A Stitch in time:

MOURNING THE UNNAMED

Kim Collins

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ABSTRACT

This project uses archival material and artistic production to think through the institutionalization of people labeled with intellectual disabilities, forced textile labour and those who remain unnamed in both records and in death. It asks us to question how we can mourn for those we cannot name. This project begins with two archival records. One a yearly Annual Report of the Orillia Asylum for Idiots written in 1887, the other a 1928 Industrial Training document for the Ontario Hospital School Orillia. Both documents relate the history of Huronia Regional Centre, though neither bore its name. It aims to employ art to tell stories that lawsuits and policy can not; that art as remembrance, as mourning, as responsibility, will allow us to mourn those we cannot name.

KEYWORDS:

Archival material, arts-informed, institutionalization, people labeled with intellectual disability

POINTS OF INTEREST:

- People labeled with intellectual disabilities in Ontario were placed in institutions like the the Orillia Asylum for Idiots and the Ontario Hospital School, Orillia.

- People died in the institution. Many people in the 1800s were listed by patient number not names in archival material.

- Women were forced to sew different items in the institution including coffin liners.

- Many people who died in the institution did not have respectful burials.

- This project uses arts-informed methods to think about how we can mourn for those who are unnamed.

- To learn more about this project go to:
  https://astitchintimemourningtheunnamed.wordpress.com

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To patient 357 and all those who lived, died, and survived this institution, thank you for sharing your stories. You are not forgotten.

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PROLOGUE

Photography Courtesy of Anne Zbitnew
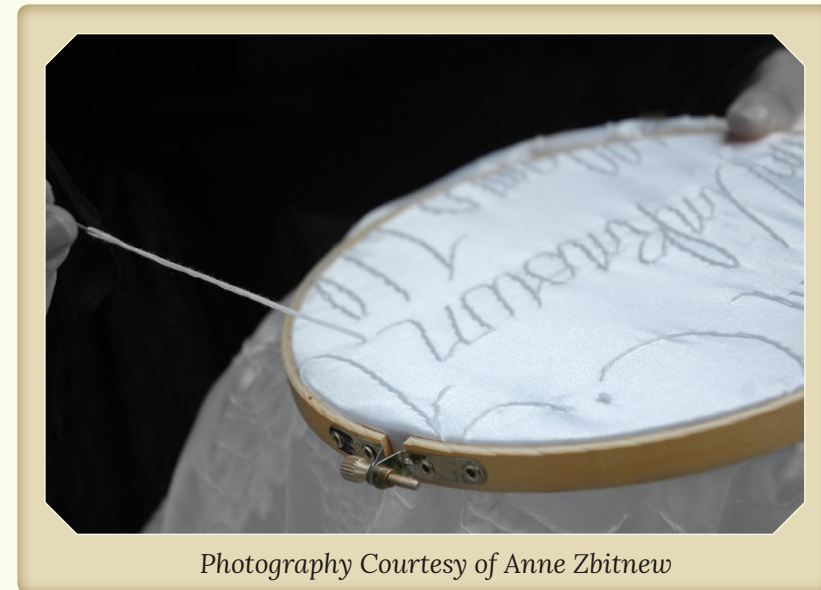
"*Stories are all we are*"
(King, 2003, 32).

For those who were incarcerated in institutions like the Orillia Asylum for Idiots and the Ontario Hospital School Orillia, traces of lives are seen through absences. It is through the appearance and disappearance of patients in institutional records that stories can emerge. From these records a story will be embroidered in textile. This story revolves around the appearance and disappearance of patient 357 and the forced exploitative patient labour of women in the sewing department during the late 1800s and early 1900s.

According to sociologist Thomas Cottle (2002), any interpretation of a story is in fact a "reaction to a reaction; it is a reflection" (p. 539). Cottle goes on to state that, "in this regard, every encounter with a narrative represents an invitation, a calling to confront the Other constantly lurking in my own being" (p. 540). We may choose not to see the Other in ourselves, to

renounce this reflection, but we can never leave that story behind. Cherokee storyteller Thomas King tells us that the stories we hear "are ours now. We can do what we want with them, retell them, forget them, cry over them," but we can never "say in the years to come that [we] would have lived [our] [lives] differently if only [we] had heard this story. [We've] heard it now" (King, 2003, p. 119).

The process of witnessing these stories is fraught with complexities and responsibilities. Philosopher Emmanuel Levinas, as cited by social work professor and critical disability studies scholar Ann Fudge Schormans (2011), argues that there are responsibilities when we have a relationship with the Other. Levinas asserts that being attentive to the Other and their knowledge, their stories and their memories, involves four responsibilities. They are "to learn and study them (listen and read), to teach them (speak and write), to keep and preserve what has been learned (repeat lessons learned, find new questions) and to remember them" (Fudge Schormans, 2011, p. 17). Fulfilling these responsibilities requires that we are attentive to how we attend to the Other. While Levinas's articulation of these responsibilities contains within it ableist assumptions about normative minds and bodies, it does articulate the need to hold the stories of others and to share them in whatever ways we can and in whatever ways the story demands.

As a witness to the memory and stories of the Other how might we embody listening? Social anthropologist Paul Connerton (1989) posits that memory is "sedimented in the body and in objects" (p. 13). Working with stories in an embodied practice of textile and fabric art stirs up the sediment of memory. Recently memory studies has made a cultural turn. Cultural historian Marek Tamm (2013) asserts that a cultural approach to studying memory understands memory as culturally produced and mediated rather than an incidental product of social groupings (p. 461).

Like weaving embroidery floss in and out of fabric, sewing theory and mourning stitch a story in the present. Psychologist Jerome Bruner (1987), quoting Sartre, states "a man is always a teller of stories, he lives surrounded by his own stories and those of other people, he sees everything that happens to him in terms of these stories and he tries to live his life as if he were recounting [them]" (p. 5). Bruner (1987) takes this argument further by stating that the way in which we form narrative becomes a pattern for how we organize and understand our experiences and memories as well as how we will conceive of events in the future (p. 9). Thus the weaving of memory through fabric opens up space for us to reimagine the future and tell stories through artistic practice.

Anthropologist Parin Dossa (2009) states that stories "restore our humanity because they provide flesh to what may otherwise remain abstract" (p. 5). This project is one of storytelling. My aim is for this project to add flesh to the lives, labour, and deaths of those patients from the Orillia Asylum for Idiots and the Ontario Hospital School Orillia who remain hidden in archival records, obscured behind institutional typeface. After all, in the end "stories are all we are" (King, 2003, p. 32).

Photography Courtesy of Anne Zbitnew

Chapter One:

ORIGIN STORIES

This black and white photograph features me sitting on a low stool in Victorian/Edwardianesque mourning garb embroidering a panel of a white casket liner in the centre of the Huronia Regional Cemetery. This mourning garb is drawn from Victorian mourning practices (Hoffman & Taylor, 2007; Smart, 2011; Strange, 2002; Bedikian, 2008). The low stool symbolizes the number of Jewish patients at the Orillia Asylum for Idiots and the Ontario Hospital School Orillia who were denied respectful, culturally appropriate mourning rites, such as sitting Shiva in which mourners sit closer to the ground (Schottenfeld, 2006; Rubin, 2014-15; Ontario Hospital School Orillia, 1971a, n.p.; Ontario Office of Prisons & Public Charities, 1887, p. 26).

At the Huronia Regional Cemetery there are 571 marked graves and numerous unmarked graves ("Huronia Regional Centre Cemetery", n.d.). The number of unmarked graves within this cemetery is disputed by survivors (Dolmage, personal communication, 2015). The grave markers listed with patient numbers have been moved and

Photography Courtesy of Anne Zbitnew

disturbed both by people stealing the markers and the installation of sewage pipes (Oved & Alamenciak, 2013; Oved, 2015).

The lack of respectful burial for those incarcerated in this space is an example of dehumanizing treatment contributing to the institutionalization of violence and neglect (Malacrida, 2015, p. 60-63, p. 99-102). The structure and organization of total institutions created space in which dehumanization became commonplace (Goffman, 1961, p. 6; Malacrida, 2015, p. 59-60).

Photography Courtesy of Anne Zbitnew

The photograph is intended to shed light on the ways in which the past can tangle and twist the present, the ways in which one story is often linked with several, the generations who lived and died, now left unknown. It draws attention to Canada's process of erasure of both labeled people and the Indigenous people who originally inhabited the land on which the institution is situated. This project is not just mourning those unnamed and past, but also the present and the potential dystopian future.

Reflexive Introduction

I have been thinking recently about time. About the time needed to think through and reflect upon beginnings and endings. How we understand them, how they shift in our memory over time, how we ritualize them, and how our understandings of beginnings and endings assist us in making sense of our world and tangle us in a relationship with the 'Other'.

Perhaps the start of my research interests began years ago; my face pressed against the cool orange, brown, and yellow paisley-patterned linoleum listening to the hum of my mother's sewing machine. Or perhaps it began much later when I worked at a day program with labeled people where I ran an expressive arts program. We sewed, at first for pleasure, to collaboratively produce art, then for agency profit. Or perhaps it began more recently with my foray into the archival material and a 1928 industrial training document which outlines how to teach low-grade imbecile women and girls how to sew and lists what they were forced to produce (Ontario Hospital School Orillia, Ontario, 1928, p. 21). The 1928 description of how to teach women and girls how to sew is not dissimilar from the document I was asked to write at the day program.

These beginnings are interwoven, requiring time for reflection as they weave their way through my memory and onto the page. It is through this weaving of memory and stories that I position myself in this research. Reflexivity allows the researcher to trace their movement in the process (de Freitas, 2008, p. 3). As such, I will be using reflexivity to negotiate my way through this project. I do this with some hesitation. Disability studies scholar Brenda Jo Brueggemann (1996) suggests that reflexivity has the potential to elide the position of the Other with that of the researcher (p. 19). My desire is to situate myself within my research and I aim for a more ethical relationship with the Other (de Freitas, 2008, p. 8). This process of reflexivity is not without risk. It is often easier to leave things unsaid, unwritten; however, this obscures a dynamic process of research (Crooks, Owen, & Stone, 2012, p. 59). As a researcher currently living without a disability label, I understand the importance of this reflexive process as I position myself both within this project and within disability studies more broadly. In this way I attempt to reflexively story myself through and in this research.

The story of the Orillia Asylum for Idiots begins in 1876 under the direction of Dr. Wallace who argued that "care for 'idiots'" required social isolation (Rossiter & Clarkson, 2013, p. 6). Over the next thirty-five years the grounds expanded as did the patient labour force (Rossiter & Clarkson, 2013). When the asylum first opened it was home to 114 patients, but changes in public policy led to an increase in the number of residents (Radford & Carter-Park, 1993, p. 109). By the mid-1960s the facility housed over 2000 people (Jones, 1992, p. 341).

In 1936 the institution changed its name to the Ontario Hospital School Orillia to reflect a more progressive ideal; however, the level of care did not change. It has been noted that the cost per patient at Huronia was actually the lowest in the world (Rossiter & Clarkson, 2013, p. 13). The institution began training programs which provided it with free labour and allowed for a decrease in staffing costs. Patients labored on the farm, did laundry, sewed, cooked meals, cleaned, and took care of other patients. While the original function of institutionalization was to ensure a level of self-sufficiency once patients were released, their capacity became critical to the expansion and sustainability of these institutions (Beckwith, 2016, p. 9). Those most capable were then confined both because of their disability and their ability. Those patients deemed capable of moving into community settings were too valuable to the economic functioning of the institution to be released (Radford & Park, 1993; Beckwith, 2016; Malacrida, 2015).

Disability studies scholar Jihan Abbas and Mad studies scholar Jijian Voronka (2014) assert that institutions did not consider intellectual disability but were concerned with those people assumed to be socially and economically marginalized and thus deemed feebleminded (p. 122). Once adults and children entered the institution, they were unlikely to leave.

The Orillia Asylum for Idiots and the Ontario Hospital School Orillia were constructed architecturally to control. Abbas and Voronka (2014) posit that the architecture and spatial geography of institutions speak to the notion of patients as threats (p. 124). The institution was set back from the roadway so not to be visible; groups of patients were segregated into wards overlooking the inner courtyard while staff offices faced the lake or roadway; there was no privacy in toilets or showers but a continued state of surveillance; tunnels connected buildings ensuring that some patients never left the confines of the buildings; and wire-crossed shatterproof glass was used in doors and windows. This emphasized that those housed within the locked rooms were subhuman, in need of management and segregation (Abbas & Voronka, 2014). Survivors have stated that they were told they would never leave, that there was no way to escape the institution, that they would die there (Seth, personal communication, 2015).

While the terminology of spaces and labels that people encounter has changed since the days of the Orillia Asylum for Idiots, I would question whether the underlying ideology has changed. Historian Dustin Galer (2014) notes that institutions operated under a cultural fear of idleness. It was believed that this idleness would have detrimental effects on the social and physical functioning of disabled people (p. 4). The sewing program at the Orillia Asylum for Idiots thus both reduced the cost of incarceration and kept the women free from idleness. This sewing program began by the second medical superintendent, Dr. A.H. Beaton, was a gendered program in which women and girls sewed and mended items used by patients and staff within the institution. In my experience in day services, labeled people are still engaged in sewing and other labour with the idea of staving off idleness rather than being seen as producers of art or as valued employees.

The changing name of the institution––from the Orillia Asylum for Idiots, to the Ontario Hospital School Orillia, to the Huronia Regional Centre—reflects cultural and social changes towards the treatment of people labeled with intellectual disabilities (Rossiter & Clarkson, 2013, p. 13, 22). The agencies I worked for also changed their names to reflect emerging cultural values and new funding models––from integration associations to community projects and social enterprises, all providing what is commonly known in the field as day services. The changing language and names rarely changed the day-to-day lives of those 'served' by the agencies.

The labels people attract have also changed since the opening of institution. The introduction of the IQ test in 1904 brought with it three classifications of those deemed feebleminded. Idiots were described as the lowest functioning, imbeciles were believed to attain the mental age of a three to seven year old, and morons were considered to have the highest functioning and were therefore not easily identifiable (Carey, 2009). These classifications were not fixed identities but moved with scientific advancement and eugenic theory. Throughout this project I will use the term "labeled people" as a method of demonstrating the fluid and illusory nature of labels. I will also use the term "survivors" and person-first language when a person has self-identified with such language.

Sociologist C. Wright Mills (2004) asserts that we should start from where we are; doing so, however, requires that we attend to where we have been (p. 54). The origin story of my interest in this research and that of the institution are linked, weaving in and out of each other like embroidery floss through fabric.

Research Purpose and Questions

This project uses archival material and artistic production to think through forced textile labour, the institutionalization of people labeled with intellectual disabilities, and those who remain unnamed in both records and in death. It asks us to question how we can mourn those we cannot name. This project begins with two archival records: one an Annual Report of the Orillia Asylum for Idiots for the year of 1886 written in 1887, the other a 1928 Industrial Training document for the Ontario Hospital School Orillia. Both documents relate the history of Huronia Regional Centre, though neither bare its name.

The Annual Report in 1887 lists the death of patient 357. A boy of nine, his life and death are reduced to one line of text (Ontario Office of Prisons & Public Charities, 1887, p. 96). The little boy with the initials W. A. J. was identified in the record as 357. He lived in the institution for two years, seven months and 24 days. He died March 7, 1886 of hepatic disease (Ontario Office of Prisons & Public Charities, 1887, p. 96).

There are several ways in which hepatitis can be contracted: through contaminated food and water, through sexual activity, and through unsterilized medical equipment ("Hepatitis", n.d, n.p.). Over a number of decades medical inspectors noted the filthy and overcrowded conditions in which patients were forced live within the institution. Several reports mention blood and pus on bedding, dried fecal matter, patients bathing in toilets, patients sleeping two to a bed, and the constant and overpowering smell of urine and feces (Ontario Hospital School Orillia, 1931, p. 3-4, 12; Ontario Hospital School Orillia, 1937, p. 2-3, 6; Ontario Hospital School Orillia, 1946, p. 3). Inspectors also noted medical equipment that was not properly cleaned (Ontario Hospital School Orillia, 1931, p. 9). In 1971, a report notes

that several boys have rectal gonococcal infections and suggests "these boys often were quite defenseless and may well have been used by residents from other cottages" (Ontario Hospital School Orillia, 1971b, n.p.). Survivors have also related horrific abuse, including sexual assault, at the hands of staff (Dolmage, personal communication, 2015). It is possible that patient 357 contracted hepatitis before entering the institution; however, there are a number of ways in which patient 357 could have contracted the disease—through abuse, neglect and violence—during his short-lived time within the institution.

Photography Courtesy of Anne Zbitnew

The Industrial Training document from 1928 describes how to teach low-grade imbecile girls and women how to sew. The training document lists the items these girls and women were forced to produce, including coffin liners (Ontario Hospital School Orillia, 1928, p. 21). Exploitative patient labour has long been part of the history of institutionalization. In 1876, the year the institution was opened as the Orillia Asylum for Idiots, the Medical Superintendent Dr. J. M. Wallace, in his first yearly report to the Inspector of Asylums, Prisons and Public Charities, envisioned a training program to be offered at Orillia. He stated that the buildings are well positioned for "the purposes of a Custodial Asylum, but the training department must be small and imperfect until more extensive and suitable buildings are erected" (Ontario Office of Prisons & Public Charities, 1876, p.

261). Ten years later, in 1886, the Medical Superintendent, Dr. A. H. Beaton, writes that while there is still limited space for male work, the "females, of course, are always engaged at domestic work the year round" (Ontario Office of Prisons & Public Charities, 1887, p. 91). Beaton goes on to highlight the knitting being done by patients and the beginnings of patient labour in the sewing room (Ontario Office of Prisons & Public Charities, 1887, p. 9). These documents and research questions demand both artistic production and accessible dissemination.

This work uses a feminist lens to make connections between gender, female labour, institutionalization, and the deaths of unnamed patients, including patient 357. Relations of care have long been a feminist concern (Kittay, 2011; Morris, 1997; Watson, McKie, Hughes, Hopkins, & Gregory, 2004). The care of those who lived, laboured, and died within the Orillia Asylum for Idiots and the Ontario Hospital School Orillia directly relates to feminist ethics and frameworks.

The history of forced institutionalization and forced textile labour for those labeled with intellectual disabilities is slowly fading from public memory. Or perhaps more accurately, it is actively being forgotten. This project weaves and tangles the threads of memory and forgetting in its artistic production. I wonder about the ways in which art can tell stories that lawsuits and policy cannot; art as remembrance, as mourning, as responsibility, will allow me to mourn those I cannot name.

Photography Courtesy of Anne Zbitnew

Chapter Two:
HOW DO YOU SEW THEORY?

This photograph features me sitting on a low stool embroidering a casket liner in Victorian/Edwardianesque mourning garb while in front of the statue of Egerton Ryerson at Ryerson University.

Ryerson's namesake, Egerton Ryerson, served as Superintendent of Education for Upper Canada between the years 1844 and 1876 ("Egerton Ryerson", n.d.). Ryerson believed that education, particularly of the poor, immigrants, and Indigenous people, was essential to society as these groups were the "harbingers of a worse pestilence of social insubordination and disorder" (Harper, 1997, p. 193). Ryerson insisted that an investment in a common school system would instil habits of discipline, punctuality, and good conduct. He sought a kind of discipline exerted through obedience. He wanted students to internalize respect for authority and make it the essence of their character; to 'civilize' their behaviour (Milloy, 1999). Egerton Ryerson promoted separate and forced education of Indigenous children in residential schools, with the intention of ensuring these children "would be made French in heart and mind" (Milloy, 1999, p. 14).

This photograph is intended to shed light on the ways in which the history of the university, as a structure which reproduces the normative values of Western culture, is entangled with the institutionalization of labeled people and residential schools for Indigenous children (Dolmage, 2015; Carey, 2009; Carlson, 2010; Milloy, 1999; davis halifax, 2017). Disability

Studies scholar Jay Dolmage (2015) asserts that academia in Canada has as its foundation ableist understandings of ability. It was academics who developed and implemented testing methods which separated those who were deemed capable from those deemed feebleminded. Disability justice activist Mia Mingus (2011) asserts that ableism "undergirds notions of whose bodies are considered valuable, desirable and disposable" (para. 18). This photograph also highlights the rise to prominence of medical superintendents and social workers through the education system (Dolmage, 2015; Carey, 2009; Carlson, 2010).

Reflexive Introduction

Push the needle up through the bottom of the fabric. Don't pull too hard. Bring the needle backwards and make a line. Pull through, but not too hard. Bring the needle up through the bottom of the fabric. Weave the needle tip back in, halfway through the previous line. Pull the floss through. Don't pull too hard. Repeat. Repeat. Repeat. Thinking about those I never knew, I watch the wooden embroidery hoop turn in my hand and the needle stitch its way through the fabric.

A warm blast of air hits me as I step into the workshop. Sunlight streams over bolts of fabric, macrame plant holders cradle baby spider plants, and the sound of sewing machines drowns out the noise from the street. I choose tan linen fabric, forest green thread, and a spiral pattern. So much of my life feels like spirals, coming to a similar point again and again. Sometimes less neatly than others. I am here to learn how to sew theory, or at least I think I am. I am not even sure I understand that sentence—what does it even mean to sew theory?—let alone know how to 'do it'.

My mother first taught me to sew. I loved the sound of the machine, the power of the needle as it raced and ripped through the fabric and occasionally through my fingers. My mother taught me the tricks that her mother taught her, which she learned from her mother before her. I come from a long line of 'crafty' women. The painstaking detail of embroidery was something I never mastered. My parents' basement is still full of my abandoned, half-finished projects.

Fabric, floss, and hoop in hand, we follow the instructor up the stairs to a large table surrounded by stools. Awkwardly we introduce ourselves; the woman across from me starts. It's an artsy bunch. All of the women around the table crochet or knit or sew. When my turn comes, I pull at the weight of my bag and bring out a single, slightly creased, piece of paper.

"I am here to learn how to sew theory," I say, "and I would like to begin by following these instructions." This statement is followed by a rather incoherent attempt to describe my project.

I hand over the sheet and look around. The instructor takes it and without a word we begin. First how to hold the needle, next how to thread it. Next the stitches, then more complicated techniques. No variation in instruction from 1928 to now. I don't share the weight of this document or the instructions we are now following. I don't yet know how, or perhaps more honestly, I am not sure I want to share my complicity in this history.

Months later in a dank, dark pub after a long day at a conference, the beer goes down smoothly. I catch the end of a discussion.

Someone queries, "But what is affect?"

"It's a reaction to the poststructuralist focus on discourse" comes the reply.

The woman next to me leans over, whispering, "I thought discourse and emotion were linked?"

"Me too," I say.

I am not sure how you can separate one from the other. In my mind they swirl, froth, and ferment like the beer in front of me. Maybe it's like the spiral pattern I started with at the workshop: it's not a linear movement of one from another, but a tracing of genealogy. So this is where I will start from. Not at the beginning but just a spot on the spiral.

Push the needle up through the bottom of the fabric. Don't pull too hard. Bring the needle backwards and make a line. Pull through, but not too hard. Bring the needle up through the bottom of the fabric. Weave the needle tip back in, halfway through the previous line. Pull the floss through. Don't pull too hard. Repeat. Repeat. Quietly thinking about memory, death, labour, and all those beginnings and endings left unsaid, unnoticed, buried.

Feminist Poststructuralism

Poststructuralism asserts that people engage in and produce "social and psychological realities" (Davis, 2000, p. 88). This engagement, called discursive practice, is understood as foundational to language and language-like systems which work to create dominant and resistant meanings. Chris Weedon (1987), cultural theorist, argues that language and symbols work to demarcate and strengthen particular norms (p. 94). That these facts are positioned as 'common sense' often works to obscure the power relations which have produced them. This can work to hide the instability of meaning and possibility for resistance.

Historian Joan Scott (1992) argues that by positioning experience as central to knowledge building we have dismissed the historical realities that created those experiences. Under this framework experience is interrogated (p. 25-26). Thus experience becomes part of discourse in which subjects are constituted and reconstituted (Leavy, 2007, p. 96). Education

scholar Bronwyn Davis (2000) asserts that poststructuralism allows us to see that the "specificity of those experiences, and their intensity, need not be markers of the bounded self, but, rather, the moments at which an experiencing being comes to know the possibilities being made available" (p. 31). This multiplicity of possibilities drives and is derived from the subject's presence in the collective: the subject and the collective are both engaged in constituting, continuing, and re-imaging the discourses made available (Davis, 2000). Using this framework there is no one way of knowing, no one true experience, no single story. It takes into account the social, historical, and lived realities of the subject and the entanglement with discourse as that which creates experience.

Davis (2000) goes on to state that within a poststructuralist framework, answers, truth, and stories are always shifting depending on our position within discourse(s). Stories can emerge in and through multiple discourses, shifting and transforming depending upon the symbols and language used, the issues, judgements, and the discursive spaces open within these factors (Davis, 2000, p. 89). In this way we narrate ourselves and others into existence within these multiple, contradictory and tangled discourses.

Gender and Women's Studies scholar Lynee Lewis Gaillet (2012) suggests that the essence of archival research is

Photography Courtesy of Anne Zbitnew

storytelling (p. 51). Unlike other archival work, this project does not seek to triangulate or confirm data; rather it takes archival material, stories, as the basis for artistic processes. Historian and art critic Hal Foster (2004) writes that artists working with archival material aim to bring to light historical information which is lost or displaced (p. 4). The aim of archival art is to bring viewers into engaged discussion with the work (p. 6). The desire of archival art is to "turn belatedness into becomingness, to recoup failed visions in art … to transform the no-place of the archive into the no-place of a utopia" (Foster, 2004, p. 22). Taking this further, this project seeks a heterotopic space, one in which art can act as a mirror and open disability as "multiple, as always emergent, and as intra-corporeal" (De Schauwer et al., 2017, p. 277; Foucault & Miskowiee, 1986).

Feminist theory starts from the understanding that the plights of individual women are connected to each other (Mann, 2012, p. 9). This is not to conflate or confuse the history of institutionalization experienced by women at the Orillia Asylum for Idiots or the Ontario Hospital School Orillia with my position as a former staff person at day services or my position as a researcher, but rather to consider the larger systemic issues affecting labeled women and their relation to all who identify as women. However, it is important to highlight some potentially hidden dangers within this feminist viewpoint. Fudge Schormans (2011) posits that "difference does not create alterity, rather alterity is what determines difference" (p. 13). Citing the work of Levinas, Fudge Schormans (2011) argues that a "collapsing of myself and the Other" is a form of violent erasure, and that alterity must be recognized without "normalizing knowing" (p. 13-14). Rather it is a relationship of responsibility in which the humanity of the other is acknowledged and valued (Fudge Schormans, 2011, p. 17).

Poststructural feminism rejects the idea that there are core features of any group or core identities. Rather as feminist sociologist Susan Archer Mann (2012) argues, "group concepts and identities are simply social constructs—social fictions—that serve to regulate behaviour and exclude others" (p. 215). This is important when considering how difference is constructed and internalized. It is our unconscious acceptance of language which dictates and governs our sense of self and our understanding of normalcy (Mann, 2012). Poststructuralism takes the epistemological stance that all knowledge is valid and attempting to prioritize one truth over another is a fallacy of a master narrative. In this way, poststructuralism argues that reality is dependent upon discourse.

Stories and narratives told through textile and fabric art have long been a site of resistance for non-disabled women. Feminist theory and its focus on other methods of constructing knowledge is in line with weaving narratives through textile art (Mann, 2012, p. 180). For example, the violent history of warfare in Afghanistan has been told by women through the weaving of rugs. These rugs highlighting the hardships of women and families began to surface during the 1970s and feature images of weaponry and military machinery. The difficulty in tracing the carpet weavers has meant that the art form is still shrouded in some mystery ("Modern Afghanistan: Making Meaning in the Aftermath of Conflict", 2015, n.p.).

Embroidery has long been used as an accessible art medium. The feminist art collective, Feminsto, in the 1970s, used embroidery to question the exclusive nature of art (Parker, 1984, p. 208). Textile work has formed the basis of resistance to exploitative labour practices as well. Frau Fiber and the Synchronized Sewing Squad use choreographed, public sewing as an accessible form of "theory-making" that highlights the need for reflexivity

Photography Courtesy of Anne Zbitnew

and reframes conversations about memory, death, and textile labour (Beasley, 2008, p. 99-100). Changing the conversation about memory and remembrance is an important aspect. Connerton (1989) states that "knowledge of all human activities in the past is possible only through a knowledge of their traces" (p. 13).

These traces of lives and stories from the past weave into arts-informed research which is concerned with a particular art form, one that flows from the substance of the research (Cole & Knowles, 2008, p. 9). The archival material in this project informs the primary choice of medium—textile. Following the natural flow of the project, other mediums and method/ologies have been added to relate to multiple audiences.

For many labeled women, textile art and art in general have not often been a site of resistance but of therapy. A prime example of this is the Judy Richardson collection of art by Huronia Regional Centre residents. Richardson was an occupational therapist who worked at Huronia Regional Centre and organized an art therapy class for residents to 'express' themselves. Years after her death the collection was donated to the Creative Spirit Art Centre. This collection has been exhibited, always under Richardson's name. The names of the disabled incarcerated artists are lost. Only letter designation and brief description remain for some. For example, "K. is almost non-verbal. She will only draw sometimes. Near Xmas, she will

draw Dad's house(s), tree, sister, family events" (Dempsey, 2013, para. 17). This is demonstrative of the ways in which disabled artists get erased from their art and their labour. The Toronto Star article about a recent exhibition of Richardson's work describes her as a hero, but other than two references to 'patients' it makes no mention of the artists who produced the work (Dempsey, 2013).

When thinking through art production/process and allyship with labeled people this is an example of the dangerous and precarious ways in which non-labeled allies can prioritize or be prioritized rather than the labeled people producing the art/knowledge. Little is known about Richardson (Dempsey, 2013). Did she view herself as an ally? What did allyship mean to her? Did she feel comfortable with her work at Huronia Regional Centre? The fact that she took labeled people's art with her when she left, thus erasing their contributions, is disconcerting. My hope for this project is not prioritize my position as an ally, but rather to tell stories of, and mourn, those hidden within archival records.

Chapter Three:
CREATING A PATTERN

This colour photograph is taken outside of a Toronto Community Housing Corporation building in downtown Toronto. It features me sitting on a stool in Victorian/Edwardianesque mourning garb embroidering names and patient numbers of the dead on a panel of white casket liner.

This photograph is intended to highlight patterns, to draw attention to issues of deinstitutionalization, transinstitutionalization, housing, and the desires of survivors (Seth, Slark, Boulanger, & Dolmage, 2015). The movement towards deinstitutionalization gained momentum in the 1970s after the deaths of two patients from the Rideau Regional Centre and an influential report on the care of people labeled with intellectual disabilities authored by Walter Williston which urged deinstitutionalization (Rossiter & Clarkson, 2013). The closure of the institution in 2009 and the process of moving patients into the community did not necessarily bring with it freedom from terrible conditions or surveillance. Rather many survivors may now find themselves living below the poverty level on the Ontario Disability Support Program, living in deplorable conditions in subsidized housing (if they can access that service) and subject to the continued surveillance of these social programs. Political economist and Mad studies scholar Tobin LeBlanc Haley (2011) asserts that many of the "legacies of institutionalization, such as isolation, poverty and social stigma are reproduced within and through welfare state structures and community based institutions" (p. 1). Survivors

have stated that this transfer from one form of institution to another is not what they wanted; what they wanted were homes (Seth, personal communication, 2015).

Reflexive Introduction

It's late afternoon as I write. I am sitting on a public bench enjoying the last rays of a surprisingly sunny February day. A man saunters past carrying a copy of the Tibetan Book of the Dead; two children run past me, one with his fingers shaped like a gun; the nearby funeral home locks up for the evening; death and mourning are all around us. Like disability, death is made in the spaces between us. Mourning is an attempt to understand the meaning we make of death, collectively and individually.

Political historian Jason Glynos (2014) asserts that how we understand death is mediated by others' responses to death; for death to become loss, for grief to become mourning, death must be publically acknowledged or witnessed. Philosopher and gender theorist Judith Butler (2004) reminds us that it is through the process of mourning that we can understand the connections between us. Through mourning "something about who we are is revealed, something that delineates the ties we have to others, that shows us that these ties constitute what we are, ties or bonds that compose us" (p. 22). Glynos (2014) posits that to determine how death matters to us we must determine how those who are deceased demonstrated our connection to the world, both real and symbolic (p. 145). Through acknowledging the symbolic, our fantasies, we can begin to think about loss and mourning as a creative, political force for individual and social change.

The rays of the February sun have faded, reams of papers and pencils lay scattered around our living room. I am on my knees forcing my hand to remember cursive while I scrawl the names of those believed to be buried in the Huronia Regional Centre Cemetery onto a to-scale paper pattern. It's an uncomfortable process. My knees ache, my hand is cramping, the muscles in my back rebelling against the hunched position, and my mind reeling with the pages and pages of names. I had not fully considered the ways in which patterns can hurt.

Among my patterns are drawings and aerial photographs of the Huronia Regional Centre Cemetery. It seems impossible to believe that all of the people listed in a still incomplete registry were buried in such a small area of land. The early dimensions of the cemetery are, in fact, still under dispute (Dolmage, personal communication, 2017). The Ministry of Community and Social Services (MCSS) asserts that the site was originally smaller than it is today (Dolmage, personal communication, 2017). One of the outcomes of the class action lawsuit against the government of Ontario by survivors was the creation of a registry of names of those buried in the cemetery (Seth v. Her Majesty the Queen in Right of the Province of Ontario, Settlement Agreement, 2013, p. 22). A full registry completed to survivors' satisfaction has yet to be finished.

British historian Julie-Marie Strange (2003), in writing about pauper burials in England during the Victorian period, states that these burials highlighted the shame of poverty and resulted in the denial of mourning rituals and customs (p. 150). Strange relates a newspaper article in 1892 in which the need for graves had outpaced the space available. Employees dug up the graves and smashed coffins in order to deposit the bones into a basket and then into a rubbish heap (Strange, 2003, p. 159). This example, while from England, can offer some insight into how the small space of the Huronia Regional Centre Cemetery could potentially hold such a large number of bodies.

Archival material reveals little documented evidence of burials. In a 1931 report, Dr. Fletcher states that "generally the burial service is read in the case of indigent funerals by the chief attendant" (Ontario Hospital School Orillia, 1931, p. 9). He goes on to relate that this is scandalous but ultimately not the fault of the hospital, but rather the local church (Ontario Hospital School Orillia, 1931, p. 9). With this information in mind it seems unlikely that patients were buried with coffin/casket liners. Currently, in Ontario, those living on social assistance can receive financial support for funeral costs, if, of course, they meet all of the requirements (Antonacci, 2013; "Funeral Expenses", n.d.). Young and Russell (2017) write that those labeled as homeless or unclaimed are "buried in single graves, often on the outskirts of cities. There is no name on the grave — usually just a number, corresponding to their file in the cemetery's record system" (para 21).

The cab pulls into the cemetery grounds and spirals through winding roads. Elaborate headstones and monuments dot the manicured landscape. With a chuckle under his breath and a "have fun" the cab driver lets us out at the Funeral Centre. The ground floor is spacious and beige, the subtle smell of over-blooming flowers wafts from the crematorium wall. There is an air of opulence. Ushered into a smaller room, we find seats. The room and its occupants are varying shades of white. A life cycle celebrant begins the session with chimes, candles, and jokes about RRSPs. Drifting off, I wonder about the bodies under those monuments. Who made their casket liners?

A 1945 report on the profit-generating programs at the Ontario Hospital School Orillia states that the institution made $14, 931.96 that year (Ontario Hospital School Orillia, 1947, p. 1). While it does not specifically list what items were included in the industries sold, it is clear from earlier records that sewing was an industry at Orillia from at least as early as 1886 (Ontario Office

of Prisons & Public Charities, 1887, p. 91). One could speculate that items produced in the sewing room were sold for institutional profit. Or perhaps these liners were made for staff as patients sewed staff uniforms and many staff lived and died on the institutional grounds (Ontario Hospital School, Orillia, 1968, p. 4; Ontario Hospital School, Orillia, 1948, para. 3; Ontario Hospital, Orillia, Ontario, 1928, p. 21).

It's an early morning in late February. The sunny skies have given way to cold, blowing snow. Huddled in our living room, I sit surrounded by patterns and cemetery maps. Piles of paper everywhere, pens, scissors, tape, tea, the obligatory paper cut; creating a textile pattern is surprisingly similar to creating a research design. Both begin with an idea, a starting point. That idea changes and morphs over time—a seam allowance here, an extra inch there. Eventually the idea, the pattern, begins to take shape, and you are left with yet another starting point. Throughout this iterative process, I have noticed absences in text, in archival material, and in my own praxis. Patient 357 weaves in and out, appears and disappears. And I wonder, how can we mourn people we cannot name? Or perhaps more succinctly, how can we mourn?

Method/ology

This study engages in interdisciplinary method/ology. It flows in and through theory to weave together archival, historical, narrative, feminist, critical disability, visual and arts-informed approaches. It is through storying that theory and method/ology emerge (Dossa, 2009).

This project draws from arts-informed practices; it is influenced by the arts although not arts-based (Cole & Knowles, 2008, p. 6). The purpose of this research is to engage in alternative formats and representations in order to reach a variety of audiences and to think through a question in an

"accessible, evocative, embodied, [and] empathic" way (Cole & Knowles, 2008, p. 6, 8). As an interdisciplinary inquiry, this project tangles and twists theory with method/ology in order to provide a response to the current situation (Savin-Baden & Wimpenny, 2014, p. 7) and to highlight the patterns of the past.

The archival material from which this project springs was accessed through the online index of the MCSS. The mass of 65, 000 records released as a result of the class action lawsuit brought against the Ontario government by survivors has been sorted via a series of search terms. These search terms have snowballed; one term has led to another and increased the scope of the search. Searched terms have included the following: industrial training, vocational training, yearly reports, medical reports, Annual Reports of the Inspector of Prisons & Public Charities, inspection reports, death records, burial records, sewing, sewing machines, restraint records, and laundry reports. The records have ranged in date from 1876 to 2007. This was done to offer a long-term view of the institution, to provide a sense of the transition from industrial training to vocational training to sheltered workshop and finally to the closing of the institution.

While the research encompasses a large range of archival material, it directly flows from two records, one from the Victorian period and one from the Edwardian. The mourning process in the Victorian and Edwardian era required female labour. Women, often family, or the local midwife or hired women, prepared the house, the mourners, and the body (Smart, 2011; Hoffman & Taylor, 2007). In many cases this necessitated the production of a coffin/casket liner. With this in mind, I have started the mourning process for those unnamed in the 1886 document by making and embroidering a casket liner. Following archival images of post-mortem photography

(Donovan, n.d.) and the increased production of rectangular-shaped caskets over tapered coffins in the late Victorian period (Smart, 2011; McKillop, 1995; McIlwraith & Hummer, 2005; Little, Lanphear & Owsley, 1992), I have chosen to produce a casket rather than coffin liner.

Despite having sewn for years, I felt it was important to follow the steps set out in the 1928 document. I have attended sewing and embroidery classes with the expressed intent of embodying each step in the industrial training document. The liner design has been based on archival post-mortem images, Victorian/Edwardian coffin/casket design, and the historical widths of fabric available during the time period (Donovan, n.d.; Smart, 2011; McKillop, 1995; McIlwraith & Hummer, 2005; Little, Lanphear & Owsley, 1992; Strange, 2003; Strange, 2002; Kiplinger, n.d.).

Patients and their labour appear in the margins, almost as afterthoughts in the documents. Patient numbers from the 1886 Annual Report of the Inspector of Prisons & Public Charities and names from the cemetery registry are embroidered on the periphery of the casket liners in the same colour thread as the liner. In this way patient names and numbers are only visible through close inspection or through touch, through feeling––almost all but lost as in the institutional documents. In a similar way the voices of those institutionalized are all but lost in academia and in the

Photography Courtesy of Anne Zbitnew

historical records as they need to be more than just thought; they need to be felt. The names of those from the registry were chosen to match the time frame of the two documents from which this project flows.

Gary Cole and Ardra Knowles (2008), working and researching in adult education and creative inquiry, assert that in some cases academic language does not have the ability to communicate the full complexity of our experiences (p. 4). When thinking through how to mourn those you cannot name, words seem to fail. Rather it is the thoughts and imaginings evoked through art that perhaps best capture the emotion of this research question.

While there are lists of those who are assumed to be buried in the Huronia Regional Centre Cemetery, these lists are far from complete as they do not include those whose deaths went unrecorded, including those who survivors say were murdered and buried on the grounds of the institutions (Seth, 2015, personal communication; Ovid & Alamenciak, 2013). To underscore the ways in which those lives left unnamed, unrecorded, or redacted intersect with our own, threads from the embroidery will be left to hang, to tangle, to remind us of patients, like 357, whose deaths we should mourn and bear witness to (Ontario Office of Prisons & Public Charities, 1887, p. 96). The back of the liner is messy; some threads of the names and numbers of those embroidered are connected, others are dangling, just as lives were/are messy and lived, beneath the institutional typeface. Names and numbers are also connected together; sometimes the floss between them is knotted, other times not. To highlight the unknown names of patients who died within the institution, every third, fifth, and seventh name is listed on the casket liner as 'unknown'. These names and numbers are handwritten in cursive. In the archival material the names and numbers of those mentioned in the records are always typed; only the medical superintendents have handwritten names

in the yearly reports. My intent is to personalize these names and numbers, to feel them, through handwritten cursive script.

Through engaging with feminist theory this project seeks to expand our understanding of what counts as theory and what counts as knowledge (Mann, 2012, p. 11-12). People labeled with intellectual disabilities have often been on the margins; excluded from the creation of knowledge, their personal lives and stories are discounted. Theorizing disability from a feminist perspective requires that we reimagine disability, difference, and what we think we know. Disability studies and feminist scholar Susan Wendell (1996) asserts that valuing disability would involve learning about and respecting different ways of being in the world, both in mind and body (p. 84).

Poststructural feminism also highlights the need for new discourses which can open up space for difference and the desire for difference. Disability Studies scholar Eliza Chandler (2014) suggests that through desiring difference we can create communal spaces which can make new meaning of ontologies and epistemologies of disability (p. 38-39). This centering of the non-normative is required for research which hopes to engage with labeled people. A feminist understanding of allyship informs my desire to open academic spaces for

Photography Courtesy of Anne Zbitnew

traditionally excluded, non-normative modes of knowing, production of knowledges, and art processes. This desire requires my reflexivity in order to engage with the precarity of allyship and artmaking within the bounds of

university structured research. This framework takes into consideration the opportunities provided by failure and non-normative moments while also being grounded in the discursive.

The project includes a series of photographs taken by Toronto artist Anne Zbitnew. The photographs feature performative embroidery, each highlighting how theory tangles with method/ology, relating it to the time period in question. One of these photographs, a modern take on a Spirit photograph, features actor Andreas Prinz and crimson roses made from the death records of 11 patients in 1886. Inspection reports from 1933 and 1937 list the horrid conditions in which patients lived but mention that the institution could be improved with the addition of cut flowers (Ontario Hospital School Orillia, 1931; Ontario Hospital School Orillia, 1937). Crimson roses were chosen, as this colour of rose was used to symbolize mourning in the Victorian period (Stott, 2016; "Flower Meanings", n.d.). There are 15 roses; the sum of three plus five plus seven.

Photography Courtesy of Anne Zbitnew

The project is hosted on a Wordpress.com site titled "A Stitch in Time: Mourning the Unnamed" (https://astitchintimemourningtheunnamed.wordpress.com/). The website contains the photographs from the project, music composed by Toronto-based musician Jeff Scarrott in response

to reading selected archival material and viewing the production of the casket liner, and plain language information about this project. The site also includes links to advocacy and survivors groups, documents from the litigation, Huronia Regional Centre cemetery information, and clear language instructions on how to access archival records, both through the online index of the MCSS and the Archives of Ontario.

Chapter Four:
LETTING IT FLOW

This colour photograph features me in Victorian/Edwardianesque mourning garb on a low stool embroidering a panel of a white casket liner with the names and patient numbers of the dead by the banks of the Humber River in Toronto. This photograph highlights my experiences with self care while working on this project and the importance of location, the 'where' of methodology—the geographical location—and its effect on myself and the research (Anderson, Adey, & Bevan, 2010, p. 590).

The photograph was taken in the Étienne Brûlé park in Toronto. Étienne Brûlé was one of the white colonizers who traveled beyond the Saint Lawrence seaway, living and moving among the Wendat ("Étienne Brûlé", n.d.; Turner, 2015). The Humber River, originally part of the Carrying Place Trail, was used by early colonizers as a trade route. The Carrying Place Trail was a path to the north used by Indigenous communities who traveled by canoe up to Georgian Bay (Turner, 2015; Robertson, 2010). This route went from the Humber River, across the Holland River to Lake Simcoe, and on to Georgian Bay. It is part of the reason the land on which Orillia is located was settled by colonizers through treaty rights, and this location was central to establishment of the Orillia Asylum for Idiots (Radford & Carter-Park, 1993; Turner, 2015; Robertson, 2010).

"Goin home, goin home by the waterside I will rest my bones/ Listen to the river sing sweet songs to rock my soul"

(Hunter, 1970, track 7)

I love this river. The concise, clipped, ripping sound a flock of geese make when eating grass around you, watching as their flight startles the salmon into jumping; deer hiding in the trees; the overgrown path that leads you unexpectedly to an explosion of daffodils; tiny orange feet as ducks wag their feathered bottoms in the air; regal, black-crested cormorants spreading their large wings to dry while lounging on rocks; the weasel who lives in the cracked rock; the way the river, frozen and flooded over the banks, creates a new world of ice blocks; the sound of snow crunching under your boots on crisp February mornings; the little purple flowers that bloom in the woods heralding the coming of spring; the feeling the electricity in the air when you are caught in the rain on a humid summer day sheltering in the widespread arms of a maple tree; and the musical score that your partner brings to every communal river encounter.

But with the river comes death. The pollution that flows down to the lake, the dying and decomposing salmon after the fall run, the fallen leaves and broken trees after a windstorm, the destruction of the river bank and path after the frozen river overflows, the white colonizers who traveled up the Carrying Place Trail and brought with them the practice of institutionalization, and the way the flowing water makes present and simultaneously erases the presence of linear time.

As feminist scholar Kristin Blakely (2007) suggests in their work on feminist research, my intention has been to feel through this research, not just think it (p. 60). This process has been been an affective and emotional one. In this way, my process has become part of the product (Reinharz, 1992, p. 212). My emotional engagement has served "as a resource in this process for exploring new ways of writing and representing research" (Blakely, 2007, p. 64). Anthropologist Ruth Behar (1996), citing ethnologist and psychoanalyst George Devereux, asserts that what is happening within the researcher, the emotional process, must be made known if we are to understand the research (p. 6). However, this process of feeling my way through this project has not been comfortable.

The sun is barely up. It's already hot and humid. My t-shirt clings to me as I weave my way through the tangle of trees, shrubs, and grasses to the river bank. I have been up for hours. I tell my partner that it's too hot to sleep, but the weight of archival material keeps me up. Reading over documents I move between rage and heartache. I am not sure I know how to hold space for both emotions; I am not sure I know how to bear witness. But I do.

Like the performative mourning of the Women in Black, my stance "is not that of the victim or survivor, but of the witnessing listener and empathic bystander, the mediating agent who speaks for others, those turned into 'bare life'" (Athanasiou, 2005, p. 46). It is the "silenced memory of collective" traumatic deaths that demands my witness "when nothing is left to be said, and, at the same time, to echo what has gone unsaid and remains to be said" (Athanasiou, 2005, p. 46). Writer and political activist Susan Sontag (2003), citing writer Henry James discussing the horror of witnessing war, writes "the war has used up words" (p. 22). In a similar fashion, I wonder about the inadequacy of words as they relate to the horrors hidden within archival records.

I hesitate. I waffle and wait. I wonder at the ways this project will fail—fail to mourn, fail to bear witness. I fear this despite knowing that art, writing, and photography all require forms of failure, that they ultimately encompass death. Philosopher Jacques Derrida would tell us that all writing is marked by death (Naas, 2003, p. 75). In a similar fashion, literary theorist Roland Barthes argues that the punctum, a point in the photograph, is always "already dead and gone" (White, 2015, p. 183). Whether an image, a word, or a piece of art, once produced it is static, lost in time. Sontag (2003) writes that a photograph freezes memory (p. 19).

Months later, a friend and I trample through the path by the river. The grass is wet and slick. I try to keep upright, balancing the stool on one arm and the dress bag on the other. The weight of the stool, ornate with metal and glass claw feet, the weight of history, threatens to topple me. We are stopped by the beauty of an arching branch framing the path. While we fumble with the dress fasteners I tell Victorian jokes.

"Do spiritualists move in high society?"

"No, they are just mediums" ("Victorian London", n.d.).

Encased, I perch precariously. White embroidered fabric billows down my lap like a waterfall. There is a mixing of past and present, a tangle, of what was, and is, that breaks my heart.

If everything is flowing like the river, what else is there to hold onto besides feeling?

Art making and accessible dissemination

The process of art making has been one of moving in and out of expectations, of failure, of re-imagining. Feminist disability studies scholar nancy viva davis halifax (2009) writes that failure opens up new ways of perceiving and understanding, but that the process of getting it wrong, of

failing, is not an easy one (p. 76). Philosopher María del Rosario Acosta Lopez (2014), thinking through Friedrich Hegel, suggests that art opens the door to remembrance, transforming facts into a living history (p. 72). American philosopher Angelica Nuzzo (2012) postulates that art is the memory of spirit. This recalling enables history to be understood in a new way, to be seen differently (p. 141). The type of memory produced through art becomes "a reconciliation between subjective-collective memory and world history" which is both "historically past and fully present" (p. 143). Art is therefore not the opposite of forgetting, rather it is a form of resistance to oblivion (Lopez, 2014, p. 72). Art's resistance, its remembering, opens up space for both mourning the past and exercising justice (p. 73). My aim is not to foist a responsibility for resistance onto art, but rather to work with the tangled and knotted relationship between art, mourning, and failure.

My intention on each of the four panels of the casket liner was to ensure that every third, fifth, and seventh name was listed as 'unknown'. Despite this intention and the following of a paper pattern, this did not happen. There are lines in which the third or the fifth or the seventh is listed as a name rather than as unknown. There is something telling about these unintentional omissions. Those lives that remain untold in records continue to remain unknown in the production of art intended to mourn their deaths. Literary scholar Christian Moraru (2000), referencing Levinas and Derrida, asserts that we are
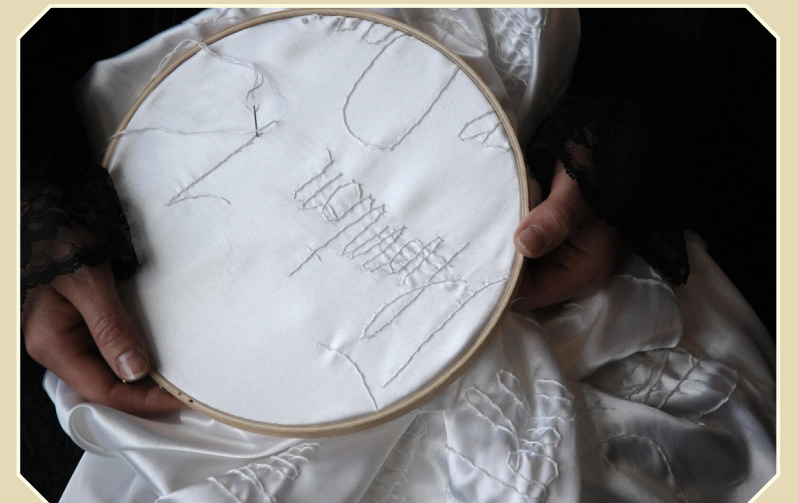
Photography Courtesy of Anne Zbitnew

accountable to the Other and it is through naming that this responsibility is made evident (p. 53). This highlights some of the difficulty in mourning those we cannot name, as both Levinas and Derrida suggest that it is through proper names that we come to embrace the Other. In using 'unknown' to indicate those who remain unnamed in the records, I am naming and re-naming, claiming and perhaps re-claiming, stories that are not my own, both attempting and failing to fully embrace the Other and my responsibility to them.

The threads from the embroidery on the casket liner which were intended to hang, to tangle, and to twist into the present, often wound themselves back into their own names or into the names of others. I wonder at how this might mirror the reality of these lives and stories. How many of these lives still tangle in the present? Kathy Jones (1992) writes that those who lived in the institution shared a sense of commonality, community, and history (p. 342). How many of those in the institution wound back into themselves or each other like the threads on the liner in order to survive the institution? It can be difficult to find these storied lives in the archival material. They must be actively sought out, unwrapped where possible, but are often still left tangled and knotted. Storytelling, like embroidery, is not always linear; it can often be fragmented, looped, disjointed.

The photographs were an attempt to play with traditional Western Victorian gendered norms and mourning rituals. In Victorian iconography seamstresses were often depicted as angelic, often in white, often looking heavenward (Edelstein, 1980). In the five images framing each chapter, I am looking directly at the viewers, challenging them to engage. Photographer Tom Gallovich (2014) suggests that the viewer will follow the gaze of the subject (p. 59). In this way, the photographs both act as a mirror and attempt to bring the viewer into conversation, not only with the need to publicly mourn the deaths of those unnamed and unknown, but also with our complicity in both this history and its present.

Through the adoption of mourning dress in the photographs, I am both employing and subverting Victorian gendered mourning traditions. Victorian mourning rituals were stringent. After the death of Prince Albert, the mourning practices of Queen Victoria became widely followed by all classes (Bedikian, 2008, p. 40-41). Relatives of the deceased were to wear black clothing as a public display of respectable grief for the three stages of mourning (Linkman, 2002; Bedikian, 2008; "19th Century Mourning Practices (revised)", 2011). This display of mourning was dependent upon the relation to the deceased and the mourner's gender. Women, widows and daughters, were expected to wear black crepe, eschew all jewelery, social events, and mirrored surfaces for the first stage, also known as full mourning. In the second stage, or half mourning, women were able to incorporate jet jewelry and at time pearls or gold could be worn and secondary colours such as grey could be added to dresses. In the final stage, female mourners were able to rejoin society (Linkman, 2002; Bedikian, 2008; "19th Century Mourning Practices (revised)", 2011). The development of life insurance, Funeral and Burial Societies, and a booming mourning industry enabled working classes to have access to mourning clothing and funeral rites (Bedikian, 2008, p. 40-41).

I am not a relative of those who died at the Orillia Asylum for Idiots in 1886, yet I adopted the mourning dress for those I do not know. As with the performative mourning of the Women in Black, this public mourning for those unknown whose lives were made 'bare life' displays "an inexcusable aberration from the customary propriety of mourning" (Athanasiou, 2005, p. 43).

After the advent of photography, post-mortem photographs of the deceased in their casket or group shots of mourners (often surrounding the casket) were not uncommon (Linkman, 2002). Large groups of mourners were preferable for these images as they indicated the respectability of the deceased (Linkman, 2002). Yet in four of the chapter framing photographs, I am pictured alone, but attempting to call the viewer in to join me. Artists and education scholars Stephanie Springgay and Rita Irwin (2004), referencing artist and writer Suzi Gablik, suggest that mixing art with social responsibility embraces a participatory aesthetics which encourages the viewer to no longer merely observe but become part of the creation process through opening up space for a multiplicity of interpretations (78). It is through an exploration of interwoven mediums—textile, text, photography, music, discourse—that social relations and identities can become clear (Springgay & Irwin, 2004, p. 78).

The photographs attempt to tangle temporalities, to position this work on a spiral rather than in a linear fashion. Suzanne Thomas (2004), founding member of the Centre for Arts-Informed Research, referencing art critic John Berger and photographer Jean Mohr, suggests that photography "embodies the ambiguous nature of knowing in arresting temporality, and releasing temporality to create an abyss that exists in space between the moment of recording and the moment in which a reader engages with an image text" (p. 66). The use of black and white in "Beginnings," which frames chapter one, is an attempt to set an historical stage, while the photographs titled "Institutions" and "Patterns" both use reduced colour levels and shading to mix history with present. "Take me to the River" is fully in colour to draw the viewer back into the present in which these stories and histories still twist and tangle with our own. "Desiring Disability" uses black and white, textured effects coupled with the red of the roses to blend past, present, and future.

Art historian Nicola Foster (2008), thinking through Barthes, asserts that it is through both words and images that we can be connected to what it means to be human, to the Other (p. 83). Going further, Barthes posits that the image can offer an unexpected and immediate experience prior to discourse (Foster, 2008, p. 84). Citing philosopher Giorgio Agamben, Foster (2008) suggests that a good photographer "knows how to grasp the eschatological nature of the gesture" (p. 85). It is through the affect opened by punctum that multiple readings of the photograph can unfold (davis halifax, 2008).

Throughout this project I have been journaling not only as a reflexive exercise but also as a way of marking progress. I experimented with alternative forms of journaling as a method of representing the various forms and mediums used in this research project. I used Instagram to document aspects of the research; as a method of recording the ways in which one reading led to another and where this reading took place; as way of acknowledging and marking that geography can affect the nature of knowledge production (Anderson, Adey, & Bevan, 2010, p. 590). Much of this project took shape by the banks of the Humber River, often without pen or paper, so voice memos and text notes on my phone were also used for journaling.
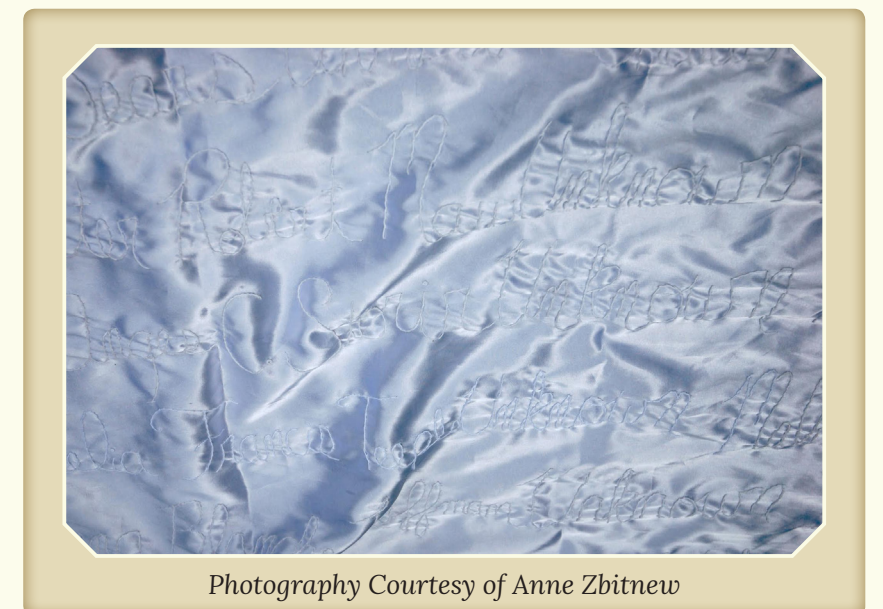
Photography Courtesy of Anne Zbitnew

It was while journaling by the banks of the river that the importance of sound became apparent: the sound of needle through fabric; the sound of water rushing over rocks; the sound of music as it embodies experiences. Western Protestant and Baptist Victorians also used the language of music to transmit an understanding both of death and the afterlife (Smart, 2011; Hoffman & Taylor, 2007). Sanford Fillmore Bennett, writing in the late 1860s, composed the lyrics for "In the sweet by and by," writing "we shall meet on that beautiful shore" ("The Music of Mourning", n.d., para 3). In 1864, Robert Lowry composed "Shall we Gather at the River," writing "Yes, we'll gather at the river/The beautiful, the beautiful river" ("The Music of Mourning", n.d., para 5). The impact of geography on the mediums used to understand the terrain of mourning cannot be understated. The usage of alternative mediums for communication, songs, or poetry can open up space to create different forms of knowledge (Douglas & Carless, 2013, p. 55).

My intention with this project has been to ensure as much access as possible for labeled people, survivors of institutionalization, community members, and those in the academy. There are a multitude of ways researchers are attempting to increase access: through discussions around plain language, through the use of technology (including websites), through the integration of arts-informed methodologies, and through the enhancement of co-production techniques and the use of alternative formats (Garbutt, 2009; Cumming et al., 2014; Kidney & McDonald, 2014; Rice, Chandler, Harrison, Liddiard, & Ferrari, 2015).

Disability studies scholar Ruth Garbutt highlights the ways in which plain language is a practice to which academics should aspire. Garbutt (2009) suggests following the title of an academic paper with a website in which information is provided in a number of accessible formats (p. 370). This project has taken up the suggestion of a website as a method of accessible dissemination.

For myself, engaging in slow scholarship—that is moving through a graduate program at a part-time pace—has allowed me the time and space to realize how little time and space I have and to learn that my process requires a great deal of both. Working within institutional timeframes and funding constraints has meant that some of the ideas I had hoped to bring into this project were not possible to realize.

This project is an attempt to work within these time constraints and to ensure as much accessibility for labeled people, and all people, as possible. Thus my research dissemination includes a plain language website, photographs, music, links to other organizations and archival material, and tactile textile art; it has also welcomed suggestions from labeled people on how best to present the material in an accessible format.

Access is a moving target, one that we are always striving for but rarely reaching. And I suspect art is similarly always in motion.

Photography Courtesy of Anne Zbitnew

Chapter Five:
DISCUSSION AND CONCLUSION

This final black and white photograph with textured scratches is a modern take on a Victorian spirit photograph. Photography was newly invented in the Victorian period (Sontag, 2003). During this period in Western culture, the Christian tradition was still dominant but there was a growing belief in science and an interest in the spiritual and otherworldly realms (Cadwallader, 2008). There was also a belief that photography could capture the spirits of the departed. A number of photographers were charged with fraud because of these spirit photographs, not because the grievers wanted the charge brought but rather because the state demanded prosecution (Cadwallader, 2008).

In Victorian spirit photography the mourner would be featured with an ethereal version of their loved one (Cadwallader, 2008). For the first time the griever was fully present as such photography was not focused on mourning rituals but allowed for the display, forever etched onto film, of grief (Cadwallader, 2008). These photographs represented the afterlife as an idealized world, a world for which the Victorians were striving with their campaigns to clean up slums, educate the poor, and house and train people labeled with intellectual disabilities (McLaren, 1990). This idealized world was one in which patient 357 and those housed in the institution would not have been desired.

In this version, Andreas Prinz, an actor who self-identifies as person with a disability, is featured as the departed in the idealized world, and I take the role of the griever. By inserting disability into a Victorian Spirit photograph I use feminist disability studies scholar Alison Kafer's notion of 'desiring disability' to present a future or a reading back onto the past in which labeled people not only exist but are valued (Kafer, 2013). While this notion of desiring disability carries with it Western and white understandings of disability, it can be useful in thinking through ways in which disability might be anticipated.

This photograph features me sitting on a stool looking at the camera while wearing a Victorian/Edwardianesque mourning garb with my hands folded on my lap. To my right side is a small table with black tablecloth upon which there is a white pitcher of roses. To the right of the table is the ethereal spirit of Andreas Prinz. Two of the medical inspection reports outline the deplorable conditions in which people were forced to live and argue that cut flowers would make the situation better (Ontario Hospital School Orillia, 1931; Ontario Hospital School Orillia, 1937). The inspectors were wrong.

Reflexive Introduction

I have been embroidering for hours now. My body tells me in no uncertain terms that I am not physically made to do this for so many hours in a row. Yet we forced others to do so in institutions. Globally women's bodies are still forced to labour in these ways. My clothing tells the history of their labour. I, on the other hand, can put down my hoop. I get up and walk away and I sink back into the couch upon my return.

I pick up the needle again. Eliza Jane Carr. Mary Young. Unknown. 357. Unknown. Euphemia Stevenson. Unknown. The floss and fabric become names, lives I never knew, but mourn. As the needle moves in and out of the fabric my partner flicks on the TV. The Manchester benefit concert, One Love, is on. Thirteen days ago 23 people were killed in Manchester. Four days ago over 90 people were killed in a bombing in Kabul. One hundred and thirty-one years ago 11 people died while incarcerated in the Orillia Asylum for Idiots.

Social anthropologist Athena Athanasiou (2005) asks us to question what forms of life are considered human. Who is valued, cared for, and mourned (p. 44)? Disability and equity studies scholar Anne McGuire (2010), thinking through Butler, asserts that some "lives are understood to be more liveable than others" (p. 10). Disability is often understood as unlivable life. "Non-disability is wholeness, where disability is brokenness; non-disability is life, where disability is 'not quite a life' or mostly death" (p. 13). Sociologist Rod Michalko (2004) writes of how Tracy Latimer's parents grieved the loss of their daughter at her birth as a disabled baby (p. 108-109). This eugenic discourse framed and continues to frame the lives and deaths of those who experienced institutionalization, not only in segregated total institutions but also today with perhaps more subtle forms of neo-eugenics (McGuire, 2010; Goffman, 1961; Carlson, 2010; Malacrida, 2015; Seth et al., 2015).

It's late afternoon as we walk and roll into the classroom. Awkwardly we attempt to form a circle with only square desks. Once achieved, we each tentatively take a sheet of paper and read aloud: "What are your cultural practices around death/dying?", "In a routine week when does death/dying come up for you (in conversation, in media, in your work, in your activism)?", "When did you first become aware of death?", "What are the aesthetics of death?", "How are you planning for your own death?"

Silence follows. Collectively we decide to begin with what feels safest—

our first memories of death. There are stories of farm life, the loss of grandparents and pets, and funerals. The conversation circles and twists, thoughts and ideas tangle and spiral back onto one another. One person mentions the #IfIDieinPoliceCustody trend on Twitter, another writing their own obituary, another how death doulas are a growing trend among those with privilege but how women of colour have been doing this work for years. I tell a story.

Walking up the steep steps to the head office of the 'community project' at which I worked I wondered about the location of the main office in an area the 'members' couldn't access. I had been summoned to pick up fabric; the expressive arts program I ran was now deemed profitable and we were to sew sellable items only, mainly aprons and bags. I settle into a uncomfortable chair in the director's office. While chatting, I learn that a family member of a woman in the arts program had just died, but the family was not going to tell her.

Wistfully, the director reflected, "She's lucky, really, she doesn't have to deal with the hassle of the funeral or grieving."

Critical disability studies scholar Madeline Burghardt (2015), considering the family narratives surrounding the institutionalization of family members, writes, "we are all formed within the stories of our families" (p. 1071). In her study, the siblings told ambiguous family stories in which the institutionalized sibling was often absent (p. 1072). Family members articulated understandings of these secrets in terms of shame and protection and navigation and maintaining the secret. These secrets and silences did not end with the closure of institutions (p. 1081). Some people labeled with intellectual disabilities still experience silence around mourning and grief.

Literary scholar Marianne Hirsch (2016) states that "we share a common

vulnerability emerging from the condition of living in bodies in time" (p. 80). However, Hirsch (2016) notes that this vulnerability is produced and imposed based on social, cultural, economic, and political differences. Early eugenic ideology positioned labeled people as being in need of protection, which justified being secreted away into segregation within institutions; neo-eugenic practice continues to use forms of institutionalization to position labeled people as outside of normative mourning rituals (Carlson, 2010; Malacrida, 2015).

The story finishes in silence. Other stories begin to flow. A person tells of working in a group home with labeled people where attending funerals was discouraged as it might make the clients 'behavioral'; another person speaks of a labeled family member who was not allowed to join the family at the hospice to say goodbye. I ponder the spaces of mourning and the ways in which we deny our own or others' connections to each other and the Other.

Photography Courtesy of Anne Zbitnew

Butler (2004) writes that there is a distance between us and the Other, but also a connection, an unknowingness: "I am nowhere without you … I cannot muster the 'we' by finding the ways in which I am tied to 'you' if I am to know you." (p. 49). We are tied, tangled, inexplicably. We are undone by each other.

Discussion and Implications

King (2003) tells us that storytelling is dangerous. Similarly Derrida (2001) asserts that mourning is dangerous. Neither warning should stop us from engaging in such practices, but rather suggest that we proceed with caution and careful deliberation. In fact, King and Butler would both posit that storytelling and mourning can be transformative (King, 2003; Butler, 2004).

Derrida (2001) writes that all successful mourning must ultimately fail as it is impossible to fully internalize the Other.

> What is an impossible mourning? What does it tell us, this impossible mourning, about the essence of memory? And as concerns the Other in us, even in this 'distinct premonition of the Other,' where is the most unjust betrayal? Is the most distressing, or even the most deadly infidelity that of a possible mourning which would interiorize with us the image, idol or ideal of the Other who is dead and lives only in us? Or is it that of the impossible mourning, which, leaving the Other his alterity, respecting thus his infinite remove, either refuses to take or is incapable of taking the Other within oneself. (Derrida, 1990, p. 6).

Jack Halberstam (2012), writing in gender studies, states that transformation is inevitable, that it occurs on the margins, in failure (p. 27). Failure can be understood as a method of invoking the disability commons. Those on the margins, those failing, expose the norms and make clear the boundaries of normality. For those who fail to meet social norms there is space outside of these boundaries to create non-normative alternatives. In these spaces collaboration and collective alternatives can be developed and fostered. It is in these spaces that critical disability studies scholar Dan Goodley and Katherine Runswick-Cole argue that the disability commons allows for subversion of normative standards.

Goodley and Runswick-Cole (2014) state that dis/humanism "simultaneously acknowledges the possibilities offered by disability to trouble, reshape and re-fashion traditional conceptions of the human (to 'dis' typical understandings of personhood) while simultaneously asserting disabled people's humanity (to assert normative, often traditional understandings of personhood)" (p. 2). In a similar vein, Davis (2000) writes that there are tensions between the "access to specificity" and "access to group membership" (p. 24).

The failure to comply with normative understandings opens space for resistance and subversion. Runswick-Cole and Goodley (2015) invoke the disability commons and articulate that this commons draws on the history of disability politics and non-normative moments in order to make roome for resistance through "imagination, appropriation and subversion" (p. 179-180). This type of poststructuralist feminist theoretical framework takes into consideration the opportunities provided by failure and non-normative moments.

While failure can present alternatives and possibilities, its felt experience should not be forgotten. Writer Merri Lisa Johnson (2015) refers to the "feels like shit" quality of failure; that is of being a body that does not meet non-disabled norms (p. 255). However, it is important to note that the common space has often been a space of exclusion for many. Sociologist Jonathan Short (2014) writes that it is difficult to think about the management of such spaces without "confronting the problem of social difference" (n.p.).

Thinking through the commons with critical social work scholar Kristin Smith (2015), we can see that mourning "shapes ideas we hold about who we are, about nationhood, and the ways we mark (and unmark) who belongs with the borders of citizenship" (p. 33). Derrida (2001) writes that political

organization requires spaces/places of mourning (p. 19). People incarcerated within the Orillia Asylum for Idiots and the Ontario Hospital School Orillia were positioned outside of and excluded from the rituals and the political organization of mourning.

When speaking about white social workers mourning losses of social services, Smith (2015) writes that comprehending loss only becomes possible through "failed knowing" in which we understand history as always in process and fluid (p. 25). In this way, Smith argues, we can live with our complicity and our responsibility to account for this harm (p. 25). Smith (2015), citing Charlotte Delbo writing of her experiences in an Auschwitz concentration camp, writes that, through failing to listen to the stories of those who have suffered, we fail continuously in our attempts to face extreme suffering (p. 37).

Derrida articulates a respect for the alterity of the Other, which frames the act of mourning not only as failure but also as a call to responsibility. Drawing on educational theorist Michalinos Zembylas, Smith (2015) states that this type of inconsolable mourning is one in which we embrace a relationship with the Other and a history for which there is no closure (p. 40). For Smith (2015), constructing the "past as always partial, always in process, and forever in need of interrogation" can allow social workers to move past the confines of 'white amnesia' (p. 42). Thinking through Smith, I wonder about the ways in which this critical witnessing and inconsolable mourning opens up space for us to reshape our encounter with disability and to move past a disability amnesia also often imbued with and framed through whiteness. Feminist theorist Sara Ahmed (2005) states that it is only in the face of suffering and rage, in the tangle of past and present, that we can hope for change (p. 84).

Derrida asserts that mourning is work and in this way our mourning has the potential to do something. Mourning is a type of work which does let us go (Smith, 2015, p. 39). Athanasiou (2015) writes that "if the process of 'letting go' is what differentiates 'normal' mourning from 'pathological' melancholia" the performative mourning of the Women is Black is instead focused on refusing to let go and "rearticulating public mourning as a historically situated practice of dissent and alternative responsiveness in our present world as it is now" (p. 48).

Having spoken with survivors, I know that grief and individualized mourning occurred for those who died in the institution. This project is not an attempt to supplant survivor mourning with my own, but rather to bring into conversation the connections between art, mourning, failure, past, and present, "to solicit a becoming, to investigate a transformation, to petition the future always in relation to the Other" (Butler, 2004, p. 44)

Endings

Photography Courtesy of Anne Zbitnew

EPILOGUE

I sit on the subway. The shadow of the black dress bag looms as it hangs from the handrail. It is headed back to the costume shop, the piles of paper that have covered our living room for months are now smaller, tidier, replaced with piles of books I have been saving for later since the project began; the paper, as you can read, is almost finished. And yet. There is a gnawing feeling, an ache in my chest, one I am not sure I can articulate.

Derrida writes that this work of mourning leaves remnants, it entangles us with the ghosts of those we have mourned and continue to mourn. He writes:

> That is to say, the dead are taken into but don't become part of us. They just occupy a particular place in our bodies. They can speak for themselves. They can haunt our bodies and ventriloquize our speech. So, the ghost is enclosed in a crypt, which is our body. We become a sort of graveyard for ghosts. A ghost cannot only be our conscious. The Other's unconscious speaks in our place. It's not our unconscious; it's the unconscious of the Other, which plays tricks on us, it can be terrifying. But that is when things start to happen. (as cited in Smith, 2015, p. 43)

Thinking through Derrida, Butler (2004) suggests that mourning requires both loss and transformation, that it is through mourning that one is forever changed(p. 21).

I lay among the clover and common mullein. Water rushes over rocks, birds call to one another, leaves rustle in the wind. My thoughts tumble and flow. Mourning, creation, transformation, poesis. The setting sun plays in shadows. My eyes closed, I feel it set. The dead occupy a place in us. I do not lay alone. Richard Wyatt Flood, Ellen Birch, Unknown, Ruben Depew, Unknown, 381. They lay with me. These stories settle and unsettle. According to King (2003), the stories we hear "are ours now. We can do what we want with them, retell them, forget them, cry over them," but we can never "say in the years to come that [we] would have lived [our lives] differently if only [we] had heard this story. [We've] heard it now" (p. 119).

REFERENCES

Abbas, J., & Voronka, J. (2014). Remembering institutional erasures: The meaning of histories of disability incarceration in Ontario. In L. Ben-Moshe, C. Chapman, & A. C. Carey (Eds.), *Disability incarcerated* (pp. 121-138). New York, NY: Palgrave Macmillan.

Ahmed, S. (2000). *Strange encounters: Embodied others in post-coloniality*. New York, NY: Routledge.

Anderson, J., Adey, P., & Bevan, P. (2010). Positioning place: polylogic approaches to research methodology. *Qualitative Research*, 10(5), 589-604.

Antonacci, J. P. (2013, November 9). Dying with dignity. *Brant News*. Retrieved from: https://www.brantnews.com/news-story/4200362-dying-with-dignity/

Athanasiou, A. (2005). Reflections on the politics of mourning: Feminist ethics and politics in the age of empire. *Historein*, 5, 40-57.

Beasley, M. M. (2008). Frau Fiber and the synchronized sewing squad: Political theory and choreographing labour. *Performance Research*, 13(1), 99-104.

Beckwith, R. (2016). *Disability servitude: From peonage to poverty*. New York, NY: Palgrave Macmillan.

Bedikian, S. A. (2008). The death of mourning: From Victorian crepe to the little black dress. OMEGA, 57(1), 35-52.

Behar, R. (1996). *The vulnerable observer: anthropology that breaks your heart*. Boston, MA: Beacon Press.

Blakely, K. (2007). Reflections on the role of emotions in feminist research. *International Journal of Qualitative Methods*, 6(2), 59-68.

Bruner, J. (1987). Life as narrative. *Social Research*, 54(1), 11-32.

Brueggemann, B. J. (1996). Still-life: Representations and silences in the participant-observer role. In P. Mortensen & G. E. Kirsch (Eds.), *Ethics and representation in qualitative studies of literacy* (pp. 17-39). Urbana, IL: National Council of Teachers of English.

Burghardt, M. (2015) 'He was a secret': family narratives and the institutionalization of people with intellectual disabilities. *Disability & Society*, 30(7), 1071-1086.

Butler, J. (2004). *Precarious life: The powers of mourning and violence*. New York, NY: Verso.

Cadwallader, J. (2008). Spirit photography and the Victorian culture of mourning. *Modern Language Studies*, 37(2), 8-41.

Carey, A. (2009). *On the margins of citizenship: Intellectual disability and civil rights in twentieth-century America*. Philadelphia, PA: Temple University Press.

Carlson, L. (2010). *The faces of intellectual disability: Philosophical reflections*. Bloomington, IN: Indiana University Press.

Chandler, E. (2014). Disability and the desire for community. (Doctoral dissertation). Retrieved from: https://tspace.library.utoronto.ca/handle/1807/68432

Cole, A., & Knowles, G. (2008). *Handbook of the arts in qualitative research: Perspectives, methodologies, examples and issues*. Thousand Oaks, CA: SAGE publishing.

Connerton, P. (1989). *How societies remember*. Cambridge, UK: Cambridge University Press.

Cottle, T. (2002). On narratives and the sense of self. *Qualitative Inquiry*, 8(5), 535-549.

Crooks, V. A., Owen M., & Stone, S. (2012). Creating a (more) reflexive Canadian disability studies: Our team's account. *Canadian Journal of Disability Studies*, 1(3), 45-65.

Cumming, T. M., Strnadová, I., Knox, M., & Parmenter, T. (2014). Mobile technology in inclusive research: Tools of empowerment. *Disability & Society*, 29(7), 999-1012.

Davis, B. (2000). A *body of writing*, 1990-1999. Walnut Creek, CA: AltaMira Press.

davis halifax, n. v. (2008). (intimate images) intimacy, disruption, photography. In L. Neilsen, A. L. Cole, & J. G. Knowles (Eds.), *The art of visual inquiry* (pp. 3-17). Toronto, Canada: Backalong Books.

davis halifax, n. v. (2009). *Disability and illness in arts-informed research: moving toward postconventional representations*. Amherst, NY: Cambria Press.

de Freitas, E. (2008). Interrogating reflexivity: Art, research, and the desire for presence. In A.L. Cole & J.G. Knowles (Eds.), *Handbook of the arts in qualitative research: Perspectives, methodologies, examples, and issues*. Thousand Oaks, CA: SAGE Publishing.

De Schauwer, E., Van de Putte, I., Van Goidsenhoven, L., Blockmans, I., Vandecasteele, M., & Davies, B. (2017). Animating disability differently mobilizing a heterotopian imagination. *Qualitative Inquiry*, 23(4), 1-11.

Dempsey, A. (2013, June 6). Mystery woman behind collection of art from Huronia centre for developmentally disabled. *Toronto Star*. Retrieved from: http://www.thestar.com/news/gta/2013/06/06/mystery_woman_behind_collection_of_art_from_huronia_centre_for_developmentally_disabled.html

Derrida, J. (2001). *The work of mourning*. P. A. Brault & M. Naas (Eds.). Chicago, IL: The University of Chicago Press.

Dolmage, J. (2015, June 1). Disabling studies, Disability studied, and disability studies, Keynote address delivered at Canadian Disability Studies Association Ottawa, Canada. Retrieved from: https://disablingstudies.files.wordpress.com/2015/06/cdsa-keynote-dolmage2.docx

Donovan, D. (n.d.) [Deceased woman in coffin]. (C 128-1-1, barcode B379736). The Archives of Ontario, Toronto, Canada.

Dossa, P. (2009). *Racialized bodies, disabling worlds: Storied lives of immigrant Muslim women*. Toronto, Canada: University of Toronto Press.

Douglas, K. & Carless, D. (2013). An invitation to performative research. *Methodological Innovations*, 8(1), 53-64.

Edelstein, T. J. (1980). They sang "The song of the shirt": The visual iconology of the seamstress. *Victorian Studies*, 23(2), 183-211.

Egerton Ryerson. (n.d.). In *The Canadian Encyclopedia*. Retrieved from: http://www.thecanadianencyclopedia.ca/en/article/egerton-ryerson/

Étienne Brûlé. (n.d.). In *The Canadian Encyclopedia*. Retrieved from: http://www.thecanadianencyclopedia.ca/en/article/etienne-brule/

Flower Meanings. (n.d.). Retrieved from: http://www.allflorists.co.uk/advice_flowerMeanings.asp

Foster, H. (2004). An archival impulse. *October*, 110, 3-22.

Foster, N. (2008). Photography and the gaze: The ethics of vision inverted. *Parallax*, 14(2), 78-92.

Foucault, M., & Miskowiec, J. (1986). Of other spaces. *Diacritics*, 16(1), 22-27.

Fudge Schormans, B.A. (2011). The right or responsibility of inspection: Social work, photography, and people with intellectual disabilities (Doctoral dissertation). Retrieved from: https://tspace.library.utoronto.ca/bitstream/1807/29725/1/FudgeSchormans_BeverleyAnn_201106_PhD_thesis.pdf

Funeral Expenses. (n.d.). Retrieved from: https://www1.toronto.ca/wps/portal/contentonly?vgnextoid=10ac4308da628510VgnVCM10000071d60f89RCRD

Gaillet, L. L. (2012). (Per)forming archival research methodologies. *College Composition and Communication*, 64(1), 35-58.

Galer, D. (2014) "A place to work like any other?" Sheltered workshops in Canada, 1970–1985. *Canadian Journal of Disability Studies*, 3(2), 1-30.

Gallovich, T. (2014). *Power composition for photography: Develop your artistic eye*. Amherst, MA: Amherst Media.

Garbutt, R. (2009). Is there a place within academic journals for articles presented in accessible format? *Disability & Society*, 24(3), 357-371.

Glynos, J. (2014). Death, fantasy, and the ethics of mourning. In L. Van Brussel & N. Carpentier (Eds.), *The social construction of death: Interdisciplinary perspectives* (pp. 137-160). London, UK: Palgrave Macmillan.

Goffman, E. (1961). *Asylums: Essays on the social situation of mental patients and other inmates*. New York, NY: Anchor Books.

Goodley, D. & Runswick-Cole, K. (2014). Becoming dishuman: thinking about the human through dis/ability. *Discourse: Studies in the Cultural Politics of Education*, 37(1), 1-15.

Halberstam, J. (2012). *Gaga feminism: Sex, gender, and the end of normal*. Boston, MA: Beacon Press.

Harper, H. (1997). Difference and diversity in Ontario schooling. *Canadian Journal of Education*, 22(2), 192-206.

Hepatitis. (n.d.). Retrieved from: http://www.phac-aspc.gc.ca/hep/index-eng.php#a3

Hirsch, M. (2016). Vulnerable times. In J. Butler, Z. Gambetti, & L. Sabsay (Eds.), *Vulnerability in resistance* (pp. 76-96). Durham, NC: Duke University Press.

Hoffman, F., & Taylor, R. (2007). *Much to be done: private life in Ontario from Victorian diaries*. Toronto, Canada: Dundurn Press.

Hunter, R. (1970). Brokedown Palace. *On American Beauty* [CD]. California: Warner Bros.

Huronia Regional Centre Cemetery. (n.d.). Retrieved from https://www.findagrave.com/cgi-bin/fg.cgi?page=cr&CRid=2327137

Johnson, M. L. (2015). Bad romance: A crip feminist critique of queer failure. *Hypatia*, 30(1), 251-267.

Jones, K. (1992). Listening to hidden voices: Power, domination, resistance and pleasure within Huronia Regional Centre. *Disability, Handicap & Society*, 7(4), 339-348.

Kafer, A. (2013). *Feminist, queer, crip*. Bloomington, IN: Indiana University Press.

Kidney, C. A., & McDonald, K. E. (2014). A toolkit for accessible and respectful engagement in research. *Disability & Society*, 29(7), 1013-1030.

King, T. (2003). *The truth about stories*. Toronto, Canada: House of Anansi Press.

Kiplinger, J. (n.d.). A stroll through fabric stores 1920–1959. Retrieved from: https://info.fabrics.net/a-stroll-through-fabric-stores/

Kittay, E. F. (2011). *The ethics of care, dependence, and disability. Ratio Juris*, 24(1), 49-58.

Leavy, P. L. (2007). Feminist postmodernism and poststructuralism. In S. Hess-Biber & P. L. Leavy (Eds.), *Feminist research practice: A primer.* London, UK: SAGE Publishing.

LeBlanc Haley, T. (2011). Gendering psychiatric boarding homes: a gendered analysis of the policies governing psychiatric boarding homes in urban Toronto in the era of transinstitutionalization. Paper presented at Canadian Political Science Conference, Waterloo, Canada Retrieved from https://www.cpsa-acsp.ca/papers-2011/LeBlanc.Haley.pdf

Linkman, A. (2011). *Photography and death.* Islington, UK: Reaktion Books.

Little, B. J., , Lanphear, K. M., & Owsley, D. W. (1992). Mortuary display and status in a nineteenth-century Anglo-American cemetery in Manassas, Virginia. *American Antiquity*, 57(3), 397-418.

Lopez, M. D. (2014). Memory and fragility: Art's resistance to oblivion (three Colombian cases). *The New Centennial Review*, 14(1), 71-98.

Malacrida, C. (2015). A *special hell: Institutional life in Alberta's eugenic years.* Toronto, Canada: University of Toronto Press.

Mann, S. A. (2012). *Doing feminist theory.* New York, NY: Oxford University Press.

McGuire, A. (2010). Disability, non-disability and the politics of mourning: Re-conceiving the 'we'. *Disability Studies Quarterly*, 30(3/4). Retrieved from: http://dsq-sds.org/article/view/1282/1309

McIlwraith, T. F., & Hummer, M. (2005). Grave and nave: An architecture of cemeteries and sanctuaries in rural Ontario. *Ontario History*, 97(2), 138.

McKillop, H. (1995). Recognizing children's graves in nineteenth-century cemeteries: Excavations in St. Thomas Anglican Churchyard, Belleville Ontario, Canada. *Historical Archaeology*, 29(2), 77-99.

McLaren, A. (1990). *Our own master race: Eugenics in Canada*, 1885–1945. Toronto, Canada: University of Toronto Press.

Michalko, R. (2002). *The difference disability makes.* Philadelphia, PA: Temple University Press.

Milloy, J. S. (1999). A *national crime: The Canadian government and the residential school system*, 1879 to 1986. Winnipeg, Canada: University of Manitoba Press.

Mills, C. W. (2004). On intellectual craftsmanship. In W. K. Carroll (Ed.) *Critical Strategies for Social Research* (pp. 54-66). Toronto, Canada: Canadian Scholars' Press.

Mingus, M. (2011, February 11). Changing the framework: Disability justice. How our communities can move beyond access to wholeness. Retrieved from: https://leavingevidence.wordpress.com/2011/02/12/changing-the-framework-disability-justice/

Modern Afghanistan: Making meaning in the aftermath of conflict. (2015, May 27). Retrieved from: http://resources.primarysource.org/content.php?pid=197720&sid=1654239

Moraru, C. (2000). "We embraced each other by our names": Levinas, Derrida, and the ethics of naming. *Names*, 48(1), 49-58.

Morris, J. (1997). Care or empowerment? A disability rights perspective. *Social Policy & Administration*, 31(1), 54-60.

The music of mourning. (n.d.). Retrieved from: https://friendsofoakgrovecemetery.org/the-music-of-mourning/

Naas, M. (2003). History's remains: Of memory, mourning, and the event. *Research in Phenomenology, 33,* 75-96.

19th century mourning practices (revised). (2011, July 10). Retrieved from: http://passionforthepast.blogspot.ca/2011/07/19th-centurt-mourning-practices-revised.html

Nuzzo, Angelica (2012). *Memory, history and justice in Hegel.* New York, NY: Palgrave Macmillan.

Ontario Hospital School Orillia. (1947). *Annual financial report also comparative per capita cost statement with comparative statement of revenue for the year ending March 31, 1947.* Retrieved from: http://www.mcss.gov.on.ca/HuroniaPDFs/CR020118.pdf

Ontario Hospital School Orillia. (1971a). *Annual progress report adult training unit.* Retrieved from: http://www.mcss.gov.on.ca/HuroniaPDFs/CR086105.pdf

Ontario Hospital School Orillia. (1948). *Annual report of the Ontario Hospital School, Orillia, for the period ending December 21, 1948.* Retrieved from: http://www.mcss.gov.on.ca/HuroniaPDFs/CR006423.pdf

Ontario Hospital School Orillia. (1968). *Department of Health Ontario Hospital School, Orillia, appraisal and report.* Retrieved from: http://www.mcss.gov.on.ca/HuroniaPDFs/RCR011949.pdf

Ontario Hospital School Orillia. (1928). *Industrial training of patients at the Ontario Hospital School, Orillia, Ontario.* Retrieved from: http://www.mcss.gov.on.ca/HuroniaPDFs/CR212939.pdf

Ontario Hospital School Orillia. (1946). *Inspection report: Ontario Hospital School, Orillia, January 29, 30, 31, Feb. 1, 1946.* Retrieved from: http://www.mcss.gov.on.ca/HuroniaPDFs/CR006463.pdf

Ontario Hospital School Orillia. (1931). *Report of inspection at Ontario Hospital School, Orillia, Ontario, 1931.* Retrieved from: http://www.mcss.gov.on.ca/HuroniaPDFs/CR158273.pdf

Ontario Hospital School Orillia. (1971b). *Second annual report prevocational unit Ontario Hospital School Orillia.* Retrieved from: http://www.mcss.gov.on.ca/HuroniaPDFs/CR064384.pdf

Ontario Office of Prisons and Public Charities. (1877). *Ninth annual report of the inspector of asylums, prisons, and public charities for the Province of Ontario,for the year ending 30th September 1876.* Toronto, Canada: Legislative Assembly of Ontario. Retrieved from: http://bit.ly/2v4wzls

Ontario Office of Prisons and Public Charities. (1887). *Nineteenth annual report of the inspector of prisons & public charities for the Province of Ontario for the year ending September 30th, 1886.* Toronto, Canada: Legislative Assembly of Ontario. Retrieved from: https://books.google.ca/books?id=3QBAAQAAMAAJ

Oved, M. C. (2015, July 31). Group says it found a sewage pipe in Huronia cemetery. *Toronto Star.* Retrieved from: https://www.thestar.com/news/gta/2015/07/31/group-says-it-found-a-sewage-pipe-in-huronia-cemetery.html

Oved, M. C., & Alamenciak, T. (2013, September 24). Identities of unnamed dead at Huronia Regional Centre emerge. *Toronto Star.* Retrieved from https://www.thestar.com/news/gta/2013/09/24/identities_of_unnamed_dead_at_huronia_regional_centre_emerge.html

Parker, R. (1984). *The subversive stitch: Embroidery and the making of the feminine.* London, UK: The Women's Press Limited.

Radford, J. P., & Carter-Park, D. (1993). The asylum as place: An historical geography of the Huronia Regional Centre. In J. R. Gibson (Ed.), *Canada: Geographical interpretations: Essays in honour of John Warkentin* (pp. 103-130). North York, Canada: York University Press.

Reinharz, S. (1992). *Feminist methods in social research.* New York, NY: Oxford University Press.

Rice, C., Chandler, E., Harrison, E., Liddiard, K., & Ferrari, M. (2015). Project re•vision: Disability at the edges of representation. *Disability & Society,* 30(4), 513-527.

Robertson, H. (2010). *Walking into wilderness: The Toronto carrying place and nine mile portage.* Winnipeg, Canada: Heartland Associates, Inc.

Rossiter, K., & Clarkson, A. (2013). Opening Ontario's "saddest chapter": A social history of Huronia Regional Centre. *Canadian Journal of Disability Studies,* 2(3), 1-30.

Rubin, S. S. (2014-2015). Loss and mourning in the Jewish tradition. OMEGA, 70(1), 79-98.

Runswick-Cole, K., & Goodley, D. (2015). Disability, austerity and cruel optimism in big society: Resistance and "the disability commons". The *Canadian Journal of Disability Studies,* 4(2), 163-186.

Savin-Baden, M., & Wimpenny, K. (2014). A *practical guide to arts-related research.* Rotterdam, Netherlands: Sense Publishers.

Schottenfeld, S. (2006). The shiva. *The Massachusetts Review,* 47(1), 68.

Scott, J. W. (1992). Experience. In J. Butler & J. W. Scott (Eds.), *Feminists theorize the political* (pp. 22-40). London, UK: Routledge.

Seth, P., Slark, M., Boulanger, J., & Dolmage, L. (2015). Survivors and sisters talk about the Huronia class action lawsuit, control, and the kind of support we want. *Journal of Developmental Disabilities,* 21(2), 60-68.

Seth v. Her Majesty the Queen in Right of the Province of Ontario, Settlement Agreement. Court File Number: CV-09-376927CP0. (2013). Retrieved from: https://kmlaw.ca/wp-content/uploads/2015/07/080659_SettlementAgreement_17sep13.pdf

Short, J. (2014). Esposito, Foucault, and the commons. *Theory & Event,* 17(3), 1-7.

Smart, S. (2011). A *better place: Death and burial in nineteenth-century Ontario.* Toronto, Canada: Dundurn Press.

Smith, K. (2015). Mourning the death of social welfare: remaining inconsolable before history. In C. Janzen, D. Jeffery & K. Smith (Eds.), *Unravelling encounters: ethics, knowledge, and resistance under neoliberalism* (pp. 21-45). Waterloo, Canada: Wilfrid Laurier University Press.

Sontag, S. (2003). *Regarding the pain of others.* New York, NY: Farrar, Straus and Giroux.

Springgay, S., & Irwin, R. (2004). Women making art: Aesthetic inquiry as political performance. In A. Cole, , L. Neilsen,, G. Knowles, & T. Luciani (Eds.), Provoked by art: *Theorizing arts-informed research* (pp. 71-83). Halifax, Canada: Backalong Books.

Stott, R. (2016, August 15). How flower-obsessed Victorians encoded messages in bouquets. Retrieved from: http://www.atlasobscura.com/articles/how-flowerobsessed-victorians-encoded-messages-in-bouquets

Strange, J. (2002). 'She cried a very little': death, grief and mourning in working-class culture, c. 1880-1914. *Social History,* 27(2), 143-161.

Strange, J. (2003). Only a pauper whom nobody owns: reassessing the pauper grave c. 1880-1914. *The Past and Present Society*, 178(1), 148-175.

Tamm, M. (2013). Beyond history and memory: New perspectives in memory studies. *History Compass*, 11(6), 458-473.

Thomas, S. (2004). Art-making and theorizing through the language of imagery. In A. Cole, L. Neilsen, G. Knowles, & T. Luciani (Eds.), *Provoked by art: Theorizing arts-informed research* (pp. 62-71). Halifax, Canada: Backalong Books.

Turner, G. (2015). *The Toronto carrying place: Rediscovering Toronto's most ancient trail.* Toronto, Canada: Dundurn Press.

"Victorian London" (n.d.). Retrieved from: http://www.victorianlondon.org/joke/random.htm#.

Watson, N., McKie, L., Hughes, B., Hopkins, D., & Gregory, S. (2004). (Inter)dependence, needs and care: The potential for disability and feminist theorists to develop an emancipatory model. *Sociology*, 38(2): 331-350.

Weedon, C. (1987). *Feminist practice and poststructuralist theory.* Oxford, UK: Basil Blackwell Inc.

Wendell, S. (1996). The rejected body: *Feminist philosophical reflections on disability.* New York, NY: Routledge.

White, R. (2015). The dialectics of mourning. *Angelaki*, 20(4), 179-192.

Young, L., & Russell, A. (2017, February 22). Dying alone: Hundreds of bodies are going unclaimed in Ontario and Quebec. *Global News.* Retrieved from: http://globalnews.ca/news/3262664/dying-alone-more-peoples-remains-going-unclaimed-in-ontario-and-quebec/

APPENDIX

Appendix I:

Informed Consent

Date: February 24, 2017

Study Name: A Stitch in Time: Mourning the Unnamed

Researcher: Kim Collins, Graduate Student, Masters
York University
4700 Keele St, Toronto, ON M3J 1P3
collinsk@yorku.ca or kimberlee.collins@ryerson.ca

Purpose of the Research:

My research will use art praxis to mourn the lives of unnamed patients from Huronia Regional Centre. It will ask us to question collectively: How we can mourn for those we cannot name?

What You Will Be Asked to Do in the Research:

You will be asked to do one of the following: help embroider a piece of textile art for the project, take photographs/videos, appear in a photograph, or compose an original musical score. These will appear on an accessible website which will provide plain language information about this project. The time commitment varies for each section of the project. Participants may withdraw at any time.

Risks and Discomforts:

You may be disturbed by the history of institutionalization at Huronia Regional Centre. Some of what happened in the institution may be upsetting, especially if you have a connection to former patients or if you have experience with institutions or with labels. If you wish to speak to a counsellor about your discomfort the name of a one-time only free counselling service will be provided.

Benefits of the Research and Benefits to You:

Your participation will become part of the data for my Major Research Project. You will be a co-producer of knowledge in this arts-informed research.

Voluntary Participation:

Your participation in the study is completely voluntary. You may choose to stop participating at any time. Your decision not to volunteer will not influence the nature of your relationship with York University either now, or in the future. You will not be paid for your participation.

Withdrawal from the Study:

You can stop participating in the study at any time, for any reason. Your decision to stop participating will not change your relationship with Kim Collins or with York University. If you decide to stop participating,

all associated data collected will be immediately destroyed as possible.

Confidentiality: All information you supply during the research will be held in confidence and unless you specifically indicate your consent, your name will not appear in any report, publication or presentation of the research. You will not be photographed, videotaped or recorded unless you specifically indicate your consent with a photograph/video release form. The data will be safely stored on a password protect computer in a private file and I am the only person with access to this information. The data will be stored for a period of two years and destroyed after the study. Confidentiality will be provided to the fullest extent possible by law. Your name will not appear on your artwork unless you indicate your consent. You will be asked to sign a release form. You may choose to display your work anonymously.

If you have Questions About the Research:

If you have questions about the research or about your role, please feel free to my supervisor, nancy viva davis halifax by email at nhalifax@yorku.ca.

 The proposal of this research has been reviewed and approved by the Ethics Review Committee of Critical Disability Studies Graduate Program and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Critical Disability Studies Graduate Program Office (Tel: 416-736-2100 extension 44494; Email: gradcds@yorku.ca).

Legal Rights and Signatures:

I_____consent to participate in *A Stitch in Time: Mourning the Unnamed* conducted by Kim Collins.   I have understood the project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Signature   **Date**
Participant

Signature   **Date**
Principal Investigator

Photograph & Video Release Form
A Stitch in Time: Mourning the Unnamed

I give permission to Kim Collins to use my image, likeness and sound of my voice as recorded on audio or video for her research project.

I understand that there will not be any payment.

I understand that my image may be edited, copied, exhibited, published or distributed.

I give up the right to inspect or approve the finished product.

I give up any right to royalties or other compensation arising or related to the use of my image or recording.

I also understand that this material may be used in diverse educational settings within an unrestricted geographic area.

Photographic, audio or video recordings may be used for the following purposes:

- Master of Arts Research project
- dedicated research website
- conference presentations
- educational presentations or courses
- informational presentations
- online educational material

By signing this consent form I understand this allows Kim Collins to use photographic or video recordings of me in her research and on a research related website.

I will be asked about the use of the photographs or video recording for any purpose other than those listed above.

There is no time limit on this consent release.

I have read, understood and agree to this release. I release any claims against Kim Collins using this material for educational purposes.

Full Name_____

Signature_____ Date_____