NEED TO BE ADORED

by

Lisa Elin Figge

A thesis submitted to the Department of Cultural Studies
In conformity with the requirements for the
Degree of Doctor of Philosophy

Queen’s University
Kingston, Ontario, Canada
May, 2016

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Abstract

Faced with a diagnosis of multiple sclerosis, I began with the objective of discovering methods for creating art that were still accessible to me. Along the way, I encountered others who had travelled this road before me. Their experiences led me to examine, not only my art, but also my political orientations, my love obligations and my transitioning self. In my varied art pieces, I conjure something from diverse sources and different worldviews, including contemporary feminist performance art and disability cultural theory.

My thesis is a project. I make things: puppets, videos and performances, which included the exhibition, Need to be Adored (2014), staged in the digital media lab of the Isabel Bader Centre for the Performing Arts in Kingston, Ontario, Canada. The exhibition introduced thirteen of my puppets and a thirty-two-minute looped video. Following the exhibition, I put the puppets away and spent two years reading. Finally, taking my inspiration from Carolyn Ellis’s The Autoethnographic I (Ellis 2004), I turned my processes into words. I wrote out my experiences. I created an alternative text of my identity from an able-bodied cis-identified woman into a disabled trans-feminist artist academic.

The writing required an uncomfortably intimate examination of my life. Nothing less than complete honesty would allow me to understand my new location. The resulting text is a lyrical and sometimes whimsical flow of consciousness that invites the reader to imagine what it might be like to engage in such a candid review of everything one holds close to one’s heart.

Contained within are all my identities. In this text I let some out. This is a story of unsettling. I am working on my art practices, creating a cast of characters from cloth. Puppets. El becomes the exulted main character of a fictional accounting. She uncovers her queer roots and begins to see that she is at the
centre of a very strange geography. Her desire to make film is revealed as she re-remembers her childhood through a disability lens.
Acknowledgements

Gary Kibbins, my supervisor, for a great wide-open canvas. Colleagues Mansoor Behnam, Jeff Barbeau, Donna-Lee Iffla, Adelle Pacificar, Jaspreet Bal, Jessie Barr, Lise-Melhorn Boe, Nevin Lochhead, Meaghan Frauts, Erin Sutherland, Karl Hardy, and, Trish Van Huesen, Jane Kirby, Tracy Guptill, Zaira Zarza, Meredith Dault, Hugh Box, and so many more for collaboration, cultural exchange and friendship.

All my other teachers, including Natalie Rewa, Daniel David Moses, Magda Lewis, Kathleen Sellars, Ted Rettig, and Clive Robertson. My daughter, Miranda Figge, my partner, Mark Figge, and my son, Derek Figge for filming and everything else. Susan Korba, and Alexandra Simpson for reading and commenting on early work. My sister, Paula Baker, and my mom Orma Baker for editing. Jane Tolmie, for introducing me to Carolyn Ellis and nudging me with an injection of confidence. Pia Banzhaf and Annie Milne for their puppets and their unflinching drive to tell their stories. Petra Kuppers for allowing me to tag along to all of her many disability cultural events and for the books. So many books.
# Table of Contents

Abstract .............................................................................................................................................. ii
Acknowledgements ........................................................................................................................... iv
List of Figures ..................................................................................................................................... viii
Chapter 1 Introduction ...................................................................................................................... 1
  1.1 Introduction ............................................................................................................................... 1
  1.2 Methodology ............................................................................................................................. 3
  1.3 Aftereffect ............................................................................................................................... 11
  1.4 Dear Friends and Family, both chosen and blood, ................................................................. 13
  1.5 February 17, 2016 .................................................................................................................. 15
Chapter 2 Disability Crip Politics ...................................................................................................... 16
  2.1 A Disability Rights Remembering ......................................................................................... 16
  2.2 Reaching Out .......................................................................................................................... 18
  2.3 Making Connections .............................................................................................................. 19
Chapter 3 Learning Disability ......................................................................................................... 20
  3.1 Experiencing Disability .......................................................................................................... 20
  3.2 Puppetmaker-Puppeteer ....................................................................................................... 22
  3.3 New Skills ............................................................................................................................ 23
  3.4 Need to be Adored .................................................................................................................. 25
  3.5 Remember to Think .............................................................................................................. 29
  3.6 A Culture of Disability .......................................................................................................... 30
  3.7 Inception ................................................................................................................................ 31
  3.8 Re-energized .......................................................................................................................... 32
  3.9 Maker-Me ................................................................................................................................ 34
  3.10 Narrative Prosthesis ............................................................................................................ 38
Chapter 4 Transitioning Away from the Desire for Ablebodiedness ................................................ 40
  4.1 Taking steps ............................................................................................................................ 40
  4.2 Pain ......................................................................................................................................... 40
  4.3 Shortly, Earlier, Later ............................................................................................................. 41
  4.4 Quitting ................................................................................................................................... 42
  4.5 New Resolve .......................................................................................................................... 43
Chapter 5 Immune Respect ............................................................................................................. 44
  5.1 My puppets don’t speak—they are mimes ............................................................................. 44
Chapter 9 Autoethnography Notes ........................................................................................................ 94
  9.1 Conjuring Identity ............................................................................................................................. 94
  9.2 My Puppets are not Me ...................................................................................................................... 95
  9.3 Note to Self ....................................................................................................................................... 97
Chapter 10 In Conclusion .......................................................................................................................... 98
Appendix A List of Puppets ........................................................................................................................ 111
Appendix B List of 11 Videos .................................................................................................................... 113
Appendix C An Incomplete List of the Artists Who Have Influenced Me ................................................. 114
Bibliography ............................................................................................................................................ 101
**List of Figures**

Figure 1: A character composite from my notebook. An author smokes a cigarette or joint. She says, “I'm telling you my story,” and looks straight out of the page. Two small figures in the foreground listen.......... 4

Figure 2: Experimenting with lighting a scene. ................................................................. 5

Figure 3: Little Green from the Exhibition Need to be Adored is reclining on a bed of three mattresses, which are on top of a round platform with wheels. Three fabric circles lay in the foreground............... 6

Figure 4: Jane does circus. I photographed her performing in downtown Kingston in 2014. .................. 7

Figure 5: My stage, viewed from a standing position near the middle-rear of the room. It is a runway with all you can imagine that might entail. The puppets strut and blow in the wind. Small, puppet-sized spotlights illuminate the runway. In the distance is my projection.......................... 8

Figure 6: Playing at being a performer with my orange ball. ................................................... 9

Figure 7: One of my stages. I hold the camera. I roll the tape. I look out my front window............... 10

Figure 8: Micro Architecture. I sit in Confederation Park AKA Flora McDonald Park, which is on Haudenosaunee and Anishinaabe peoples’ traditional territory. The park borders a cove where boats anchor off wooden boardwalks. A round, stone Quonset hut floats in the harbor, celebrated as a colonial outpost. El’s small blue mobility scooter is behind her, and she and her miniature green humanoid sit on a brown blanket spread on the grass. Their arms are outstretched, holding threads that animate the marionette who hovers over a puppet-sized bed. ............................................................... 11

Figure 9: My apartment and the couch on which I sleep and work. ............................................. 13

Figure 10: Me in bed with my headphones and pink blanket. .................................................... 14

Figure 11: Lying down for a break. My pink blanket and the sweater knit by my mother-in-law, Ruth. .. 15

Figure 12: Me in my purple nightgown holding a watercolor sketch. At the bottom, it says “Grief twists us into new shapes”.......................................................... 20

Figure 13: THIS DISTORTION IS SO BEAUTIFUL TO ME: An experiment in image making. .......... 21

Figure 14: A post-production image of me and some puppets on my back ramp.......................... 23

Figure 15: A white puppeteer’s hands hover over red and brown fabrics. Cut-out letters spell the message “how do you know you are alive.” ............................................................. 24

Figure 16: The puppet stage from the rear of the gallery. The camera condenses all the different puppets into a busy street or workbench................................................................. 26

Figure 17: A still from the animation Fingernail Moon. The image is upside-down because that is how I work. My camera hangs upside-down over the kitchen table. I flip the images in the editing process..... 27

Figure 18: Ellyfigbee dancing in the periwinkle................................................................. 28

Figure 19: One of my watercolour and India ink on paper drawings. ........................................... 29
Figure 20: Three puppets. Ellyfigbee, Little Green, and Chester hang from wooden dowel stands. ....... 33
Figure 21: Abstract of my scooter and walker draped in fabrics. .................................................... 34
Figure 22: An image from the thirty-two-minute looped video. Here the puppets are dancing together. .. 37
Figure 23: This shot of the puppets is blurred, giving a sense of the night street scene...................... 53
Figure 24: Winter is hard. ................................................................................................................... 59
Figure 25: Unfishable.......................................................................................................................... 61
Figure 26: Fingernail Moons.............................................................................................................. 73
Figure 27: In bed preparing puppets for a Skype performance, while living at the bed and breakfast in Ann Arbour in January of 2013.................................................................................. 77
Figure 28: Here I try to paint what it feels like to feel music. I use my own likeness. I photograph myself listening to music and then try to paint it while I feel music. ................................................................. 90
Figure 29 Performing at the University of Michigan’s student art gallery........................................... 92
Figure 30 Performing at the University of Michigan’s student art gallery......................................... 93
Figure 31: Bird ..................................................................................................................................... 99
Chapter 1

Introduction

1.1 Introduction

As Socrates said, the unexamined life is not worth living. Unorthodox as it may be for a dissertation, what follows is a one hundred page poem where I reflect on living with multiple sclerosis. Or maybe it’s not a one hundred page poem because it is full of shaky prose that often raise complicated points and abandon them nearly as quickly. Things are juxtaposed in fraught ways. The information is scattered in random, idiosyncratic, out of time sequences that do not figure out answers to the question how to live with disability or how to be an artist or even what an academic text should strive to be. In another way this text can be understood as a film script written through a disability lens. It is an experimental rendering.

Over the last six years I made art at a frantic pace: drawing, painting, sewing puppets, making video, doing performances. I produced so much that gathering these objects and events up to be viewed in one place, here, in this thesis document, is enough to send me fleeing off to some created un-urgent destination. That or I sit here in front of my screen, anxiety in my chest and shoulders, and can hardly stand the feeling of writing, of trying to sort out these disability experiences, because they are not yet tested by the words that might articulate their existence.

This is a part of my multiple sclerosis experience. There is no way to avoid experiencing all the feelings, so I’ve made room for them. It is these physical feelings and events that I want to restructure in my thoughts and dreams of right now and the near future. I do this to escape from a place of pain, to live with a newly forming disability identity and to express my politics.
There is an infrastructural demand that one move around in society in prescribed ways. I want to go faster but I can’t. I’m talking of the physicality of moving around in the world, coming up against imbedded notions of able-bodiedness: the expectation of “cultural ideals of normalcy and ideal form and function” (Kafer 2013 8). One example of normalcy that I notice is how people always turn around to face forward in elevators. I know this because I don’t turn around. I drive in and back out on a smallish mobility scooter. This is some kind of disability cultural knowledge and I incorporate the discomfort into a creative disabled refusal to turn and face front. It’s much more practical in a scooter to face the rear wall. I’m not happy about it. I do my best to make myself fit. For small elevators, I have to cantilever, setting myself and my scooter on an angle to the rear wall so the door will close.

This text is about unsettling. I am unsettling myself through a rigorous set of physical and mental art rituals and this thesis records the inner and outer phenomena that result. There are different forms of communication that I achieve in my art and this document records them for you. In the first year of my PhD, in 2010 to 2011, I took two undergrad drama courses and two cultural studies graduate courses. All four have influenced my methodology and resulted in my tunneling creatively into my cultural knowing.

As a result, I am learning about my colonial location as a very white settler fem living on Queen’s street in Kingston, Ontario. Very white settler, indeed, I live at the intersection of institutional power while I comb my memories. My methodology is crip-creative, which is a way to ruminate. I think as I make. I don’t necessarily write text. Sometimes my hands stitch puppets together. Sometimes, my hands puppet those stitched-together beings. Puppeting is a lively act. Puppeting is physical and psychic. Puppeting is spiritual communion. Multiple Sclerosis is my tool. My special proclivities are deployed in earnest towards remembering the memories that knit themselves with the present.
1.2 Methodology

My methodology is creative in the sense that Tara Rodgers describes. A professor of Women’s Studies and Digital Cultures and Creativity, who did her MA on the butterfly effect, she composes sound art using computer software like Netlogo and SuperCollider. Rodgers’ article “How Art and Research Inform One Another, or Choose Your Own Adventure” analyzes the work of thesis writing and art-making, together as a new kind of research practice (Rodgers 2015 155-161). I take my inspiration from her keywords: research, autobiography, sound, feminism, and technology. I too have been experimenting with sound. In fact, I’d like to do more of that after this dissertation. Rogers makes space for the artist/academic activities that inform the way academic research gets done—as visibly as possible. I’m trying to do this too.
Figure 1: A character composite from my notebook. An author smokes a cigarette or joint. She says, “I’m telling you my story,” and looks straight out of the page. Two small figures in the foreground listen.

Rodgers talks about her notebook works as a sort of incomplete map of the relationships, ideas, experiences, and projects that were never finished. She notices that the unfinished, partiality is a potential that could, at certain points encourage a creative turning. My notebooks brim with incomplete ideas and projects (Figure 1).

I stage my thesis exhibition Need to be Adored in the media room on the ground floor of the Isabel Bader Centre for the Performing Arts. This text is where I record some of the stories I’ve made with these puppets, on their stands, in the dark, holding gestural knowledge.
Figure 2: Experimenting with lighting a scene.

A puppet begins by stitching fabric into shapes, filling and weighting with more fabric, or seeds, with the odd orange peel and avocado pit. I cut into the fabric to sew it together in altered configurations. I am making shapes that touch each other and become movement. I cut small, irregular pieces of fabric, whip-stitching sides together with green thread. This is a puppet beginning. She begins.
Figure 3: Little Green from the Exhibition _Need to be Adored_ is reclining on a bed of three mattresses, which are on top of a round platform with wheels. Three fabric circles lay in the foreground.

Jane is also doing her work as an artist in cultural studies. We bump into each other on occasion, but disability constrains me from friendship, although that does not prevent me from admiring
her. Jane performs cloth work in the streets of Kingston with her whole bodymind. I love watching her. She is beautiful and strong (Figure 4).

Figure 4: Jane does circus. I photographed her performing in downtown Kingston in 2014.

I participated in an artist-theorists’ project with Jane and several other artists. Tracy’s workshops were for her Environmental Studies Masters theater project, a play on decolonizing, the environment, motherhood and being a daughter. Jane taught a class on aerial for one of the workshops in which I participated. She taught us in couples to do some pair lifts. It took three people to do lifts with me. Tracy asked each of us to lead a dance class but I contributed a puppet video instead. At the time, I was too physically drained to do anything more. Meredith Dault shot the video in my apartment at my kitchen table. It appears in the thirty-two-minute video collage at the end of the runway on which my exhibition is staged. The runway is also a collage of another time in my life when I was in the military (Figure 5).
Figure 5: My stage, viewed from a standing position near the middle-rear of the room. It is a runway with all you can imagine that might entail. The puppets strut and blow in the wind. Small, puppet-sized spotlights illuminate the runway. In the distance is my projection.

I’ve tried to interpret my art-making as a form of research that occurs when I make the artwork. Each attempt is something near to an autoethnographic expression. The puppets, performances, photos, and videos are not quite what Mary Louise Pratt calls an “instance of an autoethnographic text, by which I mean a text in which people undertake to describe themselves in ways that engage with representations others have made of them” (Pratt 1990 35). I guess this could be how I situate myself with disability-identity but also, I am a gendered she-artist and academic in communion with cyborg and cyber-feminists with hash tags like #saytheword and #blacklivesmatter. And that is not an identity that I am finding very easy to navigate. What is more, I don’t know what representations others have made of me.
But this is a form of storytelling that centers on the teller who is letting you know what it feels like to be. And perhaps by these turnings you will see me as other. In my work, I experience Rodgers’ concept of turning, as formative to and of my creative actions or creative processes (Rodgers 2012 155). My art practice is filled with attempted turnings. I’ve injected myself with voice, making potentials for other creative turnings. A puppet theatre can appear anywhere (Figure 7).

The focus is autoethnographic. My art practice is working to make a cyborg feminism. The hope is that my art is turning with what I think, through gesture and the movements of the puppets. These turnings arrive from desire. Letting desire turn me in this activity, I make art pieces towards applying Rodgers’ concept: turnings, as actions, that I might make in becoming a new aesthetic happening.
Figure 7: One of my stages. I hold the camera. I roll the tape. I look out my front window.

My idea is that individuals embody the potential to create an alternative political sphere through their embodied performativity. In Rodgers’ text, she situates the creative turning as something that takes place within the flows of bodies. I take her at her word and put my turnings, mine, into flows with puppet bodies and other humans (Rodgers 2014 155).
Figure 8: Micro Architecture. I sit in Confederation Park AKA Flora McDonald Park, which is on Haudenosaunee and Anishinaabe peoples’ traditional territory. The park borders a cove where boats anchor off wooden boardwalks. A round, stone Quonset hut floats in the harbor, celebrated as a colonial outpost. El’s small blue mobility scooter is behind her, and she and her miniature green humanoid sit on a brown blanket spread on the grass. Their arms are outstretched, holding threads that animate the marionette who hovers over a puppet-sized bed.

1.3 Aftereffect

My PhD work has led me towards a radical model of disability, a concept that embraces every person by reviving what Petra Kuppers calls “the bodymind” (Kuppers 2014 72). A. J. Withers shares a vision of radical access in Disability Politics and Theory, which describes a process for “looking at the essence of what disability and access mean for everyone” (Withers 2012 119). In
constructing my own model of radical disability, I think about how I have experienced a certain kind of disability segregation and strive to tell that story in my art.

Before I began my research, I would never have thought of these encounters in this manner. Now, I find my thoughts inundated with visions of disabled people around the world struggling to live. Segregation policies may seem a long way from where I am in a university town in Canada, but my impulse for solidarity with marginalized populations has been heightened by my explorations. One example that hits particularly close to home is the common immigration screening policy that prohibits disabled people from being admitted to countries like Canada, USA, and Australia. I am angry about this policy. Another example comes from my own experiences as a student and teacher. Needing an accessible classroom, I had to first visit a medical professional who authenticated my label for the university, a necessity for meeting my requirements despite the fact that my scooter is an obvious sign of my disability. Nevertheless, there seem to be far more barriers that arrive with each of my different physical setbacks and the disclosures I am forced to make. It is impossible to get my head around.

Despite my continued resistance to focusing my creative efforts around my disability, my artworks’ engagement with theory in the academic context constantly push me in this direction. Everywhere I look, everything I do, disability colours my world. It turns out that my artwork has been the conduit for my thinking and my understandings about how I fit in an ableist society in my disabled bodymind.

I’ve had to recognize how bodies are politicized through punitive, regulatory, surveillance imperatives, in order to privilege the flow of capital. Thus, part of my artworks is to resist the capitalization of my work.
Figure 9: My apartment and the couch on which I sleep and work.

This document is a record of my cultural studies creative emancipatory scrutinizing. I try to write about my experience of being scrutinized and regulated as a person with disability. And I claim disability as a political identity: a micro-political practice that begins in my art and is informed by deep-study as well as my disabled cultural location. In addition, I want to tie my aesthetic orientation towards an intersectional reaching and teaching with other thinkers, activists, and artists. I make work that strives to emancipate.

1.4 Dear Friends and Family, both chosen and blood,

I’m in the final stages of my PhD. Even as I continue to wrestle with the details of becoming a public intellectual, I recognize how overwhelming the whole idea is for me. I shrink away from the chatter my studies raise. I want to quit. It feels like it is killing me; both physically and mentally. My heart is breaking too, at what I have learned from my studies and the reality of my life.
In this text, I attend to this heartbreak. I am deeply invested in trying to communicate how it twists me. I am plumbing the limitations of my English and the magnitude of my fears. I am not a writer.

I view the university as an institution of state and colonial power. My puppets raise questions about my relationship with my educational institution. The university is susceptible to nation state demands on the work that intellectuals do, and that bothers me. While I have felt the elastic aspects of my penetration of the university’s controls, I have also experienced the restraints. Through it all, I am constantly wondering what I must do to become a responsible public intellectual.

Figure 10: Me in bed with my headphones and pink blanket.
This is a story about my life. Yesterday, it snowed a lot and I haven’t gone out since. It is too hard. But today is a fresh start. I lift myself off my bed and twist on my feet, letting myself down gently onto my scooter seat. I unplug and toss the charging cord to the side, drive to my front window and stand up, using the tiller of my scooter for support on one side and the high-chair stool from the 1970s for the other. I lift myself onto my legs, locking my weight onto my feet. I reach my left hand up to the window and place it flat to the glass to steady my swaying. With my other hand, I reach up and drag the left curtain aside to let the light of day into my apartment. As I do the other curtain, I ponder the difficulties of this little act. Looking out, I see the snow, knee-deep on my ramp.

The daylight illuminates the things that adorn my apartment; things I have chosen to bring with me. Art things, paintings, books and gifts given by people I care for. I am overwhelmed looking at them. Panic tightens my chest.

Figure 11: Lying down for a break. My pink blanket and the sweater knit by my mother-in-law, Ruth.
Chapter 2
Disability Crip Politics

2.1 A Disability Rights Remembering

I’m just reading through an account of what has happened in the USA since the ADA, (Americans with Disability Act) came into being in the 1990s. (ada.gov 2012). I think that disability shares a similar state in Canada, although there is no federal disability rights charter here. We don’t have the same history of disability rights activism as the Americans. I do recall some cross-Canada discussions of disability on CBC Radio, though.

For example, I remember Tracey Latimer’s murder trial. One of the highest profile discussions about disability took place in Canada in the mid-1990s when Robert Latimer gassed his twelve-year-old disabled daughter in the cab of his truck. He killed her, he said, because he could not bare her suffering anymore. I remember struggling with my sympathy for Tracey’s father. I wondered then what supports the medical system might or might not have offered. I could still walk back then. Now, I ask whether the identification of Tracy, as severely disabled, acted to systemically disregard her completeness as a person.

Krip Hop rap artist, disability author and theorist, Leroy Moore, mentions his childhood experiences with cerebral palsy in a Facebook post. As he ages, there are new medical interventions he needs. Moore talks about how the breaking of flesh and bones to reset them seems to be coming back into his life. I feel like I should get this right. Leroy Moore is a disabled African American rap artist. He tells us what we need to be paying attention to at the intersection of race, gender, and disability which he experiences. This is intersectional work we are doing.

What comes next?
When I hear these stories, I think about the cramping and pain I experience in my legs and feet. Tracy must have felt a great longing at not being able to communicate her experience. The dismissive descriptions paint her as a girl who functioned as a three-month-old baby. But what if she just didn’t have the right teachers to help her communicate? Think of Helen Keller whose radical politics are still so underrepresented when people raise her name in the context of disability (Davis 2003). And Tracey’s story also suggests the isolation was structural too. Robert confessed to acting on his own in order to protect his wife. He had no one to talk to about his decision. How tragic.

Another disability rights trial, Sue Rodrigues’ legal fight for assisted suicide, floats into my consciousness. This also happened before I had this more complex and nuanced understanding of how disability surrounds us as a legal and political location. The court turned her down, ruled against doctor-assisted suicide. But she did get an assisted suicide. The press said that she was too depressed from not being able to hug her son. She feared losing her independence and her staggering ideals of what motherhood should be (Northcott 2001 127). She got her assisted suicide even though the law didn’t recognize it.

About a year ago, Manitoba, the province where I was born, overturned the ruling. Doctor-assisted suicide is now legal and there is movement toward implementing the policies that would inform who gets this treatment. Neoliberalism. I want to scream. In it, they ask for a public response to the overturning of the law. They are adding dying to a physician’s services. They put out a request for feedback because “physician-assisted dying has been defined by the college as a physician giving the patient lethal medication he or she takes themselves, but also encompasses the physician giving the medication to the patient, sometimes referred to as physician-assisted suicide” (McIntyre 2016). Is Manitoba getting into the business of killing people with
pharmaceuticals? This, just as the United States is on the verge of fighting against the practice as a punishment. And those chemicals or drugs they will eventually use have been tested on prisoners with some pretty awful deaths.

So many things are wrong, how can I even take this on? I want to say that it is too scary to contemplate the nation state’s complicity in developing this as a new revenue stream. This, in the absence of a robust practice of connecting people with disabilities into everyday life. A public service! Argh. “They also filed for a sweeping publication ban that prohibits the disclosure of the patient's gender, age and specific condition. Lawyers representing numerous interests—including the medical team working with the patient, the attorney general and several local television stations—had standing at the hearing. None was opposed to the patient’s request” (McIntyre 2016). These are very deep structural deficiencies. More work needs doing to understand and refuse how the social infrastructure in Canada actively works against people who live with disability.

2.2 Reaching Out

I talked to my sister in September of 2015, about the themes I had chosen for the written portion of my PhD record. I explained that I was learning about disability in a big, broad way. I am examining Disability from as many perspectives as I can find by reading about and following people who are doing the hard work of studying disability cultures, which includes recording and keeping the public record of the forms of disability activism and rights achievements that have taken hold as well as those that have not. The more I read, the more I am struck by the enormity of the task of collecting and preserving people’s memories and stories for the purpose of shifting the attitudes of “normal” and “able” people. I ask myself how I can be a contributing voice in this discourse.
2.3 Making Connections

In this text, I draw in some of the things that occupy my thinking on an everyday basis. I feel the need to examine my deep engagement with how the Holocaust is tied to eugenics; that eugenics is tied to genetic research; that medical institutions have, in the past, often functioned as prisons for disabled and neuro-divergent people. This threat of incarceration informs my fears. Sometimes I worry that the institutions will send me on a path separate from the ablebodies.

Petra Kuppers, disability culture theorist and artist, talks about how the Holocaust Memorial is still inaccessible to wheelchair users despite active requests. (Kuppers 2014 64).

And there is more—much more—to think about here.

For example, concentration camps were institutional technologies for disposing of people identified as ‘genetically inferior’. People with disability were considered genetically inferior and that was enough reason to send them to the death camps. The idea that disability can be regulated is about enforcing unequal futures with disability at one of the ends. And. That. Sucks.
3.1 Experiencing Disability

I’ve been learning about what it means to experience disability for a while now and when I look in the mirror, I can’t really see what cracked me open. I cannot detect the damage where the pain is seeping in, but it is there. No doubt about it.

Figure 12: Me in my purple nightgown holding a watercolor sketch. At the bottom, it says “Grief twists us into new shapes”.

Let me draw in a little context. I identify as a disabled-trans-artist-theorist. Over the last six years, I made and organized eleven short scripts into puppet performances and videos (Appendix B). These works I classify as a cluster of audio-visual sculptural events. I spent my time sewing soft-
sculpture puppets and playing with them. My utopian desire is that puppets work like alternative theatre, which has the intention and potential to “transform and heal individuals and the world” (Leabhart 1989 121).

I performed with my puppet-beings using simple scripts. I also asked for help to film and document the existence of these artistic explorations. This document is a meditation on my performance art, disability culture location, and experimental video practice.

Figure 13: THIS DISTORTION IS SO BEAUTIFUL TO ME: An experiment in image making.

A writing practice takes time to arrive. The challenge is to write about the layers of organization held within my artwork. There are codes and they have been entered in the world as art. It is not
the whole picture, but from it I can trace a lineage through strength of my matriarchal structures. I have been trying to write from this space: the solidity of the light, the fragility of the figures, the winged. You can see the balance in these animation stills, in the shadows that flicker. These descriptions are a twinkle.

3.2 Puppetmaker-Puppeteer

For two years, I become a puppetmaker-puppeteer, an experience constrained by my multiple sclerosis (MS). For twenty-some years MS has altered my mind, limbs, and torso. I perform to tell part of that story. I engage my body’s synoptic resonances as material for my work. In this way, my work is a document of the physically aware slow-motion tantrum I am experiencing. I try to understand and develop my creative capacities and imagine my life as otherwise by testing myself and recording the development of my bodymind into art objects.

Since childhood, I have been a sewer. This embodied knowledge of the sewn stitch is how I got hooked into a path of making puppets as part of my PhD project-based thesis in Cultural Studies. What I am writing is an explanation of why I took to making these objects and performances in a formal academic space. The puppetry also arrived from my desire to make film. I want to tell audiovisual stories about my art practice. Often I can’t get out of bed. So I make work about that struggle. Art strategies.
Figure 14: A post-production image of me and some puppets on my back ramp.

3.3 New Skills

Now, I am forced to master new skills as I explore my relationship to theory. As an autoethnographer, I am intrigued by what Carolyn Ellis calls fictionalization: the fashioning into a literary story a fictionalization of academic research results (Ellis 2004 249). That is, I am trying to enact writing as a true-to-account fiction of my very personal experience of learning—and eventually knowing—a field of study. In all this work, I am asking myself what constitutes its knowability. That field of study is what the art-making begins to uncover. I am interested in
telling something hard and factual while I am gently performing, allowing myself to feel what it is like to be me. (Paula, my editor sister, just asked if I mean performing or pre-forming. And it’s a good question. In some ways I am pre-forming the story by performing it.)

I’m moving around a lot. Scooting around my apartment. Remembering, feeling, and trying to get comfortable. I’m out of bed, taking care of myself.

All this time making art, I feel there is something tearing me up inside. As Susan Sontag imagines: “The earliest experience of art must have been that it was incantatory, magical; art was an instrument of ritual” (Sontag 1966 3).

Figure 15: A white puppeteer’s hands hover over red and brown fabrics. Cut-out letters spell the message “how do you know you are alive.”
3.4 Need to be Adored

At the Exhibition, Need to be Adored, there are thirteen soft-sculpture puppets staged on a twenty-one-foot long, thigh-high, horizontal surface, at the centre of a rectangular room in the brand new Media Lab at the brand new Isabel Bader Centre for the Performing Arts. Each puppet hangs on a wooden and wire stand, gently blown in the wind of small black electric fans. Tiny lights cast large, barely moving puppet shadows around the room’s blank white walls. On the furthest wall, a thirty-two-minute looped video is projected. The projection flickers its collaged animation and real-time footage to tell stories composed from my disability experience and mobility scooter-self.
Figure 16: The puppet stage from the rear of the gallery. The camera condenses all the different puppets into a busy street or workbench.
For fourteen days in September and October, I sit in the darkened gallery, seeing the puppets, while watching my video work show me what I’ve made. From another distance, I observe my disembodied images, puppets and videos, swimmers, swimming across the fourth wall, performing. During the two weeks, I become alienated, compelled, and agitated as I watch these images and listen to the sounds of the video.

I am also enchanted by the one-minute animation I made in Ann Arbour, working with my roommate Adelle Pacificar, a young artist and teacher from the Philippines. We animate together at the kitchen table of our shared apartment (Figure 17).

Figure 17: A still from the animation Fingernail Moon. The image is upside-down because that is how I work. My camera hangs upside-down over the kitchen table. I flip the images in the editing process.

Another section that I fall in love with from the Need to be Adored exhibition video is the puppet dance between Ellyfigbee, a small blue calico puppet with four limbs, and a flared skirt who
pushes and pulls another puppet, Chester, made from red and white checkered gingham. I puppet these soft sculpture-beings, sitting on my knees on a circle of blue fun fur where they suddenly become animated lovers, arms dancing entangled, pushing and pulling on each other’s bodies in a dance-like love, a passionate, excruciating otherness.

Figure 18: Ellyfigbee dancing in the periwinkle.
3.5 Remember to Think

When I go to Montreal one weekend in December, 2015, I go to see some art. The brief time away from thesis writing makes looking up some of the image bank I have accumulated over the last four years slightly easier. The process of documenting and storing my work is an overwhelming undertaking. I keep track of my projects with image documentation. Much of this work sits inside computer files neither sorted nor easy to access. Some of it, like my paintings, still needs to be photographed.

![Figure 19: One of my watercolour and India ink on paper drawings.](image)

When I go to the gallery show in Montreal, I see lovely things, which reminds me to think. I can slow down my worry about being relevant.
3.6 A Culture of Disability

Disability culture writ large is engaging literary and artistic production of new images, towards making new kinships. Many of the disability theorists I read are working to show how disability continues to hide in language. In the survey, *Narrative Prosthesis: Disability and the Dependencies of Discourse*, David T Mitchel and Sharon L. Snyder show that the language of disability is everywhere in discourse and, essentially, always the object of transition (Mitchell 2000 53). For example, they read closely for how disability appears in a range of historical literary texts. In the story, *The Steadfast Tin Soldier*, the tin soldier has a missing leg. Mitchell and Snyder argue: “Disability marks a character as “unlike” the rest of a fiction’s cast, and once singled out, the character becomes a case of special interest who retains originality to the detriment of all the other characters” (Mitchell 2000 55-6). Disability is “Deviance [that] serves as the basis and common denominator of all narrative” (Mitchell 2000 55). Then traditionally, the disability is overcome for the story to end. This narrative prosthetic concept gathers together ways disability is inscribed with metaphorical powers.

Disability and crip cultural workers push to expose and re-situate these hidden practices. Crip is a linguistic appropriation of the word cripple by disabled people doing disability theory and disability cultural practices. Alison Kafer in, *Feminist Queer Crip* discusses crip theory, crip time, crip affiliations, crippling and crip politics (Kafer 2013 254). I’ve studied English-speaking disability scholars who are also artists, and activists who show me what it means to reclaim language using identification signifiers like crip. I am learning how to fight for access, to study, and to teach disability culture.

The concept of narrative prosthetics opens a space to read closely for how images of disability operate and disappear in stories. Mitchell and Snyder unpack how characters from Moby Dick to
Richard the III are disabled characters. Snyder and Mitchell’s concept of disability prosthetics redresses how “our stories come replete with images of disability and yet we lack a coherent methodology for recognizing and reckoning with that fact” (Mitchell 2000 163).

“Disability aesthetics prizes physical and mental difference as a significant value in itself” (Siebers 2010 19). It does not embrace an aesthetic taste that defines harmony, bodily integrity, and health as standards of beauty. Nor does it support the aversion to disability required by traditional conceptions of human or social perfection. Rather, it drives forward the appreciation of disability found throughout modern art by raising an objection to aesthetic standards and tastes that exclude people with disabilities” (Siebers2010 19-20). This work is political. Sebiers models different disability aesthetics towards thinking about the ranges of ‘humanness’ at the margins of its disappearance as it is practiced and experienced, altered and perceived in art. He studies the conceptual dynamics of modernity’s persistence, arguing that disability can be perceived in the incompleteness of the modern art objects. He concludes “disability checks out of the asylum, the sick house, and the hospital to take up residence in the art gallery, the museum, and the public square” (Siebers 2010 139).

I link his theory to my thinking. I imagine puppets might be prosthetic, and allow my ‘human’ desires to get out into the world, outside my body, without losing their connection to the felt thing from which they came, which might be a unique embodied subjectivity.

3.7 Inception

Natalie Rewa and Daniel David Moses partnered their different course syllabi over a year. They taught us how to tell our own stories, first through writing and then by performing for each other. This included memorization, recitation, writing, performing, watching and listening to what the
stories were telling us. At this point, I began to link my own perceptions to wider mythological and cultural texts.

“Puppetry” was a course offered in the drama department. Natalie Rewa introduced me to the possibility of this form of expression. She asked the students to see Billy Twinkle, puppeteer Ronnie Burkett’s story of a Saskatoon-born queer boyhood. The puppet show explored the world of puppetry conventions in North America and alluded to Burkett’s own journey as a queer puppeteer. The show played in an inaccessible theater in Toronto. I had to get help with the stairs because I had my walker. My seat was several steps down into the theater and I was anxious about getting in and out. There was no intermission. Once it started, you couldn’t go in and out. If you left, you wouldn’t get back in. This was announced and enforced by the people who seated you in the theatre.

The play was magical and awkward and extremely physical for Burkett. He ran all over the boat-like stage, puppeting dozens of different puppets on his own. As the play ended, I forgot that one of the puppets was a puppet. In my mind, I saw a real queer boy and the puppeteer was in full view. Powerful. This memory mixes itself into me.

3.8 Re-energized

I’ve just arrived back from Montreal. I’m in my apartment writing. I feel energy and excitement. I haven’t worried about my thesis for two days. And I should be worried. I have a very tight schedule from now until May, when I will defend. I just wanted to say I’m back in my apartment typing new thoughts about my work.
Jane asked me to get images to put into the text and I’ve been looking at the amount of work I have collected and it is quite astonishing. I made puppets but I also made several animations, and tons of experimental disability video, as well as documenting several short puppet performances. There is also a staggering number of gouache and India ink paintings on paper that fill up all the surfaces in my apartment.

I’m excited to see or be reminded of these accomplishments. It’s quite the archive. Although I don’t quite know how to think about it except to say I’m making myself into an art project and then autoethnographizing it. Well, it might be something compulsive.

Figure 20: Three puppets. Ellyfigbee, Little Green, and Chester hang from wooden dowel stands.
3.9 Maker-Me

Each of my images is an act of disability composition. In Figure 21, you see a colourful abstract of my scooter and walker draped in fabrics. I think of this image as part of my disability aesthetic where I work with line, curve, and colour, to make my disability flow from site to site. These cloths have a physical relationship to me. In everything I do, maker-me is staging a very intimate expression of myself, though the process of understanding my puppets and their images has been confusing.

Figure 21: Abstract of my scooter and walker draped in fabrics.

My complexly and newly acquired identity turns through my unconscious, able-bodied, cis-gendered identity. This work happens in bursts, including this process of writing things down,
which I am still figuring out. This is a way of life. I never want to tell anyone how to live or make art but this is my journey. I have come up against ableism.

My experience with puppets showed me how to realize some spark of their own agency, which is separate from mine, the puppeteer. Mysterious. I think this is what plays at the edges of endurance and psychic understanding. The idea that the puppeteer controls everything is wrong. Puppeteers are vulnerable to the puppet’s material agency. A puppet’s structural and material qualities—fabric, thread, stuffing—imbue their interdependent characteristics like sinew, holding together bone and muscle, and stiffness, outlining their centers of gravity, their metaphorical character bonded with their physicality, which is vulnerable to and dependent on the manipulations of the puppeteer. They are joined in my performances with my physical difference. And I made the puppets. So these vulnerabilities get expressed.

Theoretically, I am influenced by reading about disability as a socially constructed condition with which art can concern itself. “Beside comprises a wide range of desiring, identifying, representing, repelling, paralleling, differentiating, rivaling, leaning, twisting, mimicking, withdrawing, attracting, aggressing, warping, and other relations” (Sedgwick 2003 8). I propose that my writing and art-making complement each other through the concept of “beside”. Later, Sedgwick talks about her sister, Judith Scott, who has Down syndrome (Sedgwick 2003 22). Institutionalized young, she later became a conceptual artist after being rescued by her sister. Judith wrapped things. She knotted a shopping cart into one of her sculptures. If Eve’s sister, with Down syndrome expressed her agency by wrapping things in string, how do I express mine?

The death of the puppet world, as a real location of understanding what it is to be human, is a tragedy of the modern world. Prior to the 17th century, puppets were called motions and had the
power-of-agency to charge the world with meaning (Nelson 2001 49). Cool. Great. I like that idea.

Now what? I want to think about all this jarring information. Neil Evernden writes about the conceptual state of some grave concept of man that is responsible for all this mess. When he says “around the time of the Renaissance, man became an individual” (Evernden 1993 85), all I can think is, who is this man? Evernden goes on to argue, “This shift in perception [to individuality] fundamentally changed his position to the world from one who looks out from inside the world, as the Medieval man did, to one who looks out onto the world as modern man perceives” (Evernden 2003 85). So, I make a leap and decide to take from this the idea that the world is inside me and I look out of it. I will be medieval man if I can. I’ve been working on my inner life.

A close reading of my puppet agency might help. This is a complicated moment for me because I am a product of my times, and the idea that puppets have their own agency sounds odd at first. To believe puppets have their own agency and performative intuition does not fit within academic language, which arguably has a limited ability to capture the nature of magic. Rationality and enlightenment contribute to the reduction of the puppet world. Nevertheless, I decide to see what the puppets do and disability becomes etched into my political and artistic identity.

Even though the puppet world is lost, puppets still hold the potential and power to become communicators. What I try to explain is how my puppet performances open new space. When I perform, I feel the openings, and they scare me. Once I find myself in these new open spacetimes, I panic and have to shut down. So even as the puppets open a spacetime of inter-subjectivity by the performances we give, it feels too big. This is me accessing the way things feel. The puppets do this by allowing me to export what is felt inside my body, into puppet bodies. Their existence momentarily performs how my feelings feel.
Figure 22: An image from the thirty-two-minute looped video. Here the puppets are dancing together.

Or at least the possibility that this can happen is there, primarily because I allowed myself to feel them in the act of puppeting. Puppets offered an opportunity to play within the practices of inner-subjectivity, communication, and becoming. Playing with puppets the way I do in academic situations has let other ideas into the room by softening things to make new experience, agency, feeling, and connection. We express small gestures of connection. I propose the puppets offer addenda to the structure of the felt things—where pain and pleasure are constituted. I think puppets do this because they come from another time and are out of step with this world, which is too able.
3.10 Narrative Prosthesis

I started reading disability texts after I began making the puppets. Mitchell and Snyder’s *Narrative Prosthesis Disability and the Dependencies of Discourse* seduced me (Mitchell 2000). Narrative prosthesis is their disability metaphor, or more importantly, their conceptual tool, which offers to gather in a place all the many ways that disability imagery can be seen to move narratives forward. Mitchell and Snyder focus on the novel. Narrative prosthesis is concerned with unrecognized and unexamined ablest speech patterns, which can appear in just about any form and hurt people living with disability. They argue that disability is read as the force of the narrative’s movement, but it is masked.

Disability is often not really about disability experiences, but about reinforcing ablest norms by making disability disappear. For example, even if a character has a fiberglass leg, or PTSD, the most modern of disability signifiers, the story is often about something other than these disability experiences. And that reduction signals ablest practices of writing and reading. But now, with the concept of disability prosthetic, new readings of post-modernists writers like James Joyce could be done. It’s also a super-individualistic form of writing. Well, I’m not sure, but food for thought.

All this to say, I was taken in by the idea of prosthesis and began the arc of my puppet-making as a kind of creative prosthesis that could aid me in negotiating my art-soaked disabled life, much in the way I might view my scooter as prosthetic for my legs.

Actually, my scooter is my legs. The occupational therapist told me to think of my scooter as my legs. It is still weird because I also have my legs. Conceptually expanding what legs can be understood to be is the figurative work of disability culture. Disability culture exists to figure out these new grammars, which appear in praxis. I don’t walk with my legs. I roll with them.
Sunaura Taylor explains to Judith Butler in the film, *Examined Life*, how she first became politicized by reading a paper on disability (Taylor, A. Film 2009). My scooter ways are politicized. Like Sunaura, I have to make decisions about how I want to be seen when I am in public but I will always be seen as someone on a scooter and that is a different and difficult location.
Chapter 4

Transitioning Away from the Desire for Ablebodiedness.

4.1 Taking steps

These works, puppets, video performances, and the exhibition, are responses to the demands made on my body and others who experience disability, as we urgently explore how we are living at the intersections that make the quality of a disability experience. I translate the collective social ether in which I exist, into a potential-politics of my disability-cultural identity.

In one of the class conversations from Carolyn Ellis’s methodology novel about autoethnography, is an examination of academic methods (Ellis 2004 14). In it, students want to know how Carolyn, the Professor, negotiates her moral obligations towards the people in her life about whom she writes, as she writes her own deeply personal experiences. They want to know about how she deals with issues of participant consent that arise in her personal life as the writer-researcher. She incorporates these dilemmas as conversations within her writing. I found this helpful to consider.

4.2 Pain

Pain is a hard thing. I look at the clock and see it is 5:22 pm. A pain shoots through my body. It’s an emotional surge. My daughter left Kingston with her dad, at five, to return to her town on the other side of Toronto. I miss her, and the thought makes my throat tighten into the bottom of my bellybutton. I feel my eyes moisten and my face crumple. Sobs shake me and I begin to cry out loud.
Charting the experience with this narrative in mind, I sniff tears fallen halfway down my face. How much time and energy can I afford to give this eruption of emotion? It’s so painful; I am scared of its depth, of feeling any more than this. As I write, the spasms in my throat intensify and I moan my pain in long, closed-mouth whimpers that subside, but threaten deeper wounds not yet expressed or felt. I must keep on. This is my commitment to myself. It feels as if I might be dying of this heartbreak.

I’m listening to SoundCloud on my headphones and I lift the cup off my right ear to listen to my soul escaping my body. The moans intensify and then I practice breathing. I breathe out with my lips puckered into a kiss to slow the hyper-breathing that threatens to overcome me. Swallow back the dryness. Breathe back into your nose. Feel the energy course deep into your organs. Is this autoethnography? I ask. Allowing these glimpses into the battlegrounds of my writing life? Spending all this attention on the experience affects my ability to eat. I put the computer down, turn off SoundCloud, and go to vote in the advanced pole in the Canadian Federal election for a change of intensity. To vote for a change of history.

4.3 Shortly, Earlier, Later …

Ugh, I’m tired and ready for a nap before I have even started. I’m sitting in my bed, my left leg and foot cramping, repetitive and distracting, in a way that makes me want to moan and move. Get up and do what? Stretch? Breathe? Do a bit of meditation? WHAT COULD CALM THIS BODY DOWN? Whoa, that escalated fast. That is a lot to deal with. Take a breath. Take your time.

Again, I settle into my space. Shift into my office chair and put my feet up on my scooter seat. Turn my computer on, and fuss around as I wait for it to connect to the internet. It doesn’t. I push
myself to open Carolyn Ellis’s novel, and turn to the chapter on writing therapeutically, vulnerably, evocatively (Ellis 2004 135). The computer connects.

Reading Ellis’s text, I feel I am learning how to understand and respond to my work as a potential therapeutic practice. I read greedily, wanting to see how I’ve already been doing the work of writing therapeutically as I did yesterday, writing about my feelings of love for my daughter, breaching the surface of my unfishable insides. And writing through feelings I carry around, deep in the tissues that unify my body as distinct from others.

4.4 Quitting.

By September of 2015, my pain receptors are so keenly keyed up that I am feeling too ill to write anything more. I have gone as far as possible with my current attention and focus on my body and its inner and outer phenomena. I look up the procedure for dropping out of my dissertation and meet with my supervisor, Gary. I want to tell him I resign from the university levels, from grad school, because I am scared it is making me sick. Sick in a way that has a familiarity; sick in the way I feel when I am afraid my body is changing again. I recognize feelings of stress where I overdo things. And lose.

However, inertia carries me along.

Of course I put myself in the position of actively resisting the format of a conventional thesis. Of course I find myself here. To officially leave grad school requires a single-page fill-in-the-blank add/drop form, a pdf asking for name, student number, and signatures of student and supervisor.
I lose my resolve the minute my supervisor reminds me I am nearly finished. I have done most of the work already. Something I didn’t believe. I believe the hardest is to come. But hey, maybe that’s just who I am. Always seeing the weight of things. Curse of the Libra. I jam a tack through the drop-out pdf onto my bulletin board, and plan to ask the acting head of Queen’s Cultural Studies program, Professor Jane Tolmie for an accommodation.

I make an appointment to meet with Jane to see how I might chart an alternative thesis form. My sense is that what I produced over the last winter, February to September of 2015, is its own mark of my work. My focused attention had produced it and I thought it must have some value as it is. Perhaps I am committed to a kind of holistic form, like a child of the 1970s.

4.5 New Resolve

Nevertheless, I can see room for a more rigorous figuring out of my own crip-politics. The language and life of which will go along with my MS fatigue, pain, sensation spectrums, and depression. And of course, it will allow the mythical qualities of my cultural studies disability culture artist academic practice to emerge.
Chapter 5

Immune Respect

5.1 My puppets don’t speak—they are mimes.

The text, Modern and Post-Modern Mime, discusses mime and performance in theatre of mime from 1950 to 1990, exploring different movements of this kind of embodied poetical exploration, like performers of contemporary pantomime theatre who taught the next generation how to be mimes, including Grotowski, Mnouchkine, and Peter Brook (Leabhart 1989 1). These are names I am unfamiliar with except for modern mime Marcel Marceau who learned from them, working in the medium of movement. This history of 20th century mime, Brenda Gill argues, is a response of sublimated anguish, to lost speech expressed with percussive sounds and “post-verbal warbles and chortles,” which are an aesthetic choice (Leabhart 1989 2). This aesthetic is informed, Leabhart imagines, by the separation of performance from sound as an imposition dictated by the sovereign, the actual king of the land, but also places the study of movement in the sciences, which had a powerful influence on mime, theatre and dance in that time. The book introduces mime and pantomime’s development as experimental, part of the French surrealist movement, and corporeal work (Leabhart 1989 41). And these post–modern mimes used titles to help audiences understand their work (Leabhart 1989 49).

I struggle, like mime, Etienne Decroux, whose unique movement performance expresses, through tensions in the body, abstract concepts of communication. “Decroux’s in his artistic struggle, is like the corporeal mine who struggles first with his own thought; then with matter—the inertia of his own body, wood, rock, earth …” (Leabhart 1989 53). His life’s work was to give movements primacy of their own, independent of words (Leabhart 1989 59). Mime is done with the body, the torso (Leabhart 1989 63).
A contemporary example of post-modern puppetry is Bread and Puppet Theatre, a post-modernist theatre ensemble that “uses an eclectic array of techniques (puppetry, theatre, dance, storytelling) to treat complex subjects which are themselves about synthesis and juxtaposition of seemingly disparate topics” (Leabhart 1989 116). “The goal of alternative theatre has been to play for and with oppressed peoples” (Leabhart 1989 120). Decroux worked to overcome the rigid professionalization of the theatre, and his ideas still permeate alternative theatre, thought to have the intention and potential to “transform and heal individuals and the world” (Leabhart 1989 121). Leabhart goes on to posit: “… post-modern performance [as] the work of transformation, physical, domestic and planetary… a metaphor for some other shaping, that cannot be seen, but which can be hinted at through the visible” (Leabhart 1989 146). These performance stories surround me as I play my cosmetology.

5.2 El

In our September 2015 meeting, El, the main character in this thesis text, expresses deep pain over writing about many complicated loving relationships. She moves in a complex stew of identities. In her art, for many years, she has passed as able; hiding in bathrooms, waiting for her legs to work after walking to her kids’ school where she volunteers. Disability experiences are the vulnerability she anticipates. She gets help with meal-making, bathing, dressing, housework, art-making, editing, filming, and getting out of the house. El deals with interdependent feelings. Always.

5.3 El Remembers

Jane asked, “Want to write about family?” The question scares her. El worries family relationships are too full of unexpressed confidences. She is terrified she will find out she is imagining everything. Every part of her body feels on fire. Her stomach clenches acid that spreads up into her throat. Her arms and legs get heavier. Her eyes sting to close. Her back and
neck squeeze a little tighter. Her heart hurts. These emotional coursings move through her arms, legs, and torso at the thought of recording such raw kinships. As she writes these stories, El uncovers herself. Radicalization.

As I pencil down some notes, mapping this section on Pain, I find myself misremembering and conflating two of the characters from Robert McRuer’s book *Crip Theory: Cultural Signs of Queerness and Disability* (McRuer 2006). I first encountered McRuer’s crip theory early in 2012. I became radicalized, reading about Gary Fisher and Bob Flanagan. I was introduced to brand new ideas about the queer-disabled, black and trans-gendered politicized body, which raised unexamined feelings about my white, cis-gender privilege. The closer I came to knowing about my gender and sexual identities, the further my ability to communicate seemed to recede. This is an able-bodied me trying to hold onto itself in a disabling culture.

Anyway, I’d read about both people, but only remembered Gary Fisher’s name and that Bob Flanagan was the poster child for cystic fibrosis and an out, sadomasochist performance artist. Holy Church Lady, I had to giggle. Since then, I’ve seen other artists with disabilities critique The Jerry Lewis MDA Labor Day Telethon’s use and objectification of children. I’m thinking of Carrie Sandhahl’s video work which includes a cutting video mocking her experience as the character Teeny Weenie Teensy Itsy Bitsy Tina. A poster-kid’s kickass fuck-you to their oppressors.

To begin to understand how pervasive disabling narratives run through cultural norms, see Mary Johnson’s *Make Them Go Away: Clint Eastwood, Christopher Reeve and the Case Against Disability Rights* (130-250). In it, she debunks, exposes, and fights to shut down the telethon that-degraded disabled children with the imagery of no present and no future. I recall watching the
Jerry Lewis Telethon as a sixth-grader and being taken in by the demands of the people taking pledges. I wanted to send money. Disability isn’t an individual child’s burden to be overcome.

I have community support. I have one hour of help, five days a week. I live alone. I have my own space. I am acquainted with the badassness of disability and crip writers and artists, and their pain. Rereading Crip Theory’s chapter “Noncompliance: The Transformation, Gary Fisher, and the Limits of Rehabilitation” (McRuer 2006 103), I am marginally more fluent in my grasp of non-compliance as a lifestyle and rhetorical practice. McRuer does a rigorous pastiche, a theoretical unpacking of the weedy, turbulent ground of rehabilitation ideology and the counterhegemonic work done by queer crips Gary Fisher and Eve Sedgwick in Fisher’s posthumously edited and published Gary in Your Pocket (Fisher 1996).

From what I can see, crip critiques embody colonial relationships, and mess with them. Jocelyn Woods is another example of a performance artist who identifies as crip. On one of her websites, she identifies as Jocelyn Woods, “an actress, poet, mystic, playwright and model with a severe (rare and atypical) neuromuscular disease” (Woods 2015). Unable to stand or walk, Jocelyn has been semi-bedridden for eleven years, having experienced many excruciating illnesses on the threshold where life and death kiss, only to emerge with highly refined revelations and the passion to transmit them to her global brothers and sisters” (Woods 2015).

Jocelyn Woods is another example of a performance artist who identifies as crip (Woods 2015). I first encountered her work on Facebook. She blurred all kinds of lines by making her art persona and her disability into a spiritual sexual fantasy. Initially, I was upset by her work and could not understand it. It feels very complicated. Dressing as mythological and religious characters, she invites photographers to come work with her on these pieces of art, which are often filmed in her
bed. The images convey a sort of psychic and angelic demeanor, perhaps even prophesizing her own movement between life and death. She is mining her disability experience in her art practice.

Later, I heard her podcast where she talked about her crip politics. I heard how complex her claiming of a crip identity is and that gave me a new insight into her work. As a result of this new understanding, I had to go and re-examine her images and re-think what she was doing. So, I’m not exactly sure of the theoretical lands that I need to reinforce in order to align my work with my puppets, my art, and my rhetorical practice as a kind of criping. I am still working out a language for it.

5.4 Rehabilitation Ideology

McRuer argues that the work Fisher does is to respond to how the colonial system degrades him as if he is in a non-consensual relationship with the medical community (McRuer 2006 103). Fisher and McRuer raise these questions about the realities that are masked in rehabilitation as an ideology. Rehabilitation ideology means that on an unspoken level, everyone understands how the doctor-patient relationship is supposed to work and therefore, how one must perform in medically mediated spaces like hospitals and doctors’ offices. I wonder at this rehabilitation ideology.

In my understanding, rehabilitation ideology has a thread of degradation required of the ‘damaged-sick’ body that obliges acts of compliance. It is something like knowing your place. Something like playing your part at some critical point of suddenly knowing about your instability and vulnerability, which raises questions about needing the help. And then there are all the questions about knowing how to get the help you need while also facing questions like, what are the costs of compliance? How do you play along as a willing and flexible fixable subject in a system that is rigged against you?
I find myself thinking, will I survive being denied what I need? Will I end up paying for it? What is my life worth if I refuse medical interventions? It’s in my medical history. I usually do not follow doctor’s orders. My relationship with my doctors is super complex. My relationship with health maintenance is super complex. I needed three degrees to think about the medical decision I made twenty years ago.

In *Bob Flanagan: Pain Journal*, composed during the final year-and-a-half of his life, Flanagan repeatedly rails against the art world (McRuer 2006 194). McRuer notes that “Flanagan imagined crip existence as atypical and reached for something beyond the current order” (McRuer 2006 94). His performance art raises different questions about the art world that artists with disabilities must navigate. Interesting, because I feel alienated from the art world, of which I am a part, because I use a scooter. The spaces are harder, more filled with pain that I never shake. Even now that Modern Fuel, the artist-run gallery in Kingston, Ontario is accessible, I still have a different relationship with it than I did in the past. Its old location was on the second floor of the old gasworks building on Queen Street. Now it is in a new community arts centre called the TETT. So, what’s that addition to my consciousness I wonder? Why not get over it? Why do these feelings of alienation repeat and hold on?

Crippin’ is scat. A logic that disrupts, insisting on making adjustments to accommodate movement in different ways, away from neoliberal ideologies, away from where it is countable.

When I am in the hospital, they won’t give me a wheelchair. I ask but it never arrives. I have to ring for a nurse to come take me out of my bed and onto a commode every time I have to pee, shower, or shit. And there are little ropes to pull when you are done and ready to be wheeled back to bed. You can’t really do much about it if you can’t walk the fifteen or so feet to the bathroom, which I share with four other women. Dignity shifts inside and out. Nobody wants to bring it up.
It feels degrading, selfish, ungrateful. I feel cold inside and out. I split into two. One of me hides.

The other pays close attention. Listens to my body. I eat. I sleep. I eavesdrop on everyone. I contribute this witnessing. We see each other in flashes. Curiosity flickers and whispers out. We are too weary with our own exhaustions.

This is one March entry from Flanagan’s Pain Journal:

“Up again at 3 am what gives? Sound asleep since 11. Up at 3, no matter what. Thought I’d escape writing tonight, but found myself mulling over why it is I don’t like pain anymore. I have this performance to do on April 1st, and I’m shying away from doing or having SM stuff done to me because pain and the thought of pain mostly just irritates and annoys me rather than turns me on. But I miss my masochistic self. I hate this person I’ve become. And what about my reputation? Everything I say to people is all a lie, or at least two years too late - what the . . . ? It’s not 3 am. It’s only 1:30. Can’t even tell time. I knew it had to be earlier because the TV shows were all wrong.”

Flanagan’s writing raises for me the form that my own stream of consciousness writing is taking: the way I work when I try to record the minutiae of my noisy body phenomena. How I am unsure. Flanagan is writing in bed, composing from his squirming centre. Experimenting. Writing through frustration, anger, and fear. My performance, Mobility in Four Parts for the Cultural Studies Grad Student Conference “Undisciplined,” 2012, deals with exactly these same questions.

In Beauty is a Verb, “Keeping the Knives Sharp,” Jim Ferris opens with a quick paragraph about Lucia Perillo who, he notes, writes about her multiple sclerosis without mentioning it (Bartlett 2011 89). It hit me. I’m reading for my experiences of MS in her award winning poetry book, Inseminating the Elephant (Perillo 2009). I don’t want to know! Each time I read writing by people with MS, I hear things that scare me beyond my capacity to incorporate into my consciousness. It is not catharsis but a warning.
Fisher, and Flanagan, in McRuer’s hands, begin to give me a language for dismantling my white-cis-heterosexual conformity, which means to me the way I have felt obliged to perform and to resist that performance of ‘my gender’, femaleness, and ‘female’ roles I model: daughter, mom, and wife, the same three. I’ve misunderstood so much. Mothers pushing as fully as they could manage. Absence.

In The Autoethnographic I, professor of autoethnography, Carolyn Ellis, who I mentioned earlier and who I will mention again, explores, together with her students, a complex writing about intimate others. Family members become part of the autoethnography because they are in the author researcher’s life, not because they want their intimate life exposed in the service of writing vulnerably about life (Ellis 2004 151-4). Once you find yourself really close up and in this situation, anxieties start. In the novel’s classroom, Caroline discusses ways of incorporating and troubling the writer’s power to speak while family members have less control, and choice. So I’m kind of figuring out what that means in my writing. How I am getting where. How do I write an autoethnography true to my theory, art, and crip life? I think crips are pain artists. Have to be. Maybe it doesn’t last forever.

In my first meeting with Jane, I expressed this conflict that I am having in writing my story. I hear her say, “That is something you will figure out. You may at some point write about that experience of leaving your family home, which is still very painful for you and for your ex-partner and probably, even though you don’t want to deal with it, your children, too. Even though they seem resilient and supportive to the degree that they can be.” In my position as a researcher doing work about living with MS, I tell this story of personal, familial, social, infrastructural, and institutional pain to unpack its strangeness and power over life.
I write obliquely to and about people in my life, those intimate personal, private, and pivotal others who sharpen my connections to life and story. As I do this, I also stumble, falling, giving in, bracing. This writing is how I write therapeutically, vulnerably, and evocatively. These are acts of grief. The grief of taking so long to get to see myself and to gesture somewhere better, but also to try to find a way to not totally dislike who I have been. To treat myself now and again.

In the chapter called, “Living Autoethnography Life Informs Work Informs Life,” Ellis’s fictionalization practice discusses the reciprocity between living and research in a life engaged in theory (Ellis 2004 156-162). One of the grad students she teaches with, Leigh, comes in to Carolyn’s office forty-five-minutes before the class starts. They discuss a paper Carolyn wrote about caring for her mother. It was assigned as a course reading. Leigh tells Carolyn her thoughts about the paper and Carolyn is an active listener because, as she says in the narrative, “I always appreciate feedback on my stories, especially from someone who writes as well as Leigh” (Ellis 2004 163).

As I read about how Leigh engaged with the text, I begin to think of my relationships with my sister, daughter, and mother. I feel apprehensive and then I realize these are relationships I have been struggling with, too. What, as a disabled sister, mother, and daughter, I wonder, do I have to offer these women? What is so difficult about my relationships? And, I think suddenly, this is something I have been trying to understand in reading Luce Irigaray, a Belgian-born French feminist scholar who researches the difference that gendered language makes in gendering beings (Irigaray 2008 186). For her, there are, really and compellingly, two linguistic positions that children learn to occupy without being taught to do this: one male subject, the other female object. And Irigaray shows that learning about these linguistic conventions in school, beginning in kindergarten, empowers kids. Helps mitigate the harmful invisibility of gender codes in language. So yay. Add that to the research work that needs doing.
I’m sitting here on my scooter facing the curtained window, my laptop on my knees, with my feet down. I’m surprised. This writing has made me forget about the pain in my feet. But now that I am reminded, I better go move around a bit. Stretch.

Figure 23: This shot of the puppets is blurred, giving a sense of the night street scene.
Chapter 6

Symptoms

6.1 Fatigue

Expressing the specifics of my deep attention to my body, constantly monitoring it for symptoms of fatigue and marking that fatigue through drawing, sewing, and video experiments is as far as I can manage. I worry over that feeling of fatigue. Sometimes I imagine that my constant worry is becoming a mental and spiritual practice where mental equates to theory, while spiritual is the thing that arrives in the gaps we make for our souls. Disability has overshadowed everything else. So I’m always looking for ways to cope with how hard it is. One way is to eat regularly, because even this has been challenging. When I first moved into this apartment, I wasn’t sleeping at night and I was experiencing some devastating weekend-long episodes in bed where I would end up dehydrated and hungry and tortuously unable to get myself up to eat and drink. I felt pinned in bed and had to wait until I could be relieved of the weakness, to move again. I’ve been eating much better and I haven’t been pinned in bed for a while now. Looking back, I don’t think these were symptoms of fatigue so much as something more like depression. I wonder what the difference is. Both are symptoms of MS. Am I doing this wrong? Feels like I am being too internal.

6.2 Conjuring Identity

If I am transparent, how will I see you? Humph. Early in my scooter experience I started to feel othered. Hell, to be honest, I’d been anticipating the otherness quite instinctively and responding. I needed, craved and bristled at the kind of support being offered. And now five years in, I am still needing, craving and bristling around feeling uncomfortable in spaces because of my scooter. All the time! Over and over.
I’m in my consciousness journey into a disability culture worldview and realized recently enough how overwhelming and teleological an event being othered has been, really is, and continues to be. Even now this very moment, I am reminded of new solidarities in the ambiguities that disability produces and personal, solidarity fatigue. Or that might just be my mode. I get tired really easily. Just having this thought has made my eyes ache to close and the back of my neck cry out its need for tenderness. And I am jolted into my own heart’s pain. Feelings of being physical.

And not just for me either. Whoever you are, whatever you are doing, disability wakes you up whether you can stand it or not. I am telling you, it is better if I can figure out how to stand the hardest parts, and when they rise off my body, lick my wounds in solitude. I’ve been working on this and my hopes are all over the place. Disability theory comes out of a desire to struggle in practice with disability as a creative location. Resistive flows that open alters, where the overcoming supercrip doesn’t achieve superpowers. She lives.

I feel like I am having a chance to become new again.

Learning a new language.

Inventing new relationships.

Overcompensating by becoming a character is one way to cope with taking up a lot of physical space, which a scooter does. I recon (a military abbreviation for reconnaissance), with my own version of being present which has gotten way more difficult.
It’s a weird thing, but I find myself out on the streets with colourful scarves wrapped around the neck of my scooter. And I can admire this from my sitting position with my feet up on my scooter chair. But also, ugg! Like a series of rapid punches to my upper collarbone.

Yours in Disability,
El

I see from what’s above that I get lost in Disability Theory Land, which is really quite fluid but with new rules for engagement, caveats that expand modes of commitment to each other and fierce sharings of disabling practices and affordable globally accessible communication technologies and the practices that yield.

This Saturday, I attended a day-long symposium on Sex and Disability at Queens. Many things have aligned in this moment. And again I face the difficulty of writing about my personal experiences because there are people in my life. I am connecting myself for love. When do I disclose that I am a writer with disability and trans and poly? To whom does this matter? Why am I writing this here? I’m a studious crip. I’m interested in crip life. It is many different things.

The kids’ noise from across the street seeps into my living room with the sunshine. There are a lot of frilly dresses, purple rubber boots, and pink parkas. A pile of yellow leaves are packed up near the chain link fence that hems in the kids. The feeling of fall overcomes me. I can nearly remember the perfumed smell and heavy weight of raking cold, moldy, damp leaves.
6.3 Onwards

Donna Haraway’s “Cyborg Manifesto” is a great piece of political-fictional writing, which is still a rich and essential touchstone for cultural studies. When she writes, “[t]he cyborg is our ontology; it gives us our politics” (Haraway 2004 150), I take it to heart. I want to be cyborg in my ontology and politics. Written in 1985 and republished in 1991, it is of the past, and seeks a future in the present. For this future-present, I animate a fembolita—my word for a small nymph-like puppet that tweaks the social order towards raising the story of women’s lives. My nymph-cyborg is an ironic cybernetic non-human. Haraway’s work does this. She locates women inside the integrated circuit and this leads her to recognize and address the whiteness of white feminism. This is especially clear in the last pages of the manifesto. Hers is an early intersectional text, which can be read in this quote: “the cyborg is resolutely committed to partiality, irony, intimacy, and perversity. It is oppositional, utopian, and completely without innocence” (Haraway 1991 149). Haraway also raises the connection that humans have with technologies. “A cyborg is a cybernetic organism, a hybrid of machine and organism, a creature of social reality as well as a creature of fiction” (Haraway 1991 149). On my mobility scooter, in my nymph-form, I am a true cyborg.

Okay, here is what I want to add here from the MS handout about fatigue which implores the disabled to take care of themselves by managing their fatigue properly. It’s super important advice but it’s also really difficult, unpredictable, and completely uncontrollable. I don’t—I cannot—control all the things my body wants and does. Rarely do I feel in control, and keeping up with the daily activities of self-care is impossible. I need this cybernetic ontology as knowledge to understand myself. I guess I mean I can go without practical self-care for a long time—as long as my body lets me. I flash to some scenes in my head about my own solitariness. Not being able to do aerobics class. Clumsy coordination. Loss of interest. Disorientation.
Dizziness. Falling down. Fantasizing about falling down. Falling down, again. Getting hurt.

Fighting to stay down. Fighting to get up. Licking my wounds. Hunger. Eating.

6.4 Feeling Numbness

In the beginning, numbness of my fingers and toes took up much of my attention. But now, it has become my normal. It does not feel like numbness anymore.

I am unpacking how I use words as placeholders, as first instances of a thought, and then question myself as I go back through the writing. How am I using words? What is a post-human intersectional local, dating back and forth in a wave of cultural relevancies? I’d like to understand this better.

Gar.

6.5 Season’s Rage: February 22, 2016

I woke up and was unable. The winter is the worst. It’s cold and I am cold. The only warm I can generate is in my mind. I worry. No, that’s not true. I stew. Yes, simmer on low and wait; waiting, and waiting for my reasons to catch up with me. There were reasons all my words were not mine. In order. Out of order. Who is this dissertation for? Me? Perhaps. Partly. Identity is something fragile, a belief. Trying to stay awake long enough to put things together, in a timely, relevant, poetic, and transparent fashion. The language of all of this matters: in the startling, nettle of this location of pain.
Figure 24: Winter is hard.

I’ve had three stays in hospital since I began living alone. In the last visit, a class came to visit me as part of their training. And that’s where I learned about my homunculus, which is that part of the brain that joins the two hemispheres.
Chapter 7

Pulling Through

7.1 Decolonizing Thoughts

I read Katherine McKittrick’s “Yours in the Intellectual Struggle: Sylvia Wynter and the Realization of the Living” (McKittrick 2015). It blew me away. Wahoo, I thought, an analytical framework for where we might be heading, if we choose. A framework for pushing my way into an intersectional, intellectual art praxis. I don’t know how to talk about this well. I stutter over unfishable sentences. McKittrick and Wynter dialogue Western thought back together as a parable of futurity. They reframe the Christian and human mythologies that underpin colonizing processes. Wynter’s is a decolonizing writing practice that unpacks how the structures of humanness arose, in the context of Western thought myths. Slightly different from that though, she is saying that because contemporary Western stylizations of human beingness are ideologically founded in Christianity’s reproductive ethos, that Christianity was so successful because it is the foundation, the root, of colonial processes that maintain these replication imperatives.

This human replication is a kind of autopoiesis due to some difficult to imagine or hidden power dynamics. For how can one decolonize in a present to make another future replicating processes out of colonial processes altering its replication. Autopoiesis is their idea of how colonialism spreads itself, over-representing what Wynter calls man1, through Western style universities, all over the globe. For them, the originating Judeo-Christian myth underpins discourses of what it is to be human today. Autopoiesis is Wynter’s concept for how colonialisms reproduce in every geography on earth, like a thought-virus always replicating its hierarchal, always reproducing likenesses of itself. Again and again, this story of colonialism is imbedded and reproduced by the
Christian idea that earth was the pivotal place, the centre that didn’t move, where humans had fallen to live out subhuman lives until salvation in death.

Figure 25: Unfishable.

My writing is deeply concerned with making contact. I want to live Wynter’s idea of “radical collaborative and correlational narratives”, which, McKittrick argues is part of “engaging de-colonial scholarship” (McKittrick 2015 x). Sylvia Wynter: On Being Human as Praxis works within black intellectual history to engage in Wynter’s lens for re-fictionalization of a creation narrative that decenters racist, sexist, and ablest norms (McKittrick 2015 6). “Wynter does not simply convey a set of ideas; rather, she demonstrates the difficult labor of thinking the world anew” (McKittrick 2015 6-7). I’m learning to think too.
7.2 Acts of Submission

I am trying to learn how to decolonize myself by reading through texts and searching for clues on how it is done. I pay attention to how I am treated in situations when there is an expectation that I will submit to someone else’s ideas of who I am and what I need. That seems to be a regular happening in my life now that I have to deal with a body that does not function as one might expect. I remember an experience I had at the hospital recently when a neurology class went on around me as a patient with multiple sclerosis. I was their object of study, which was strange. In order to cope, I imagined I was in my own show. How else does one get through the experience of objectification, other than to actively insist on subjectivity? I guess there is also some white and academic privilege happening in that space. I imagined I felt these things happening and worked to keep up with the changing circumstance of a class being conducted about my messy bodymind.

7.3 Artist Affirmations: Discomfort and Enchanting Proximity

There is a letter I helped draft for a friend about getting the accommodation she needs for a scent-free environment at one of the prisons near Kingston. I used my voice in that letter and it had an academic tone and I’m afraid for her. Anyway, it’s my academic clout that I have begun to gather. I didn’t realize the force of my writing. I used what I have learned at school and it may help her out. It’s the prison. That’s it. I can’t say more. Can I? What are my politics? Who do I love? How does one write about real things? Could she go to the press? What punishment might she face? I overstepped, saying I will be with her through the whole struggle without realizing how big the task might be. So I need to focus on how institutions in Canada are doing in going scent-free. This is important because so many people have multiple chemical sensitivities. Good policy reduces the impact on people affected. It’s the numbers. They add up. Perfume triggers. Floor cleaner triggers. Smoke triggers. So reduce these.
But what if ablest notions are the norm? They are. How can one be normal when one needs workplace accommodations, which require others to change how they think? How do workplaces do this? Education? Bringing in experts? Bringing in scent-free cultural practices? It seeps in.

In the prison every relationship is more complicated. The prisoners have to buy their personal grooming products from the prison store. The prison is where they live; their forced homes. So some might get comfort from scents. Anyway, it’s just a thought.

There is work to be done.

It’s a big conversation. How is this work going across institutions? Who is winning in their ability to institute and produce scent-free chemically reduced work place environments? Who and where are our allies? This is how big the job seems.

7.4 Body Animation

Learning Disability, Pain and Fatigue are in one group. Body Animation, Intimate Likenesses and Conjuring Identity are in another. Grouping these themes is part of the process that I use for constituting identity under disabling conditions. They suit my mind’s need for containers, for allowing ideas to surface and shift, in the crip spacetime I occupy. They can contain and hold the fragmented memories that mark my body animation, which are expressed through my puppet sculptures, performances, videos, my online and academic political practice, and finally, in my writing. I’ve approached it naively, conceptualizing the tensions one deploys when falling. I’ve been refining, literally, the act of falling down stairs. But it’s not my chosen path entirely. The absence of sensations has become my altered state.
I’ve got a story of how the absence of feeling or sensation manifested from a recent dinnertime visit with friends. I’m learning to fall. Well that’s not quite right. I know how to fall. I’m learning how to accept help. But I insist on something; some way to shed myself. No, but being in shared motion together is a part of a consensual practice. Here’s what I mean: Meredith and Hugh live near my place, easy scooting distance. And there is a step to get into their apartment. I have a very emotional response in trying to talk about how our friendship has evolved. They are people who I love. Our friendship is made possible by the work they do to make their apartment accessible to me. That’s a lot of story. Something I’m still upset about is that I can’t visit other friends in their homes. I have no friends who live in accessible homes. Yes. Now I drive a scooter. I use it like it’s a wheelchair. Ugg. No justifications. Another vein please.

I am obsessed with the way stairs were, are and continue to be such a big problem, but I am learning to narrow and focus my attention, finding the disability time and space to exist, and joining them to push for access. And that’s been hard. So falling. But I am making progress. I feel. Sometimes when I think and write about all the wonderful people in my life who are near enough to walk into my living room from the sidewalk ramp into my apartment, that makes me feel a part of community. I like living near campus and downtown.

My apartment is all fall free, retrofitted nearly well enough to be a safe fall zone. I’ve got grab bars in the bathroom and shower, and a grab bar by my bed. And I can drive my mobility scooter everywhere in the apartment. Conceptually, it is as safe a space as I can manage. It’s luxurious, nearly. There is room for me and this scooter where I can lay down whenever I feel the need. I can get to the bathroom. Oh god. I feel weirdly intimate. Weird intimacy. My queerness.

Feels like I’m doing this wrong. Okay, so you know when you see a walker (someone who walks upright on two legs), and they are walking along and they trip and fall, there is this incredible
flush of shame. You know what that feels like? Right? What that emotion is all about? I’m just saying. Why does that emotion accompany the pain? So, yeah, the feeling of falling. Shame. And fear. My goal is to get beyond that feeling, which is much deeper and complex than I can explain while at the same time maintaining some distance from it. I want to learn how I can begin to engage expectation intentionally. I need to begin to figure out how to manage what form acceptance takes. I accept hard landings but I do many things to prevent them. And if I fall and have a hard landing, I also know hard landings are pain and hurt that can be lived through. I have a mantra: Take all the time you need to get back up. Don’t let anyone rush you just to make everyone comfortable that it never happened. So that consciousness development has been a lot of work. I live with depression nearby. Behind every moment.

I’ve made myself ridiculous. Watch your language. I hear ringing somewhere in my ear. Are you really ridiculous? I’m watching the Netflix TV show, Hemlock Grove, which starts with a murdered white female body. So much violence on girls and young women’s bodies are born here. Watching Netflix stories that depend on this naked white slain being as the ground the story is visually grounded within. The film plants itself there. I want to know why there is this need to ground TV and movies in the story of the image of post-violence. A story of after-violence. An erotic slaying through the soundscape. Could it be something else? The soundtrack? These are complex matters.

This isn’t a unique experience. Pain and the kind of fatigue—and I’ll add fog—that attaches itself to me. I think suddenly of justice fighters. What other word for activists? The exhausting political work of trans, environmental, social, racial, disability, queer, crip, Indigenous justice fighters. I see through the veil of my pain into the generations of activists who become exhausted. And I see Indigenous women fighting where they face one of the harshest intersections of structural oppressions.
While writing, I like to listen to CFRC, the Queen’s University radio station. The stories of two young indigenous women of Canada seep into my consciousness. They are spreading the word that they are here; that the Four Directions Aboriginal Students’ Centre is reaching out to make safer spaces. Space safer. Place. The radio show is about northern food insecurity. The young women hosts are discussing events planned for Aboriginal Awareness Week. They suggest writing letters to people who live on northern reserves. Ask about how they are doing, what’s happening and such, they suggest. Post about it. Get in contact with a family. But it goes beyond thinking about one family. These young women plan to go to Queen’s Park and explain why it is essential to send help. These are the new citizens, acting out their own examples as performance artists using their bodies.

I read life through a Conceptual Art lens, something I have come to understand about myself. It’s rather an eclectic lens that has been developing since I was introduced to it in the first year of my undergrad degree. *Machine Life* (2002), the exhibition and course work for second year Contemporary Art History class introduced me to contemporary and conceptual art. It was like my intellect received an aesthetic injection, immunization, an education; something historical but speaking as anti-history or dis-history. A Deleuzian way of thinking about the art object that carries the past in the present, and is a fold from which the future arrives. A set of cultural phenomena that are inexplicable when tested for their ‘use value’. Through conceptual art, one encounters the work of another people; a people imbued with the spectacle of contemporary performance artists and curators working with things deeply familiar to everyday life. To speak so deftly, new ideas. New. Ideas. That refuse work.

totality and its continuation, stirs a desire for gestalt. They, those three artists, them, their collective are part of my art-life knowledge ethos. Their work is crowded into my worldview, along with many others.

I’ve been less interested in painting for most of my time at school. After all, there was so much else to learn at art school and in environmental studies and cultural studies. But now having come this far I am terrified. I spend my time running to catch up to myself. To find myself, I paint and draw abstractly, as an expression of my creative anxiety. To explore that controlled movement, stilling excess energy I can’t burn off with my body. Instead, the pen or brush expresses this excess through the marks and tailings of the ink on paper. There are some weird things happening as I type this section on body animation.

Hmm hmmm hmmmm. I’m feeling panic as I type and things come out muddled. I type the words ‘write type the words of not gonna work.’ Suddenly, I am thinking of abject art and Anselm Kiefer, Kiki Smith, and Kelly Marks. Why these three? They are all outsider artists. Are they disabled? Well, actually these three are also inside contemporary art: their art, ideas, and images are seeds into my mind’s eye. Lots of installations, performance, scholarship, and exhibitions have gone into their work, in order for me to encounter their influence. They are influential: academically, artistically, and worldly. Of course, that’s just the thing. Isn’t it? Art tells a story of spacetime; when it is made, where it is brought together, exhibited, and curated. Who curates? Who tells the stories? Like at the exhibition I encountered at the Museum of Fine Arts in Montreal last weekend. The Beaverton Group was the special exhibition: dozens of oil paintings of women from paintings done in Montreal in the 1920s.

After visiting the busy museum for an hour or more, I have to find an accessible bathroom. I am forced down under the street through a below-street hallway to get to the accessible bathrooms in
a neighboring institution or maybe it was still the Musée des Beaux Arts. On the way there, down elevators, under stairways, I enter the atrium of the sculpture area in the basement. Of course! I forgot. Sculpture is traditionally in the basement. I am blown away, all the way back to why I make art. I love how it makes me feel. I love how it charges me.

It’s December 16th all of a sudden. Anyway, I am up reading and writing. I check my emails and reply to the one that required a response and start deleting the others. My automatic group followings all come to my email now. Notifications of blog posts, urgent calls from political parties, tea specials from the tea company, academic publications in disability studies. Groups I joined this last summer, and flight deals from Air Canada. Each email is a story of my reaching out. Disability has me everywhere I go.

For example, last summer I looked for spots in downtown Kingston where I can feel comfortable alone. A lot of the downtown shops and restaurants and coffee places are inaccessible to me because there are steps to get inside. I tried out David’s Tea again. Inside David’s Tea there are hundreds of choices to navigate. It’s a compromised comfort. I re-experience the uncertainty of the space. Its accessible front door without an automatic door opener, its accessible bathroom and its inaccessible back garden oasis, with places to sit and study, and drink tea. There are three stairs to get into the garden. I reimagine it; make it accessible in my mind. I landscape, redraw the space, edit it in time, and make room for me and others who might like access but are wheeled. However my imagination doesn’t change its hard surfaces, so I sit in my scooter in the front window where they have two overstuffed chairs looking into the store. I sit looking out the window putting my feet up in the big cushioned chair. I can hardly stand it. I agreed to this month-long contract with them. I bought the twenty dollar teal mug and with it they give me tea for a dollar. And so I go every day during summer’s hottest days, trying to feel some kind of flow in my writing process and just trying to stay moving.

Many things are rushing through my head as I remember the candy-coloured décor of the tea shop. Pink and teal! I chose the teal mug, of course, but I loved the pink too. However, the pink is so scandalous in the modern world. What do modern artists do? What do they do!? “What artists do and what they “ought” to do constitutes a territory of public debate in which we seek a broadened paradigm for the meaning of art in our times” (Lacy 1995 171). Lacy published this in 1994 but I still feel it’s true and in a way, it is part of my job as a contemporary artist to think about the complex of crip spacetime simmering within my work in order for me to grow.

I posted an image of the cover of Lacy’s book to my Instagram a couple of weeks ago and one of my much younger art colleagues, a blossoming conceptual artist, but struggling (OF COURSE! WHAT ELSE DO WE DO?). She heart-liked the image and commented: something like, “Reading Lacy’s book changed my life.” Her name is Christine Dawanker and I’d like to know more about what she is up to. Lacy changed me too. Particularly encountering her conceptual projects where she worked to intervene against social barriers. She orchestrated operatic scale encounters, putting divided people in contact with each other to talk and share and work on the distinct worlds of inner-city New York. I first learned about Lacy’s contemporary conceptual performance, video, sculpture and installation art practice from my teacher Kathleen Sellars who works in the Fine Art Program at Queens.
In *Mapping the Terrain, New Genre Public Art*, Lacy draws an artist jobs graph. (Lacy 1995 174). She divides the artist’s work up into private-public, public-private, or public-public intelligence in their work. Artist-as-experiencer is considered private. Artist-as-reporter less private, artist-as-analyst is public and artist-as-activist is more public. Can there never be a private-private relationship to one’s own art? Is there never an inside anymore? No, says Lacy and Kathleen and I have to agree. At least if I really want to tell my story, I have to navigate the fear. Lacy insists that artists are always working on these different levels at different times to different degrees (Lacy 1995 174). She believes one of the most basic elements of art to be “the experiencing being” (Lacy 1995 174). “As artists begin to analyze social situations through their art, they assume for themselves skills more commonly associated with social scientists, investigative journals, and philosophers” (Lacy 1995 174). Indeed. No wonder I am exhausted.

Back to the materiality of my art-making; the desire to make small marionette-like beings and to perform with them as an artform, staging the limits of my body. I perform and record the experiences of making, as a person engaging disability aesthetics. Then I edit the work together, sometimes adding sounds that resonate with my noisy body. A noisy body is how my friend Diane Forrester describes the sensations MS creates. We each monitor and manage the noise in our bodies in different ways.

I break for lunch with rose tea and local honey made by the bees tended by my partner, Mark. Probably you don’t need to know that. There is more of course. Different minutia I experience and aestheticize.

I just checked my email. That’s where I was going before I got sidetracked with memories of last summer’s writing experience at David’s Tea. The air-conditioning inside was bracing. And the shop had a strange kind of bubble-gum bounce that felt oppressive.
Adam Kotsko makes a point in “On the Desire for Slavery” (Kotsko Blog 2015) about Agamben on humanism; on the master-slave narrative in speculative fiction. Fiction that charts new territory. Of a slave. To no longer chart the idea of human that is such by its ability to enslave. He suggests that a major theme in science fiction’s bigger meaning is to give voice to the machine/slave of utopian literature and whatever that desire is, to finally abandon the project of humanization (Kotsko Blog 2015). So Kotsko looks at how Agamben points at the object body or body as object and the linguistic forms that maintain its invisible founding. Kotsko ruminates: “Or to put it more radically—and this is what I think Agamben is driving at with his investigation of slavery in The Use of Bodies—the problem isn’t the sub-man, but the man. The problem isn’t dehumanization so much as humanization itself” (Kotsko Blog 2015).

I see that Sylvia Wynter has the related impulse. I begin to unpack what she is arguing in another section of her novel text. The paradigm shift Wynter suggests with her scholarship; a changing but still somehow the oppression of religion continued in the form of colonization of the globe by what’s known now as ‘the West.’

This thought can go somewhere else now. Oh my. Can’t believe I’m bringing up Agamben. I’ve read him. I encountered him through a phenomenological and materialist lineage. Anyway. Kotsko is a blogger I have been following for a while. I get his posts as email. My email is almost completely transformed from three years ago. I have almost no personal email anymore. Is that the automation I’m experiencing? Driving around in a mobility scooter; using elevators; using ramps; following bloggers, being ever frustrated in my desire for the communicative act.
Sometimes I look at the amount of toilet paper left in the bathroom and I wonder if I will live long enough to have to buy more. I don’t like to run out.

Getting out of the house is a problem again because I am worrying about all the things I might encounter. I am afraid of getting stuck and feeling bad. Again! Repetition!
Chapter 8
Intimate Likenesses: Symptoms of being

8.1 Redirect
When you have a chronic and progressive disease, everything that happens to one’s body can be studied as symptom. But that is not what I intend. I intend to redirect the demand to medicalize my situation even though I get close to being read as someone who is sick in the exhibition video.

8.2 Fingernail Moons

Need to be Adored includes a thirty-two-minute looped video that opens with a one-minute stop animation of painted paper characters that move over a wrinkled brown paper background. This stop motion segment, called Fingernail Moons begins with a finger pointing up from the bottom centre of the screen. A quiet voice begins: “What does it mean when the crescent moon on your fingernail disappears?”

Figure 26: Fingernail Moons.
Then out from behind the skin of the finger a sliver of moon emerges and floats to the top, becoming full, followed by a small flock of birds. My mom reads these as signs. Birds represent big fears; fear of financial distress, fear of societal rejection, fear of further disablement, fear of family life disruption. They fly and light on dangling beads that hang from the top of the screen, like jangled nerves, quivering. The flower arrives from the sky and the ground is alive with creatures. The red rain becomes part of the flower. The birds then circle the moon and find their way back into the finger. The moon too descends and enters the finger. Each moment is barely a flicker.

Across the center of the screen, yellow text provides visual description of the sound that accompanies the moving watercolors. These text descriptions describe the soundtrack, making the sound somewhat visible, or accessible, for hearing impaired, and deaf viewers. This section of the looping images was made in 2013, with the help of my Ann Arbor roommate Adelle Pacificar who animated the bits of paper as I worked the camera remote control taking still images.

We set up on the apartment dining room table with the tripod sitting, two legs levered over the surface of paper, the third leg sticking at a deep angle through the back of a kitchen chair. The tripod suspends my Pentax camera with its lens perpendicular to the tabletop, gazing its upside-down view, which we can see on the camera’s screen only for a brief moment as the image is taken. We animate with the paper cut-outs. I painted the watercolours onto brown paper bags that I collected from under the sink in the kitchen. Actually those paper bags were behind the little table next to the sink where the dishes stood to dry.

There were three of us in that apartment and we each had our own rooms, which were designed for accessibility and the bathroom had an accessible shower, proper grab bars by the toilet, and space under the sink for a wheelchair to pull up. It was my first accessible bathroom. I filmed myself brushing my teeth, showering and dressing in the space. Well that’s part of what I did and
the struggle is what to write about … to convey the dynamics of my everyday movement during
an academic research trip to University of Michigan in another country.

8.3 Brown-Eyed-Susans

After the animation Fingernail Moon ends, the video cuts to a close-up head and shoulders shot of
me, sitting facing the camera. I don’t have my glasses on and look into the lens, raising two
brown-eyed-susans, which I pinch between my thumbs and middle fingers. I bring the plastic and
fabric flowers up to cover my eyes, manifesting another fear that MS might take my sight. Again
this is my mother’s interpretation. Then a sudden brief smile and a sharp cut to an image of
Leonardo da Vinci’s Mona Lisa. I always get a giggle from this juxtaposition.

8.4 Access Bus

After the two smiles flash by, the film goes to another cut to me outside on a sunny day. I’m on
my scooter at my front door, locking my apartment. I drive backwards, my back twisted so I can
see behind, down the short ramp to the sidewalk. At 1 minute 58 seconds, a second video window
opens overtop the scene of me driving towards Kingston Access bus. It’s my first time using the
service. In order to access it, I’ve had to get a note from my doctor saying I need it. I hate that. As
if I am not able to perform myself legibly or on my own terms because of the instability of my
disability as an identity. Another head and shoulder shot of me interrupts this scene. In this shot
everything is yellow-tinged and bits of my head are missing. The head with the missing bits talks
about a film class I co-taught in the winter of 2014, where several students did multimedia or film
projects instead of essays. In the talking head’s monologue, I note that these projects turned out
very well. I remember a difficult class because of my disability experiences, which are compound
and complexly entwined, as part of the discourse I am trying to weave into this text. A dozen
images of my experiences flash by as I think about how anxious I was for that winter course.
8.5 Eyes

At 2 minutes 26 seconds, the film cuts to an exploration of watercolour on paper. In it, the camera pans over abstract shapes; purples, blues, and greens that mix with lines that looks like backbones that morph into stairs. Eyes seem to appear. Then, those me-images return, still talking about student work.

8.6 Limbo

At 2 minutes 50 seconds, I say to the camera: “I really struggled with this year because of not feeling capable of doing things. Struggling with my MS, my new move—you know having moved out of my house—being away from my family, and the kinds of other things that accrued, because of that move away from an idea of home and future.”

That winter was very difficult and even my shaved head suggests I've been stripped bare.

8.7 Bringing People into my World

At 3 minutes 20 seconds, the film shifts to a classroom where I sit on the floor preparing to present a puppet show. In the video, my walker can be seen behind me. My costume or my choice of clothing, suggestive of a Raggedy Ann’s dress, with my knee-high polka-dot socks, make me very much a part of the show. I don't attempt to disappear into the background.

What is most striking to me is that these are health-care students. The performance presents a different face of disability to them. I think they saw themselves as taking care of the disabled and being in the role of an audience member perhaps gave them a new perspective. During the performance, I remain silent, relying on sheets of paper with commands written on them to prompt the audience when I wish to have assistance. This asking without saying anything put the
students on alert. They don't know what to expect and at first, the performance seems to make them uneasy as I take them out of their usual desks to sit on the floor with me, putting them on the same level as the puppets and I. In a way, this is my political statement. The fledgling politics of disability experience is to take the students out of their normal. I begin with a ceremonial unwrapping of the puppets, and a blue circle of fun fur becomes the stage. Green, red, and blue fabrics lie on the floor and mix together as if they are an abstract colour painting.

One student makes eye contact with me. In response, I hold her gaze and hand her a note, which prompts her to plug in the coloured rotating light that I have unwrapped. I make my face a question mark and she nods nervously. As I scoot around on the floor, pulling myself around on my knees, organizing the brightly colored scarves, she plugs in the light. It barely shows up in the bright room and makes a quiet whirring noise. I drop various props including purple duct tape, brown-eyed-susans, a handful of small wooden skewers, and a stethoscope.

![Figure 27: In bed preparing puppets for a Skype performance, while living at the bed and breakfast in Ann Arbour in January of 2013.](image-url)
Using the floor as my canvas, I begin to animate the first puppet and continue to paint a story. At this point, 6 minutes 06 seconds in, the video cuts abruptly to another headshot of me talking. This choppiness and the sudden shifts reflect the daily experiences that I have with fluctuating fatigue and energy. Bursts of energy alternate with sudden and prolonged fatigue. I think this is also very apparent in my writing style. A rough juxtaposition.

8.8 Alternatives

In the next segment, I explain the logic I use to manage parts of my life. In my monologue, I outline a choice I made to refuse a super-expensive experimental drug for my MS, not knowing if it would be of any benefit. My face is tight as I discuss the medication I was urged to take. I know the side effects, its costs, and the repeated visits to the doctor’s office for keeping track. I couldn’t put myself into the role of compliant test subject. Then I explain how I chose a different kind of experiment. I say I chose art. My face lightens up. I relax. My eyes open and I smile. Although at the time I didn’t understand this drive of mine to be critical about the world and what it asks of me.

I was scared. Terrified. But the medicine wasn’t going to deal with any of that. It was some magical formula that would play in my immune system masquerading as myelin, the cushioning conduit that lets the electricity flow through the nervous system. My myelin was a battleground; not only with my immune cellular response, but also with big pharma, Canadian socialized medicine, research projects that experimented on humans at universities. So. Here I am.

I go on to explain my ambivalence towards the medical help available to me as someone with MS, and report on the tendency of doctors to look no further than my MS when I have a problem. Then, I describe my inability to access physiotherapy because that puts me back in contact with these critical readings of how disability is produced. Ted Rettig, my MA supervisor, offers artist
mentorship and he is the cameraperson as well. I tell him the thought-logics, in these circumstances, which compelled me to start university ten years after my MS diagnosis, explaining the fear, frustration and anger triggered by the impossible requirements put upon anyone requesting care or assistance from the medical system. Section ends at 9 minutes 40 seconds.

8.9 Pip

At 10 minutes 15 seconds, the interview cuts to a silent animation of a small marionette with one string, one arm and no legs. She dances and bobbles around on the table in a continual struggle to keep on and keep going. As she moves, words appear over and around her. These are synonyms for cripple that I found in the thesaurus. Words like lame, broken, bedridden, devastate, confined, hamstrung, put out of action, physically challenged, ruin, break, wipe out, put out of business, bankrupt, paralyze, bring someone to their knees, and immobilize. These words bleed onto the flatness of the video’s surface, superimposing themselves over her. But she keeps popping up, amplifying her experience as struggle. Each word disappears as she achieves some gesture; a gesture that doesn’t quite look intentional enough, a kind of co-mingling of these animations. The words fade in and then out but she continues to bob and fold and fly and fall, until she rests after the last word fades.

8.10 Freezing Mobility

12 minutes 40 seconds: The film cuts to a noisy forward-moving winter scene. The camera is perched on my red furry blanket. I balance the camera on my knees. It peeks out past my keys, which jingle in the ignition, inches in front of the camera lens. Filmed from the seat of my scooter, I am the camera that sits on my red blanket on my lap. It captures my drive through slushy sidewalks as I make my way to my first class while away studying in University of Michigan where I travelled on a Michael Smith scholarship. This is only a snippet of the
documentation I did while traveling alone to Ann Arbor. I would make this trip nearly every other
day for my whole time on campus. There is a constant clickety-clack of the scooter going over the
joints in the sidewalk and the jangle of my keys that hang off the ignition of my scooter. These
sounds are accompanied by a jarring of my backbone as I go along with the high-pitched hum of
the scooter motor. I pass a bunch of bicycles in the snow. More wheeled beings.

8.11 I’m Fine

14 minutes 50 seconds: An abrupt cut to a blob of melting wax. Why am I melting wax? I’ve
been collecting the red wax from cheese and have wanted to do something with it for ages,
hoping to melt and sculpt with it somehow. People are almost upset when they see this shot
because it’s so unexpected and seems out of place. It looks like a piece of raw liver. It’s icky. A
sharp close-up, blurry sequence of red undulating mass ends with an elevated train driving by.

Another scooter ride is jammed up against these collaged sequences. This time the camera points
upwards. I’ve set it in my basket pointing at the sky. All the viewer can see are the tops of tall
buildings and bare treetops, light stands, skylights. There is a blue sky with puffy cloud, sharp
edges, and repeated patterns. A skyscraper, occasional voices, blaring car horns, and idling
vehicles roll by to the rhythm of scooter tires clicking on the sidewalk. This goes on and on and
on. The screen is narrowed down to a fourth of its full height and the full width, shifting to the top
of the screen. A night scene and back to the melting wax which becomes a cavernous mouth, or
an eye, or a curtain, and a veil.

The camera focuses on a door from doorknob level. As the lens approaches the door, a voice
offers assistance, but I’m fine and say so. I lean forward in my scooter and reach for the door
handle, twisting it. With my other hand, I squeeze the tiller lever of my scooter and inch forward.
As I continue to hold the door with my outstretched hand, balancing the camera perfectly on my
knees, I roll into a classroom filled with desks scattered like abandoned furnishings, clinical in their disorder. I go through into this classroom, pushing these desks apart as I drive a path between them.

Back to the wax. A small green worm-like puppet floats over the stove, her body becoming more and more coated in the sticky wet wax as she dips her torso in a dance of some internal existential effort.

20 minutes 49 seconds: The scene shifts back to Kingston where I arrive at the Isabel in the Access bus. The Isabel Bader Centre for the Performing Arts is where my project work exhibition will be installed. It is the first solo exhibition held in the new space.

8.12 Havana

In the spring of 2013, I went to Cuba as a graduate student in the Cuba Course taught by Susan Lord and Karen Dubinsky. It was not a simple trip. I brought a walker and my mobility scooter. Susan and Karen both worked hard with me to anticipate what would be needed to make the trip accessible. We met several times before the trip so they could get an idea of what I thought I could do and what I would need. We talked about everything. We all went at it in a spirit of reciprocity and shared experiment. What fun we had. Zaira Zarza did so much work and so did my colleague Jaspreet Bal. We each have a mountain of stories to tell someday.

While there, people were willing to help: to lift and carry me and my assemblage scooter. They were wonderful. Nonetheless, I felt the sting of disability. The accessible entrance for the hotel was through the kitchen basement elevator. The building had two elevators and the maintenance elevator to the ground floor allowed me to drive out the hotel’s steep, gated driveway. Even getting access to this entrance was a learning experience. I don’t speak Spanish. My colleagues,
professors and friends made the experience work. But it was also painful. What I mean is: I am a public intellectual and feel reluctant to claim what I think. But there are always multiple meanings co-existing without each other’s knowing. So this is how I see my work. I don’t do disability well enough yet and at the same time I am getting better at it.

In Havana, we walked all over the city. From one end to the other, we traveled and visited the universities. We drifted in and out of hot spaces, enjoying the excitement of the architecture and the sweet, rough wind of the ocean waters as they smashed on the Malecón.

I met people in wheelchairs or walking with canes. Somebody in a chair wanted me to give them my scooter. This request also coincided with us having to rush around to find a bathroom that I could access. There is a lot of rough pavement, not unlike Kingston. Inspired by all the help I was getting, I ended up doing a performance about the rough pavement with my classmates.

8.13 Azavein

Azavein, my first puppet, is a marionette with a wooden control. I try my best to animate her with my two hands, my torso, and my legs. I control her as I struggle with my core muscles to keep first me, and then her and me, in a state of expression. We perform in my methodologies class, dividing our fifteen-minutes in half; seven for the presentation of written work, and eight working with Azavein, who has one ear with which she listens, and a small bell attached to the control that tinkles as she/we move. The classroom is set up in a square of tables that face an empty centre, where I and Azavein perform. The bell tinkles as Azavein and the other inhabitants curiously make eye contact and touch hands. Azavein cocks her one ear towards sounds and voices. A cathartic and intimate experience, it is complicated to talk about because the energy in the room dissipates as the class ends. I think Azavein found a way into peoples’ hearts.
In the prologue to Kenneth Gross’s book, *Puppet*, he talks about the madness of puppets that comes from the puppeteer’s body energies (Gross 2011 1). I hadn’t thought of my relationship to the manipulation of my puppets as a form of madness expressed in the movement of my body, but I think there is something true about this. “[T]he madness lies in the hidden movements of the hand, the curious impulse and skill by which a person’s hand can make itself into the animating impulse, the intelligence or soul, of an inanimate object …” (Gross 2011 1). This animation of a soul is something I’ve been working on and I think I have some good relationships with the puppets and parts of their souls. The more I practice and play, the more I/we learn. For me, the different puppets each recall that need to feel good performing with them. But it is difficult to sit with my arms up, holding the strings. It feels as if I am on the verge of dropping to the floor. I suffer this tug and pull of physicality as I work. It feels as if the hardest thing I do is performing with these demanding little figures. In each performance, I face my own body. The puppets are an extension of that heavy dead fatigue which hangs on my legs and torso.

Petra Kuppers was one of the first disability culture artist-theorist that I read, inducing me into the complex and expanding community of disability culture theorists. In her 2015 article titled “Occupy the WEFT: Choreographing Factory Affect and Community Performance”, she talks of her performance community work as somatic practice. In one of her outdoor performances, she asks people to engage with how their clothes feel on their bodies. This is a communal and individual experience she explains, which creates attention on the sensation of fabric, of one’s clothing, to globalized flows in capital production, including experiences and imaginaries of factory work. Feeling for the clothing on one’s body is in tension with the weft and warp of woven fabric, which constitute the diagonals of weaving. She leads her participatory actions, with the consent of others, preparing and guiding a thoughtful cooperative sensual space, in public, for people to check each other’s clothing labels, which they then map together, using a shower curtain of the globe to locate the participants and global others, directionally. Finally, Kuppers
asks participants to lean towards the global manufacturing sites of the fabrics they wear. Like tilting still lifes, the group stands, each listing towards another. “WEFT takes its name from fabric production: weft and warp, the scuttling of alternating trajectories, the histories of textile industry workers’ agencies and revolutionary actions. In this somatic set, we as disabled artists, already constantly aware of our need for interdependency, are undoing the smoothness of woven textiles to foreground the wider global interdependencies and woven connections that make up our social realm” (Kuppers 2015 402).

I am quite happily writing this May 15, 2015. I feel near the zone of writing, idiomatically. In the zone means my processes of working-writing are engaged. Composition is forming meaning. Fingers crossed, I write, hopefully. Hopefully, I write.

**8.14 Dwelling Drift**

*Dwelling Drift* is a story of the forest sprite, Azavein, who wakes up in the suburbs, which is her forest home. She and I travel across the backyard of a beige siding, suburban home. A black and blue mobility scooter is in the shot. Clearly there. Unexamined.

My daughter, Miranda Figge and friend Donna-Lee Iffla film, while Lise Melhorn-Bow puppets Topple, a can-opener, and Jessie Barr puppets Sniff, a hanky. I work with Azavein, my limbed forest sprite, fashioned from grey cotton tube socks. I asked my colleagues to come over for two afternoons where we improvised a puppet performance. In the first half of this seven-minute video, Azavein wakes in an overgrown suburban back yard, where I puppet her. As I look at it today, I recall the difficult feelings I had in moving around on that warm summer day. You can see me take a few steps with Azavein (something that I am quite sure I could not do now) and I wonder, should I not feel nostalgia here? Well, I don’t. I’m trying to learn from my experience.
Miranda and Donna-Lee followed my instructions for filming the movement of the puppets with their puppeteers as they emerged from their surroundings on Thornwood Crescent, in Kingston Ontario. Later, Mark Figge, my partner, went around the suburbs to collect photographs of all the street signs, which are named after trees and shrubs: Cedarwood, Peachwood, Thornwood, etc. These green signs, you can see flash by like a deck of cards being shuffled, causing the puppets to react by falling backwards onto the floor, lifeless.

8.15 Nobody

Nobody is filmed by Jaspreet Bal, while I perform seated on the shore of Lake Ontario, with the puppet Nobody. Nobody is pink calico with tiny blue and rose-colored blossoms. She has two legs and no arms. The video is heavily edited with visual washes, fades, and layers. The sound, as well, layered and manipulated, includes the wash of surf and wind, layered in with an increasing heartbeat. In the final scene, I walk backwards across the seaweed beach, using my walker to steady my progress, a quiet voiceover surmising: “You have to make every moment count for more than it is, when walking is so hard.”

8.16 Knight

Knight is both a performance and an experimental film. Instead of puppets, I play with costuming myself. Carrying a sword and shield in my walker, I wear a forest green cape. The action follows my slow progress as I walk, supported by my walker, towards a set of stairs. Knight has four camera-perspectives, including one on the walker, facing outward, and three others operated by Jeff Barbeau, Mansoor Behnam, and Donna-Lee Iffla. The four of us meet in the Mac-Corry cafeteria where I explain the direction of the performance with a drawing; where to move with the cameras, to capture my Knight as she walks towards, and then ascends the stairs. Mansoor’s camera instructions are to focus on a moving midrange shot that follows me. Donna-Lee films from the waist down to the ground at ninety-degrees from where I walked. Jeff set up on the
fourth floor hall window that oversees the courtyard, with instructions to come down, as I moved out of his range of view, coinciding with reaching the staircase. The fourth camera, fastened on the walker seat with Velcro, faces outward, gaping at my slow progress towards the steps into Mac-Corry, my office building. This performance action expresses my frustration and adversarial relation with getting places, with a focus on the detached discrete object of the stairs that leads to my university experience.

As I arrive at the base of the stairs, I park the walker, brakes on, and pull my sword and shield, practicing defensive, or perhaps offensive, moves that simulate thrust of a sword and parry of the shield as a protection and protest, after which, I turn and point the sword, summoning someone to assist me/us in ascending the steps. Another friend and colleague Erin Sutherland arrives, unplanned, to carry the walker. She steps into the frame, sets her coffee down, and grasps the walker. I follow using the handrail to leverage myself up one foot and one step at a time. Half way, we stop to perform a knighting ceremony. She bends to one knee. I lower the sword gently to each shoulder. She rises and we finish our climb, entering the building.

I had been having a very difficult time getting to my classes. Looking at this video three years later, I see the script for Knight as a fecund drawing of the courtyard: a depiction of the movement each camera had with the others, like a set of instructions on where and what to film, and what angles to work on. Editing this footage together, I emphasized the economy of my movements at each stage, depending on my crew to see, I minimize my walking. I do this trade-off daily, always calculating how I can manage to get from here to there.

The viewer can see my mobility scooter tucked in behind one of the concrete underpasses that leads in and out of the enclosure. I only walked the distance in the film, which we did in one-and-
a-half takes. My scooter is there waiting for me to go in through the other entrance, the one with a ramp.

My videos are experiments in directing, expressing some of my familiar experiences, which I collage, suggesting the action in particular spaces, positioning myself as puppetmaker, performer, director, and editor. One can catch glimpses of the other cameras as I walk, which I did my best to edit out. (Is it weird to call people cameras?) Although, evidence of all the other camera actors (better) is there, it seems elegant and fruitful, or like a memory record of my progression through art school.

Overall, one thing I notice in common with these mash-up puppet and performance videos is the attention to sound. The sound editing signals my interest in using the video as a medium to express affect. The soundscapes are an affective medium that works to amplify my feeling of disability. In another way, these projects are me trying to figure out how to negotiate my altered mobility which I find endlessly frustrating. Everything is a struggle. I’m working all the time. Gun to my head. I can get this done.

And I have put myself through my paces. I left my family and my family home to live in a one bedroom apartment—a ten-minute scooter drive to campus. And from there, I write, my mobility scooter snuggled right up against my bed with some of my favourite things. A warn white parka with a broken zipper and orange flames lays across the black seat, backpack hanging off the back, unzipped nearly spilling its contents.

A. J. Withers in their text, Disability Politics and Theory, argues for radical accessibility which has two tenants: “The radical model defines disability as a social construction used as an oppressive tool to penalize and stigmatize those of us who deviate from the (arbitrary) norm.
Disabled people are not problems; we are diverse and offer important understandings of the world that should be celebrated rather than marginalized” (Withers 2012 98). There is more to say on this but what I will add is that between these two statements are worlds. I feel like something is missing. I mean the kinds of things that occupy me as a person with disability, are different from before.

8.17 Mobility in Four Parts

In 2012, I also performed Mobility in Four Parts for the second “Undisciplined” Conference at Queen’s University. I'd wanted to talk about what I had learned up until that departure in my PhD, and show new work. Two days before the conference, I committed to do a performance and put a call out to friends. Shortly, I had two people, Nevin Lochhead and Karl Hardy, ready to join me. We met the next day to figure out the script, and rehearse.

I wanted to create an atmosphere. I had twenty-minutes, ten for the performance and ten for questions. For the performance, I further quartered the time into two-and-a-half-minute sections, using a toaster that took exactly two-and-a-half-minutes to make toast. In the first time slot, I stood back-to-back with Karl while Nevin started toasting the first piece of toast. Then, I pulled out a letter for my friend Julie. A letter I never sent. “Dear Julie ...” I read. After I finished reading, I tuck the note back into the neckline of my tunic. Karl holds a well-used cookie pan covered with a selection of small paring knives. I found this idea of a pan of knives in “In Excelsis”, by Anne Sexton, a poem I memorized and performed for my storytelling class with Daniel David Moses in 2012. Before that, I hadn’t ever memorized anything with confidence. So this was a great challenge and I realized I could memorize things if I wanted to.

Karl and I stand back-to-back again. I lean gently into him and this is enough to support me standing. As I finish the letter, Karl and I swivel towards each other and I take the pan from him
and hold it over my head. Pop, the toast pops. Crash, I drop the pan, and follow it, crouching to the ground. Knives jump.

This is part of my autoethnographic method. To me autoethnography is about studying one’s own situational and individual location and developing an analysis or portrayal of what is gathered together in the collection of knowing experiences. How do I figure out my own autoethnographic style? One thing has become obvious. I have an obsession with steps and curbs, streets, sidewalks, building entrances and infrastructure. I play with these environmental realities in my artwork. This performance video is one long uninterrupted shot from the start of performance to the end. The smell of nearly-burning toast circulates among us.

These videos are communications about the reality of infrastructural truths. Nevin pushes down the toast a second time as Karl joins him at a small table to the right of the presentation space. I crawl across the floor in front of the audience to my walker, which is parked several feet away, and climb up. My feet to the audience, I flop over the side while I take the one small knife that I have in my teeth, picked up from the pan, and press it firmly on my right forearm until the skin goes white around it. I look out into the audience. Some of the audience looks back.

The writing zone beckons, at last. In between, I roll out onto my back deck to dab new paint on the self-portrait that I started earlier today, the one with my headphones on (Figure 28). This last six years of thesis work has transformed the way I think, making the goal of this document to unfold some of the processes and praxis through which I transform. This is the thing that only a text can do, to express in words, the character or quality of my altered experience, perceptions that are too big to face head-on.
Figure 28: Here I try to paint what it feels like to feel music. I use my own likeness. I photograph myself listening to music and then try to paint it while I feel music.

8.18 Inside the cybernetic circle

Donna Haraway talks about a still liquid epistemology in her “Cyborg Manifesto” to see what it is to be female in the world where there is a cybernetic circuit (Weiss 2006 117). I have stories from my three months in University of Michigan attending Petra Kuppers Disability Culture course.
Kuppers is a prolific artist-theorist working in performance and theory of performance and disability culture.

While living in Ann Arbor, in the winter of 2012-13, I did four performances: one via Skype for my friends back in Kingston, two in Kuppers’ class—one of my own, and another with a group of four students—and a final show in the University of Michigan student gallery. Each of these deadlines pushed me to develop my ideas and gave me good opportunity to get images and videos of the puppets as various situations of installations.

The final show, Need to be Adored, two years later, was a reassembly in a differently intimate setting from the three small floor installations of the earlier installation performance at the student gallery on Ann Arbor’s border with University of Michigan.
Figure 29 Performing at the University of Michigan’s student art gallery.
Figure 30 Performing at the University of Michigan’s student art gallery.
Chapter 9

Autoethnography Notes

9.1 Conjuring Identity

Thanks for the meeting today. I got so overwhelmed after you left but then I did a few twists and
turns. Listened to music, (smoked), ate, had a friend over, drank beer, brushed my teeth, typed
this, went to bed... and I started writing again. It's getting very incredible for me to be
remembering these stories in the context of today. Where I am hearing for the first time about
how systemic the sexism in the military was when I joined in 1983 on my twentieth birthday.
You're my age right? And you were being harassed, working on a northern pipeline. Awful.
Anyway I felt awful when people disrespected me. It really hurt. We could have died.

Of course we will. One day. So what?

It’s Family Day today and I am alone in my apartment listening to “Democracy Now”. I just
smoked some weed and now I’m writing my thoughts. Listened to a talk by Marilyne Ware
recorded in 2005 at a university in Nova Scotia about Canada’s continued role in the globally
instituted genocides through the mechanisms of CIDA, Canadian International Development
Agency, which was shut down in 2005.

My friend Randall is looking over my shoulder as I am editing this. He asks me some questions
about what I am writing. He says carefully, “It’s more like a novel than what I’m used to seeing
for a PhD Thesis.” He has another friend doing her PhD work in the neurology department. It’s
more graphs and dry; hard to understand because he doesn’t know the language of neurology, he
explains.
“Of course,” I say. “It’s my voice. I’m just learning to use it.” I realize this is different. I am pushing at the edges of what can be read as legible, as a dissertation. And I’m working on it. Adding in the theory. I am trying to pull all the threads of my experience together here. I am tying them together because it is a requirement of the program. I am not quite ready to do that. But I do it anyway.

This is how my scholarship goes. The rebroadcast of the 2005 Marilyne Ware podcast, in my apartment in Kingston, Ontario makes me wonder. Why and when does Canada go to war? And the answer seems to be when it can oppress, while financing Canadians’ to work in local communities in occupied countries. So the kind of aid Canada gives is colonizing. Because… because?

I recently read Judith Butler’s latest ideas about where research concerned with social and environmental justice and where the public assembles and what it means for cultural studies intellectuals to think about these things together today (Butler 2015). This is to look at the different kinds of public movements bubbling up around the globe and to contend with the textures they make. Where are, they the people, in communication? Where are, they the people, in segregation? And to join these, whatever they are, to tease out ideological silences. It’s not easy being in relationship with medicalized spaces as a patient.

9.2 My Puppets are not Me

Luce Irigaray’s school of thought offers a framework to organize how the biological is a linguistics structure that in practice produces, and then re-enforces structured gender norms, where critique must intervene to loosen (Irigaray 2008 6). With hopeful clarity, she shows how if these linguistically different worlds, male and female, are talked about in grade school they lose
some of their more destructive powers for both genders. And I think that this leads to linguistic experimentation in the structures of social groups’ cultural-reality. Individual acts of growth occur through experimenting with different voices. This act of critique changes how one thinks about identity. These sex and gender flows and their linguistic pre-forms are politics that create alternatives to the heterosexual hegemonic worldviews. I have been caught up in performing myself as female without much thought about how I could survive this difficult position. Never mind that. If I get all the way over to these terms, in this document about me and some puppets, well, then good. It will be a cherished moment. All my puppets are female and disabled. All my puppets are not me.

But just to put it out there, I’ll also say the Haraway and Irigaray have appeared in disability texts on cultural critique and production. While I struggle with my disability culture location as part of my artist/theorist practice as I encounter these new ideas, I constantly circulate those which I feel are filled with hopeful practices starting with Guattari’s Ecosophy (Guattari 2000 12-13). When I describe the video I made for my exhibition Need to be Adored, it is a theme that runs through each piece. I feel the pull of Guattari’s idea of the singularity, or of relationships between things that constitute them as temporarily united. This is the partiality of human identity. I hate to bring this in so late but Bruno Latour has influenced me too. Especially in his book, Politics of Nature: How to Bring the Sciences into Democracy. In it, he contends with imagining images for the non-human complexity to come (Latour 2004 79). And he says that to do this work is to turn and face the damage. That turn is a new way of life. You have to turn to see it.

In “Disability Studies/Disability Not Disability”, disability culture theorist, Simi Linton, insists disability studies be a socio-political-cultural project of making, in an epistemology of inclusion and integration, which, she argues, must be done in the humanities, the liberal arts (Linton 98 525-6). Linton, like Deleuze, Guattari, Irigaray, Merlo-Ponty, Haraway, Latour and other
cultural studies types who I have read, works on making complex metaphors, bringing tool ideas into being.

9.3 Note to Self

Does the abruptness of some of the stream-of-thought offer an affective experience of the roughness and jaggedness of my living practice, or should I work to contextualize these anecdotes? Yes. Of course I must. I am trying to contextualize. Or, to put it in another way, there are two, maybe three distinct voices. Does it work to keep these separate and unique, or should I mash them together? How can I indicate those intentions to my reader? Or, do I need to express those intentions? Can I instead impose upon them the illegibility as an empathetic experience?
Chapter 10

In Conclusion

Disability culture is a huge area to research and then to extend to the rhetorical and physical landscape. So I decided to concentrate again on my art.

This text is full of my creative turnings. I have done them with an attitude, as art-conscious actions. I think of it as if it is as manageable as our breath. I’ve been maintaining this certain attitude of attention, and waiting for the gestures I engage to speak to me. I am miming to speak. I am a puppet-maker, a doll-maker and a post-modern mime learning my craft.

My life, and academic artist journey is now stitched together, by memory, through my art-making. I’ve widened my disability culture journey by pushing at the edges of my endurance. From the work so far, it’s difficult to know which turnings took, because the idea of a turning implies some sort of intentionality. I have been trying to perform a research turning through a deployment of my art as research methodology. I’ve looked for my potential to turn in different ways: reading text, travelling, camera-looking, drawing, painting, smoking, watercolours, animation, scooting, puppet-making, performing, editing, hyperlinking, writing and on and on.

My methodology involves taking a conceptual framework that enacts a kind of conviviality, a being together of these different works, quilting them into a cautious precariousness. Disability art as life.
Figure 31: Bird
So much of what I have done remains outside this text. I am overwhelmed by what is not here. For example, here is my puppet, Bird, (Figure 31) sneaking into this conclusion. As a hopeful gesture, she carries the weight of my concern for the world and she becomes something more than fabric and thread. And then, reviewing my bibliography, I am sent back to Agamben’s text, *The Coming Community* (Agamben 2003 1), a meditation on the limits of our potential humanness. Even in skimming the “Table of Contents”, I want to dive back into the reading and rumination.

I imagine my text, in its completion, as a hopeful gesture towards constituting, in some way, a future community.

Should I continue?

And what will I do? For one thing, I’m working on a zine, a small comic starring El. I’ll stay engaged in the decolonizing project. And I’ll monitor and play with new media forms that centre a disability aesthetic. I like the ideas I have now. I will carry them until I am gone.

If this becomes a novel about the character El’s unsettling her life, I think I will call it *Terrain*.

There is no conclusion.
Bibliography


Fritsch, Kelly. Keywords for Radicals the Contested Vocabulary of Late Capitalist Struggle. Chico, CA: K, 2016. Print


Appendix A

List of Puppets

Appendix A is a partial list of the puppets that I sewed during my disability awakening over the last six years. As a near daily task, I engaged my mind and body in performance in a process of adapting my identity as disabled artist, driving a mobility scooter in this epoch, the Anthropocene.

Exhibition Images may be viewed at: https://figgefuture.wordpress.com/2015/05/05/thesis6-2/

Pants—A doll-sized pair of blue jeans with wheels for feet.

Lump—The top half of Pants, Lump is white with red paisley and she has arms that flail energetically as she bumps along.

Nobody—Two legs and no arms.

Bird—I fly Bird around where I sit in my scooter, flapping her wings while Karl and Nevin hand out and blow bubbles around the room. Bird is calico patterns, with pinks, reds and greens. Her head goggles, bobs and floats with intention as she determines where she will go but she is always dependant on me for her flight. Expressive in her own embodiment, she flaps in small concentric circles around my legs.

Lavender—An awkward two-legged, two-armed being who walks sideways as one leg depends on the other for her to get from here to there.

Pip—A small sock puppet with blue and red triangles, Pip acts in the video Need to be Adored.

Bee—Made from scraps of a black sweater and a couple of feathers.

Lettuce—Tiny blue flowers cover her fabric. She has two legs, one pink and shorter than the other.
**Gelinda**—Made in Cuba from borrowed clothing and dental floss, she sings opera beautifully with her body.

**Green**—A small female human shape, made from a green skirt, she lies on a mattress that sits atop a wooden circle on wheels.

**Red**—Made in Ann Arbor, Michigan to perform with a group of four students from Petra’s Kuppers’ Disability Studies class in 2013. She is tall; three times the size of the other puppets. She has two long legs, no arms and a whole in her torso.

**Ellyfigbee**—Blue calico covered in nickel sized red circles. I puppet her wearing elbow-length gloves of the same fabric.

**Chester**—Made from red and white chequered fabric stuffed with socks, Chester has one leg and two arms.

**Elson**—Yellow with one blue-green arm, she is a rod puppet and one of my last.

**Azavein**—A fully-limbed, grey sock marionette.
Appendix B

List of 11 Videos

Appendix B is a list of the videos discussed above. Links where they can be viewed are on my Vimeo and YouTube pages.

Dwelling Drift (Summer 2012)
Mobility One (Spring 2012) Knight (Spring 2012)
Mobility in 4 Parts (Undisciplined 2011)
Fingernail Moon (Winter 2013)
How do you know you are alive (ECIR Puppet Performance 20 February 2013).
Wrapping up (Post classroom puppet presentation in Kinesiology Spring 2013)
Clip #188 Puppet walking upstairs
Need to Be Adored (Fall 2014)
Station 14 Video of me explaining my work
Puppet Performance in Hall of Mac Corry (2014)
Havana Performance with Cuba class and Lisa Figge: Mobility Scooter (Spring 2013)
## Appendix C

### An Incomplete List of the Artists Who Have Influenced Me

<table>
<thead>
<tr>
<th>Artist</th>
<th>Influencer</th>
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<tbody>
<tr>
<td>Adrian Piper</td>
<td>Eliza Chandler</td>
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<td>Adrienne Rich</td>
<td>Ellen Samuels</td>
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<tr>
<td>Aleks Bragoszewska</td>
<td>Faith Wilding</td>
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<tr>
<td>Alice Neel</td>
<td>Frida Kahlo</td>
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<tr>
<td>Amanda Cachia</td>
<td>Georgia O’Keeffe</td>
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<tr>
<td>Amy Tan</td>
<td>Graeae Theatre</td>
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<tr>
<td>Ana Mendieta</td>
<td>Guerrilla Girls</td>
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<td>Andrea Fraser</td>
<td>Hanna Wilke</td>
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<td>Ann Hamilton</td>
<td>Henry Darger</td>
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<td>Jane Kirby</td>
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<td>Jana Sterbak</td>
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<td>AW Lee</td>
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<td>Kathy Huberland</td>
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<tr>
<td>Colette Urban</td>
<td>Kiki Smith</td>
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<tr>
<td>Diamela Eltit</td>
<td>Kim Renders</td>
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<tr>
<td>Eli Clare</td>
<td>Laura Ferguson</td>
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114
Laurie Anderson  Rebecca Horn
Leah Decter  Rhianon Gutierrez
Leroy Moore  Robin Alex McDonald
Lindsay Fisher  Rosemarie Trockel
Lisa Bufano  Sarah Smith
Lisa Visser  Sharon Wolfe
Liz Crow  Shirin Neshai
Loree Erickson  Simi Linton
Lorelei Ericson  Sophie Calle
Lorna Simpson  Sue Austin
Louise Bourgeois  Sunaura Taylor
Marina Abramovic  Sunny Kerr
Marlene Dumas  Susan Sontag
Martha Rosler  Suzanne Lacy
Martin Ramirez  Ted Rettig
Mary Kelly  Tracey Emin
Matt Rogalsky  Tracey Guptill
Maya Lin  Trinh T. Minh-ha
Mierle Laderman Ukeles  Vanessa Dion Fletcher
Miriam Schapiro  Vera Frenkel
Nek Chand  Vaginal Davis
Orlan  Vito Acconci
Persimmon Blackridge  Yoko Ono
Petra Kuppers