention of CP or to associate with other disabled people or disability organizations, I could be sure that my lived experience of disability and expectancy of it, remained estranged. This story of my birth of disability is the story of an introduction to and recognition of disability as an uninvited guest who was there to stay. Forever. On this day my disability materialized as a “what” not a “who” (Michalko, 2002, p. 116).

But this is not the end of the story. We have the opportunity to unsettle the meaning of the matter of the disabled body as it is currently and popularly manifested. Michalko (1999) draws from Arendt’s reminder that we are always for others to remind us that as embodiers of difference, we live in the midst of many conceptions of disability; a living collective representation which are not only our own. Stories of disability perpetuated in our culture through mass media, school curriculums, literary tropes; stories of disability blared through televisions sets and whispered between people on the streets, these stories do not always tell our story. However, as Michalko reminds us through his
living *in* blindness: “Blind people have opinions about blindness too” (1999, p. 186).

Clearly, it becomes, as demonstrated through *The Two-In-One* and similar texts\(^\text{12}\), that disabled people have stories of disabilities too. Stories which neither replace or are replaced by its others; rather, these stories exist in a muddlement. It is necessary for us to contribute to this tangled knot of imagination.

**Identifying and dwelling in the “Third Space”**

When we necessarily complicate understandings of disability by entering our stories into circulation, we enter into an unsteady territory—a “Third Space”. While stories that create and perpetuate our common sensical understandings of disability may not be congruent with how we know disability in our own lives, they are undoubtedly bound to us. Recall Fanon’s story presented in Chapter Two of being recognized by the epitaph “negro” called out at him on the street. This call stuck Fanon to imaginations of blackness bound up in savagery, slave trade and backwardness—stuck him to his ancestors, common cultural understanding of blackness and hate. Although these expectations of blackness did not describe Fanon’s daily experience of his embodiment, he did not escape these imaginations of blackness unscathed. For their stickiness, they bound him to the world with their meanings and penetrated his being. The versions of blackness stuck to Fanon by the epitaph “negro” affected how he moves—slowly, crawling along. Fanon’s experience did not cancel out others expectation for him. Rather,

between himself and another— in this “Third Space”— is where the meaning of his identity grew.

Bhabha tells us: “The pact of interpretation is never simply an act of communication…” (2007, p. 36). Rather, in all interpretations, we mobilize what Bhabha refers to as a “Third Space” (2007). This is the space between myself—the subject of enunciation—and another—the subject of proposition (2007). From these words, I understand that interpretation is always an act of translation, for we—the two parts of the interpretive interaction— can never overcome our positionality. This affects how we come to “know what we know”. I suggest from Bhabha’s words that we must dwell in this Third Space when we engage the activity of translation to make it materialize as a space of significance destroying “[the] mirror of representation in which cultural knowledge is customarily revealed as an interrogating, open, expanding code” (2007, p. 37). Once the “discursive conditions of enunciation” are revealed, Bhabha so hopefully suggests, “cultural signs can become translated and read anew” (2007, p. 37).

The exchange of my otherness for another’s sameness, such as it is, is always complicated. So too is interpretation a simple transference of meaning when expectations meet experiences. These two ideological terrains are bound to leak into one another; terrains which are sometimes oppositional. When someone witnesses me walking along the street— without a trip— they sometimes stop me to say, “You walk so well!” This, my act of walking well, has disrupted their imagination of disability. This interaction, in which my walking may first appear as ‘out of the ordinary’ by another’s expectation for what a ‘normal’ disabled walk looks like, informs their interpretation of my walk. Likewise, the normate’s interpretation of the way I move penetrates how I experience
walking. After such recognition spoken to me by another, I may walk on, proud that I am “walking well” and ashamed that I am the type of person onto whom it is appropriate to extend congratulations for doing the most ordinary of activities. Ashamed, also, for the pride I feel of the compliment. This exchange proves that the act of interpretation is never simply a translation of meaning, as Bhabha (2007) suggests. Rather, together in the Third Space— in the midst of others— the meaning of disability emerges tangled up with the positionality of the interpreters within the interaction. Here, the “cultural sign” of my disabled walk can be “read anew”.

Disabled identification

Disability pride can offer the hope and possibility of negotiating the troubling field between expectation and experience and create necessary contributions to the imagination of disability. However, my experience tells me that the task of “taking one’s place” by identifying as disabled with pride does not always follow a one-way, disappearing path, erasing the markings of shame. For pride does not always write over the stories of shame—stories of frustration, pain and humiliation— with new ones full of satisfaction with one’s way of being-in the world, as the popular imagination of the prideful person suggests. In troubling times, and ordinary times, walks remain shaky regardless of the rhymes we whisper.

I return now to where I began, in sidewalk stories, to discover what new stories the togetherness of the crip community, and the togetherness of pride and shame might release into the world—our world—for us. I tell these sidewalk stories — stories of alienation, discrimination, humiliation, and exclusion— not only for the satisfaction of
uttering them into a community— although this is satisfying for me, giddy with the newness of being in a community bounded by crippness. I tell them because when they are not released into the world they dwell in my body, festering in shame. In my stories and in their telling, pride and shame materialize together. I land into a community that does not alleviate the unbearable shame of being laughed at on a street corner on a nighttime walk. Street corners no different than a playground where sticky ‘retards’ were hurled at me recklessly and carelessly. Here, pride rubs shame, pride comforts shame.

Native storyteller Thomas King tells us: “The truth about stories is that that’s all we are” (2003, p. 2). These sidewalk stories make up some of my disability truths and I tell them so as to put us in touch with the rub of expectation and experience. Much like my night on the street corner cast under the veil of a street light, my disability enters the mix, again and again, ever-challenging the expectation carved out for me, and for us. Disability experience appears, through my body, and rubs its expectation. And in this togetherness—in the midst of conflict—is where disability, my disability, materializes as meaningful. Here, neither my embodied experience of disability and my scholarly imagination of it nor its expectation receives the last, definitive word of this story.

“If you step on a crack, you’ll break your mother’s back”. This is hardly true we know, but cracks can still be dangerous. We may only regard cracks, like disability, to avoid them, most of the time. We ignore cracks as we move quickly from one space to the next, swiftly moving from the problem of disability to its solution, from living with pride to living with shame. Cracks can also be wondrous, conjoining two parts separated. So I say, from the body of disability studies and the body of my own experience, let us resist the imperative to move swiftly from one paving stone to the next; let us trip up in
the cracks and dwell in the liminal spaces of disability. These trips may be painful and these in-between spaces may be uncomfortable, but we will find that we are not alone in these trips. We know things grow in the cracks, flowers and the like. Also, more stories of pride and shame, like the ones I have shared above of being-at-home, an always-shifting home on the streets. These are my stories, told through a with-itness of CP, of my experiences of a muddlement of pride and shame. They are not an indication of you and yours. My embodied experience wavers with joy, humour, pain, embarrassment, frustration, pride, and shame. While such bodily relations may be inconsistent with the constitution of a prideful being in its popular materialization, my intimate knowledges of my body’s ambiguities tell me a complete satisfaction with my embodiment is both unattainable and undesirable. Therefore the disability pride I am proposing remains with us in troubling times.

“The truth about stories is that that’s all we are” (King, 2007). These are my stories and they are my truths. It is true, in these stories and beyond, that my pride is “sticky” and my shame is “sticky” too. To deny such stickiness, which both propels me back to times when my disability spread my alienation and attaches me to the world today, would be to deny both the history that lives in my bones and also the experience of my corporeality. The meaning of disability, my disability, materializes in the in-between-ness of expectation and experience; between the expectancy for me—living disability— as a moving body out-of-control and my experience of coming into disability—again and for the first time—by crashing down to ground beholden to and embolden with a corporeal relation never steady, wavering between pride and shame—holding them together as my own. This is a call, or orientation, to a place where a pride can exists in togetherness with
shame rather than in its abandonment; a space necessary for the release of stories, like these, which do not constitute wavering bodies of pride as “excludable types” (Titchkosky, 2007, p. 149). Disability appears in the midst of others as an indication of our togetherness. This is also where, together, we can make a pride materialize that is accessible to us all, a windy disability pride that provokes and embraces the never-steady stories we tell.

The stories sidewalks articulate pride and shame as relations. These characters require the interrelation of each other as well as the connection between myself and others for their materialization. Pride needs shame as the taken-for-granted ground from which it rises up as an actor. And I know that shame needs pride too. Shame needs pride as a comfort to exist with it in tandem rather than in its abandonment. For through pride, we can pick ourselves up and move on from the sting of shame. Pride and shame also require the relation between others to materialize. Being in the world through disability through pride gives us the space, the time, the connection and ultimately the alterity to relate differently to the shameful situations that are provoke by and occur on sidewalks. Through pride, we can dwell in shameful situations that are bound to come to us and bind us to the world without shame. To demonstrate how we can dwell in shame with pride, thereby relating to it differently (in a way other than to be ashamed), I turn again… here is another sidewalk story:

I had tripped on a crack and fallen hard the other day. Hard enough to break bones in my right hand, which typically bears the brunt of my falls. With my right hand casted now, the doctor told me to be “extra careful” in my steps. Much like the recommendation to repeat rhymes to myself when learning to walk, this bit of “professional” advice did
little to steady my shaky gate. My right foot still drags a little in its step, sometimes tripping up in the cracks that bind together paving stones. We—myself and two friends—were walking together, each carrying another’s newly purchased second-hand finds. I was also holding my casted right hand with my left hand, nestling it close into my body. And then, I tripped and fell. Though my walk always holds the possibility of tripping, each trip comes to me as a surprise. This trip was no different; I was startled as I crashed down to the ground, painfully. This time, my body turned to protect my broken hand. My head hit the ground first and felt most of the impact. As I lay on the ground, men ran out of stores, pulling down my skirt that had flown up and my friends crouched down to me carefully, shooing the others away. In this fall, shame was undeniable, potentially unbearable. But, curiously, in the midst of shame, I was not ashamed. Shame, here, had no “stickiness”. My head needed care, I knew. I bumped it quite hard. I could not get up, just yet, moving swiftly from one paving block to the next. I needed to stay here, on the ground to dwell in the crack. Though I was not feeling particularly prideful in the moments that I lay on the sidewalk, through pride I could relate to this shameful situation differently—and take care.

Eventually, I did get up… and when I did I noticed that the cast that I had so carefully been carrying was now broken too. This was too much. Embarrassment, frustration, annoyance swelled. And again, I needed to take care. I began crying hard, right there on the sidewalk, without hiding my face or muffling my heavy sobs, in the “coolest” (Michalko, 2009) part of town. This was a shameful situation, to be sure—and I recognized it as such. I dwelled in this shame, but again I did not relate to it as an ashamed subject. Through pride, I was given the possibility to linger here in the shame,
and take care. This interaction of pride and shame demonstrates that these two bodily relations can exist in togetherness. For this wavering between pride and shame makes up the reality of my embodiment, I cannot not be with a pride that does not embrace shame. I need pride to find a way out of shame’s stickiness.
Chapter 5: Final Notes

This is a thesis written through, with and for sidewalks and the wavering with-itness their stories provoke. This thesis about pride and shame is written through, with and for the crip communities disability provokes. As explicated in Chapter One, my aim at the end of my thesis is not to arrive at a destination, full of conclusions; but, rather to dwell in the in-between space of never-getting there. As such, this end will return to the idea of being-at-home in difference in crip communities and build and sustain homes where we can talk shamefully about pride, proudly about shame, and dwell in all of the in-between spaces. As I said previously in Chapter One, the only thing I hope to arrive at here is the imperative to continue.

As explicated throughout this thesis, my experience of disability pride and shame is intimately bound up in my wide-reaching crip community. A version of disability that I could relate to first appeared in the words of Clare’s poem *Gaping, gawking, staring*, as I described in Chapter Three. I felt connected to Clare, and then the possibility that I could be bounded to community by the very ties that had previously cut me off from any sense of belonging. The straight-forward lesson telling me to turn away from shame to arrive at a pride, full of an unwavering satisfaction for my disabled way of being-in-the-world did not reach out and stick me to a community. No, I felt connected to a people through Clare’s articulation of a relatable shame. “Gawking, gaping, staring seeped into my bones, became the marrow” (Clare, 2003, p. 257). These words mirrored by experience of disability in the never-steady terrain of the street. Clare’s poem reached into my bones and blood, passed understandings of disability as medical problem, through imaginations
of impairment, around movements toward charity and self-help, reaching into to massage self-hatred. These had to be the most persistent words, for the knots they were wrestling with were years-deep. Clare’s poem was sticky and stuck me to crip community for the way he articulated a wavering bodily relation.

Crip communities of disabled people are places that are not necessarily connected to physical spaces. They are places where disabled people and our allies are bounded by our expectation that disabled people will show up. Such as they are, crip communities are peculiar places, for rather than being a body to reluctantly adjust to or hesitantly accommodate when they do show up, disabled bodies are always-already a desired presence. The desire for disabled bodies is alive, even when they have yet to show up. Crip communities do reach, but they cannot reach every body at every time. Jenny Morris writes that sometimes non-disabled people view groups of disabled people as ‘subject of pity, fascinated repulsion and, sometimes, fear…” (1991, p. 171). The assumption that the bind of disability marks a pintable connection can penetrate the minds, bodies, senses and emotions of disabled people as well—such as my young self—who resultantly stayed away from other disabled people, particularly those bound together by the common thread of disability. Crip communities desire hesitantly disabled bodies too. Disabled people who drag slowly along the journey of “getting there” will always have a home in crip communities.

Crip communities can mobilize for political action for disability rights or other causes; challenge physical and attitudinal barriers; they may harbor scholarship; sport; comedy; arts and theatre. Crip communities host the most incredible dances. In my crip community, I have found a deep sense of crip love where we develop scholarship, activist
projects and share and care together. Crip communities are allies too. We can forge alliances with other identities bounded by embodied difference that may not necessarily identify as disabled. For example, other bodies, trans bodies, “may need, want, or otherwise desire” (Titchkosky, 2009) gender-neutral washrooms. Disabled people can work together to have their washroom needs, wants, and desires materialize together.

In Chapter Two, I tell a sidewalk story in which the character of my walk of “getting there” was constituted by my destination landing in a crip community. In this story, my pride did not waver in an encounter that held the robust potential for shame to swell. We may not always be physically in our crip communities; we may never have met our crip comrades face-to-face. However, as Ahmed reminds: “Homes are not static places”. (2007, p. 9). Ahmed tells us: “homes can be ‘giddy’ places where things are not always held in place, and homes can move, as we do” (2007, p. 9). We can always be with our crip community— others in the midst of moving—others—our never restful process of “never-getting-there” can be waveringly steady insofar as we are always-already there, with our others.

No, we may not always be physically at home in crip communities either in the streets or upon our arrival. But crip communities reach. They reach past borders and seep through boundaries. The stories we share in these communities are strong enough to massage our knots of self-hatred and bind us to the world and together through new ways of being in, with and through disability. These communities— these new ways of being— are not accessible to us all if they do not constitute people whose bodily relations waver with pride and shame, or are currently situated at one point or another as excludable times. Crip communities reach and connect us to our others. Let us enact our
crip communities with care and love, to be open to the many and shifting corporealities of disabled embodiments. Here, we can release the call for other sidewalk stories so that shame is never wholly characteristic of the end of the story.
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