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# A Critical Phenomenological Inquiry into Disabled Embodiment and Identity

Heather Twele, *Western University*

Supervisor: Janelle, Blankenship, *The University of Western Ontario*

A thesis submitted in partial fulfillment of the requirements for the Master of Arts degree in Theory and Criticism

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## Abstract

This thesis uses critical phenomenology to investigate disabled embodiment and identity. I argue that (in)accessible subjective accounts of disability experience reveal disability to be a unique form of ever-changing embodiment: disability is the lived experience of a critical phenomenology. I turn to eclectic art, film, and poetry case studies involving a medical, surgical gaze to explore how ableist, sexist, and racist systems structure daily experience, forcing disabled people who “misfit” to analyze and confront systems of oppression, exclusion, and stigmatization. Disability experience challenges and resists ableist binaries of ability/disability, well/unwell, subject/object, mind/body, and inside/outside. The interdependence of these fluid, intertwining threads of existence defy even the categorization of a continuum, unless, as I argue, the continuum is non-linear and allows simultaneity. Understanding the interconnection between ability and disability is a never-ending journey that will always remain incomplete.

Keywords: critical phenomenology, critical disability studies, visibility, invisibility, passing, intersectionality, disability poetry, ostomy art, surgical gaze, embodiment, identity, ableism, ability, disability, debility, lived experience

## Summary for Lay Audience

This thesis explores how disabled bodies live and form identities in a world that is designed for people who are able-bodied. Ableism is the assumption that able-bodiedness, which is found in every crevice of society, is better than being disabled. To address the intersection of ableism and disability, I turn to phenomenology which uses the term embodiment to focus on everyday experience of living in concert with other people and the world. In this study, I employ critical phenomenology, a philosophical field that attempts to foreground the numerous background assumptions that structure society, to look at the ways that art, film, and poetry engage with and inform disability experience. Ableism assumes there is a strict line, or binary, between ability and disability. However, this thesis, following other critical disability scholars, shows that disability experience challenges and resists these ableist binaries.

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## Introduction

[E]very time I give an account of experience,  
I also give an account of how it is not fully available to me.

Jonathan Sterne, *Diminished Faculties* (39)

Disability testimonies contain many instances of what Jonathan Sterne describes as “my inaccessible-to-myself-self” (40). I am fatigued; I wake up from anaesthesia; I am in pain; I am distracted. In ableist society, subjective disability experiences are often dismissed as narcissistic, hypochondriac tales of weak individuals who are not willing to participate in society, or they are praised as examples of inspiration (super abilities) to further an ableist agenda of overcoming and overcompensating. The ideology of ableism adheres to strict binaries of ability/disability, well/unwell, and objective/subjective. Maurice Merleau-Ponty’s theory of embodiment, a chiasmic intertwining of body and world, dispels the tidy ableist distinction between objectivity and subjectivity, revealing the intertwinement of subject and object. The fluid, fluctuating body schema in Merleau-Ponty’s *Phenomenology of Perception*, which is constantly being reshaped and reworked, provides a firm foundation upon which to demolish the ableist stable, static, and able-bodied normate subject. Subjectivity is an inherent part of lived experience, and complete objectivity, especially in the medical field, is a myth. The medical gaze, as Foucault theorizes, is a series of interpretations that are subjective and contextual, even with current medical imaging. Medicine, and science in general, often tries to eradicate the human subjective element, focusing on ‘objective’ facts. But the fluidity of each individual body schema evades this exclusion. Every experience is a mediated experience and contains an element of “my inaccessible-to-myself-self” (Sterne 40). Not every detail of every experience is accessible. Instead of fighting against

subjectivity, ableist society needs to accept disability testimonies as different ways of being in the world that reveal disabled people's realities. Instead of disbelief and judgement stemming from a fear of finitude, society should value disabled people rather than treating them as problems to eradicate or cure. Disabled experience contains value.

Disability is a concept that defies definition. Concepts of ability, disability, debility, and impairment swirl around in a confusing unformed haze. Where does ability end and disability begin? Is disability a social category and impairment a physical category? Where does debility, a "dynamic" process that encompasses disability (Livingston 28), fit into this picture? I began my MA research in the thick of this heavy haze of terminology, looking for precise definitions to tidily box up my experiences and the experiences of others. I did not want to use terminology wrongly and to admit that, despite having a chronic illness and a disability, I was completely unaware of how to identify myself. However, these initial questions reveal the deeply rooted ableist logic within me: the need to categorize and define. The ableist binaries of ability/disability, visibility/invisibility, and well/unwell do not adequately address the complexity of disability experience. Current disability research uses non-linear continuums to replace stifling ableist binaries. Ability and disability; visibility and invisibility; well and unwell are not mutually exclusive categories. The lack of stable definitions frustrated me until I realized that this is the nature of disability experience itself (and all experience in general): existence is unstable, fluctuating, and often undefinable. I dance around the ability-disability, visibility-hidden-invisibility, and well-unwell continuums, sometimes touching several spots simultaneously. I am not confined to one identity, and my identity changes over time. Not every experience is "fully available to me" (Sterne 40), but this fact does not detract from the value of my lived experience of disability.



The language of disability and critical disability studies does matter. Acknowledging the inherent unstable fluctuations of disability does not mean that linguistic labels lose all meaning. However, not everyone will use disability language in the same way. For example: should discussions of disability use person-first language or identity-first language? While Potheir and Devlin opt for the “least worst option” of person-first language (4), Titchkosky argues that person-first language increases the differential view of disability as deficient in legitimacy in ableist society (22). In *Redefining Disability*, Bones et al. use identity-first language in the “introduction” because it is widely preferred and accepted among disabled people in disabled communities; however, they also recognize that some disabled people prefer person-first language (3), and some choose not to identify as disabled at all (4). Ultimately, Bones et al. state that “self-definition is a key component of autonomy” (5); it is always acceptable to ask a disabled person what language they prefer and respect their “self-definition.” In my MA thesis, I use identity-first vocabulary, such as “disabled person(s),” because as a disabled person I identify more with identity-first language than with person-first language. However, I recognize that some disabled people might be uncomfortable with identity-first language and may identify more with person-first language. As Potheir and Devlin state, there is no perfect way to use the term disabled or disability when referring to persons, hence they chose what they thought of as the “least worst option.” Ultimately, it is up to the disabled person(s) to determine and express how they wish to be addressed, and it is the responsibility of the abled person(s) to respect their language of identity.

To accept disability as a valid form of embodiment requires cultural and medical language to move away from binary, stigma-laden terms such as ‘loss’ and ‘gain,’ ‘strength’ and ‘weakness,’ ‘ability’ and ‘lack.’ In ableist society, a certain level of ability is often seen as giving

people credit or value and any lack of ability can be explained away as a normal impairment, or an attribute (e.g., laziness, clumsiness, etc.) The hierarchy of ability rejects the disabled while also making it mandatory for them to be as able-bodied as possible. A fluid continuum spanning ability, disability, and debility productively deconstructs and dismantles this prevalent hierarchy of ability. Value should not be linked to productiveness, aesthetics, or ability. Disability is “different” not “diminished” (Evans 738).

The first chapter of my thesis, “The Medical/Surgical Gaze and the Transparent Body,” explores Michel Foucault’s history of the medical gaze in *The Birth of the Clinic* (1963) as a precursor to the myth of the transparent body Jose van Dijck theorizes in her study *The Transparent Body*. I also engage with Laura Mulvey’s theory of the cinematic gaze in “Visual Pleasure and Narrative Cinema” (1975) and *Afterimages: On Cinema, Women and Changing Times* (2019), exploring the “possibility” for the gaze to shift gears and operate outside of voyeurism and violence, illuminating a complicated cyclical nonlinear sense of time which folds-back on itself and challenges sexual, racial, and class oppression, analyzing and abolishing simple binaries. In Foucault, the evolving medical gaze contains the same potential to shift “the emphasis of the look” (Mulvey 988). The moment of anatomical dissection memorialized in Natasha Trethewey’s poem “Knowledge” and the biotourism in the science-fiction film *Fantastic Voyage* (1966) signals a stifling male medical gaze, but an embodied poetic voice in these texts also complicates and counters the linear, analytical, all-seeing, unmediated medical gaze. In this chapter on the medical and surgical gaze, the myth of transparency is foregrounded, analyzed, and ultimately destroyed.

The second chapter, “Embodiment and the Disabled (Extraordinary) Body,” delves into Maurice Merleau-Ponty’s theory of embodiment in *Phenomenology of Perception* in which the

fluid body schema is constantly reworked and renewed through the experience of inhabiting the world. The incompleteness and openness of “indeterminate horizons” that make up the world allow for endless generative possibilities for how human beings can inhabit the world through the material medium of the body. Gail Weiss emphasizes the importance of Merleau-Ponty’s concept of a fluid and malleable body schema to complement Rosemarie Garland-Thomson’s idea of “fits” and “misfits” in “Misfits: A Feminist Materialist Disability Concept” and *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. The fleshly messiness of disabled bodies disrupts the taken-for-granted “normate” position, disrupting the “fantasy” of the “stable, predictable, or controllable” body (Misfits 593). Two corporeal case studies in this chapter - Carol Chase Bjerke’s ostomy art installation *Hidden Agenda: ARTiculating the Unspeakable* and Emilia Nielson’s poetry Body Work on chronic illness and surgery – exemplify the importance of a shifting body schema as a “restructuring” of embodiment in critical disability studies.

The final chapter of this thesis, “Critical Disability Studies and the Ability-Disability Continuum,” examines current critical disability models that combine aspects of the medical model and the social model, specifically Tobin Sieber’s “theory of complex embodiment” (25). Focusing on embodiment as a fluctuating, shifting presence throws into relief the need to theorize ability and disability as a continuum rather than a static, well-defined binary. Visible, invisible, and hidden disabilities often commingle, revealing another non-linear continuum. Although disability in ableist society is often portrayed as a dangerous looming ‘other,’ Tanya Titchkosky shows that everyone has a relationship with disability (and debility) in some capacity (4-5). To increase the inclusivity of critical disability studies, intersectionality with gender, sex, ethnicity, race, and class must be foregrounded. Just as everyone has a relationship with

disability, everyone is either intentionally or unintentionally ableist (or both). Recognizing this allows space for disability to teach us how to value disability as a valid form of embodiment (Titchkosky 28).

To conclude this introduction, I would like to acknowledge other voices and key debates in the burgeoning interdisciplinary scholarship on the intersection of critical disability studies and critical phenomenology. In “The Problems of Access: A Crip Rejoinder via the Phenomenology of Spatial Belonging,” Corrine Lajoie interrogates debilitating systemic ableist conceptions of disability and access, particularly how the enforcement of ableist ideals do not acknowledge the relational dynamics of disability experience. These “disorientations for disabled people” in ableist society (318) are productive sites from which to engage with the possibilities and limitations of phenomenology to address and illuminate disabled embodiment, as Lajoie also argues in “Phenomenology and Disability Studies” (1). For Lajoie, crip phenomenology provides the key to the intersection of critical disability studies and critical phenomenology (1). Echoing Lajoie’s acknowledgment of the limits of phenomenology, Thomas Abrams argues in “Disability at the Limits of Phenomenology” that phenomenology needs to re-examine its “tools” through the lens of disability experience (15). Earlier participants in this discussion, Kevin Paterson and Bill Hughes (1999) also call for “a sociology of impairment” that embodies disability through phenomenological inquiry without adhering to the “medicalised and individualised understandings of disability” in classical phenomenology (597). These explorations of the possibilities and limitations of phenomenology productively reject Cartesian mind-body dualism, as specifically addressed in Abrams’ “Cartesian Dualism and Disabled Phenomenology.” Such critical phenomenological inquiries, above all Lajoie and Abrams’ explorations, have inspired my own critical disability studies research on the dynamic nature of disability experience.

In “The Body as the Problem of Individuality: A Phenomenological Disability Studies Approach,” Tanya Titchkosky and Rod Michalko also interrogate the ableist “disability-as-a-problem frame,” addressing the need to explain and find solutions for non-normative bodies (127). Using a critical phenomenological framework, Titchkosky and Michalko productively examine this frame itself and its implications for disabled bodies, a frame which often remains unmarked in the background of ableist society (127). Engaging in “[e]xistential-ontological suspicion,” disability studies researcher Teodor Mladenov also emphasizes the importance of bringing background assumptions to the foreground (2). Simon Dickel further expands the scope of critical phenomenological inquiry of disability to bring background assumptions into the foreground, addressing important discussions of race and sexuality embodiment.

I should finally note that many disability studies and critical phenomenology researchers productively turn to narrative to investigate non-normate lived experience. In “Beyond Pain Scales: A Critical Phenomenology of the Expression of Pain,” Nicole Miglio and Jessica Stanier for example examine how experiences of pain are framed within socio-political contexts (1), using critical phenomenology to explore qualitative pain research from lived experience narratives. This powerful work done at the intersection of critical disability studies and critical phenomenology provides a rich ground for future research on larger issues involving embodiment, naturalization and normativity in socioeconomic and sociopolitical contexts.

## Chapter 1: The Medical/Surgical Gaze and the Transparent Body

### **A Brief History of the Gaze: Foucault and Mulvey**

In *The Birth of the Clinic*, Michel Foucault chronologically explores the transformation of the medical gaze from the middle of the eighteenth century to the end of the nineteenth century. In true structuralist fashion, Foucault examines and categorizes the types of medicine from classificatory medicine (medicine of species) to clinical medicine to anatomico-clinical medicine and the subsequent transformation (evolution) of the gaze. In eighteenth-century classificatory medicine, medical practitioners focused on pathological classification (taught in the universities) and the principles of essential disease, analogy, and natural order (5). Since classification was primary and the patient's body was secondary, these two spaces, disease classification and corporeality (signified and signifier), could be separated in this flat, "grid" like "nosological picture" of symptoms and signs (3-14). Foucault describes the classificatory gaze as a "qualitative gaze" which is "caught up in an endless reciprocity" between visibility and concealment (by the patient) (9) and looks for a "pure nosological essence" which reveals the truth of the disease. The patient's individual specificities/uniqueness disturbs this process. Therefore, the "doctor must abstract the patient" as an extraneous detail, and the patient becomes "only an external fact" ("in parentheses") (7-8); in fact, the patient is considered "counter-nature" because he/she obscures the essence/nature of the disease. According to Foucault, this process of subtraction in classificatory medicine liberates the "doctor's gaze," and yet, the doctor's "intervention" is also considered "counter-nature" if "it is not subjected strictly to the ideal ordering of nosology" (7-8). The human element is a disturbance to the nosological process: both patients and doctors are "tolerated as disturbances that can hardly be avoided: the paradoxical role of medicine consists...in neutralizing them" (8). The patient is first treated as a

“negative element” and then the patient’s body “reappears” as a “positive” element, since this is the site where the qualitative symptoms of the disease can be observed by the “subtle” medical gaze (15).

Foucault identifies the medicine of epidemics as the first critical transformation of the medical gaze. Time, which was treated as an invariable constant in classificatory medicine, was integrated into medicine. Instead of an “enclosed medical knowledge within a defined space,” medicine became an “open, infinitely extendable” space “of constant, constantly revised information”: “the unity of the medical gaze was not the circle of knowledge in which it was achieved but that open, infinite, moving totality, ceaselessly displaced and enriched by time, whose course it began but would never be able to stop” (32-33). From finite to infinite, from closed to open, from static to variable, epidemic medicine paved the way for the highly observant, sensitive clinical gaze. According to Foucault, the clinic organized science around the gaze, a “calculating” gaze that not merely observed, but also analyzed, synthesized, and diagnosed (109). Clinicians operated under the assumption that everything is open and “transparent” to the all-consuming observing medical gaze (111). Experience, knowledge, and the gaze were integrated along with practical and theoretical components (87, 99). The “sensitive” observing gaze equaled knowledge (115, 99) and was equated with “clear visibility” (128). Visibility and language, “speech and spectacle” (142) were thought to be balanced.

The tangible thickness of the three-dimensional body was not foregrounded in medicine until the rise of anatomo-clinical medicine in the 1800s, and Foucault references this three-dimensionality in his geographical descriptions of the “atlases” of the body (200). This emphasis on the physicality of the human body departs in key ways from clinical medicine, now combining or intertwining the “volume of the body” (space) and time (171) [spatiality and

temporality combined]. Anatomico-clinical perception no longer disregarded pathological history but incorporated it within the “volume of the body,” emphasizing “localization, site, and origin” of disease (171). In pathological anatomy, the medical gaze expanded to also include other senses: “a plurisensorial structure” (202). Foucault also emphasizes that the new medical gaze was “no longer that of a living eye, but the gaze of an eye that has seen death – a great white eye that unties the knot of life” (177). Foucault refers to pathological anatomy as “the technique of the corpse” (173) because of its reliance on discovering the human body’s processes of life (and disease) through dissection after death. As Foucault poetically states, “The living night is dissipated in the brightness of death” (180), emphasizing that pathological anatomists viewed the corpse as the light of knowledge and medicinal truth. The “life/disease/death trinity” grounds disease spatially in the human body (195), and the “methodology of the visible” of clinical medicine is replaced with the methodology of the three-dimensional “dissected corpse” (196). In anatomico-clinical medicine, the cadaver allows the body to become “transparent” through dissection, whereas life “hides and envelops” the truth of the body and disease (204). Thus, clinical anatomy perception embodies “*invisible visibility*” (204): invisible during life, but visible after death. The “space of the disease” has become one with the three-dimensional “space of the organism” (235), no longer external to the human body as in classificatory medicine and early clinical medicine. Foucault states that the anatomico-clinical gaze is the “a priori of the modern medical gaze” with its emphasis on the physicality of the body and its internal organs (237).

In Foucault’s history of medicine, one begins to see the threads of the myth of transparency that José van Dijck critically analyzes in *The Transparent Body*. According to van Dijck, medical imaging’s ability to view the inside of the body has “rendered the body seemingly transparent” (x). However, when the increased visualization of the body’s interior is highlighted,



the “less visible implications” are thrown into the shadows and forgotten (x). Not every part of the interior of the body is visualizable, and medical imaging itself is often open to interpretation and relies on highly specialized medical practitioners, although in contemporary pop-culture, proliferated by mass media, body scans also become spectacles, viewed by unqualified observers. Thus, van Dijck’s analysis of the gaze moves from medicine to TV, film, and popular culture, whereas Foucault’s study situates the gaze within the confines of the medical community and circle of medical professionals (although he points to the recurring issue of unqualified ‘quacks’). The physician’s gaze in classificatory medicine and clinical medicine lingered on the exterior; it focused on external symptoms and signs. The gaze of the early clinician mined the body for symptoms, and yet the clinician/observer remained distanced from the inner workings of the interior body covered by an “opaque mass” of flesh and skin (150). In contrast, anatomoclinical medicine made the discovery of the interiority of the body a primary concern. However, before the birth of the X-ray, cinematography, and the medical imaging of live patients, pathological anatomists explored the corpse or dead human body, the deceased flesh of cadavers in elaborate anatomical theaters.<sup>1</sup> Foucault’s phrase “the brightness of death” (180) reiterates this reliance on death as a sort of transparency that gives the medical community new glimpses and new knowledge. Death and life became more intricately intertwined as anatomists dissected cadavers to explore and shed light on tissues and organs. Death now had (somewhat paradoxically) new meaning attached to it: death could help preserve life. It is easier to understand the necessary “violence” of the medical gaze in the early modern period and eighteenth and nineteenth centuries when this physical harm inflicted on the human body

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<sup>1</sup> William Brockbank’s “Old Anatomical Theaters and What Took Place Therein” (1968) connects the importance of anatomical theaters to medicine, teaching, and art. Brockbank describes anatomical theaters as “the first laboratories” where the scientific dissection of corpses was publicly displayed and theaterized (371).

enabled the professor and spectator to look, learn, and teach (102). The violence of the medical gaze associated with modern medical imaging, viewing the interior of the body, however, is more complex and nuanced. With medical imaging, the violence may or may not be physical, but violating violence still exists, and has cultural and social implications, as van Dijck argues. This does not imply that the medical gaze is sadistic; medical imaging is necessary to help with diagnosis and improving the lives of patients.

The terms ‘violation’ and ‘violence’ recall Laura Mulvey’s analysis of the voyeuristic pleasure of capitalist patriarchal society in her 1975 essay “Visual Pleasure and Narrative Cinema.” Examining “ways of seeing and pleasure in looking” in the cinema, Mulvey emphasizes the ways in which the “unconscious” is structured by “the dominant patriarchal order” (15). Employing a Freudian and Lacanian psychoanalytic lens, Mulvey examines two specific types of cinematic voyeuristic pleasure that centre on the ever-present underlying threat of “unpleasure,” of “the castration complex” (19): 1) “scopophilia” (16) and 2) “fetishism” (21). While “the scopophilic instinct” is “pleasure in looking at another person as an erotic object,” fetishism creates an “illusion” that is “stable, an object, an artifact” and lacks “curiosity” about the female form. Scopophilia faces the “castration threat” head on (with “associations with sadism”), and fetishism avoids confronting the “castration threat” all together (22). Within this realm of voyeuristic fantasy, the person, often a woman, who is being looked at becomes “an objectified other” (17). In her essay on the gendered cinematic gaze, Mulvey explicitly states that the woman “as sexual object” is merely a passive “image” without any agency (25), not a “maker of meaning,” but a “bearer of meaning” (15). Mulvey connects this “to-be-looked-at-ness” objectifying women to older traditions of heterosexual narrative, Renaissance perspective, and illusion.

The “spell of illusion” projected onto the screen, which conceals the “camera technology,” “camera movements,” and “invisible editing” that fashion the illusion, creates the conditions for the male viewer to identify with the male protagonist, who “controls the film fantasy,” as “his screen surrogate” (20). Mulvey writes that each type of voyeurism (scopophilia and fetishism) “is associated with a look: that of the spectator in direct scopophilic contact with the female form displayed for his enjoyment (connoting male fantasy) and that of the spectator fascinated with the image of his like set in an illusion of natural space, and through him gaining control and possession of the woman within the diegesis” (21). Through the active, controlling power of the “screen surrogate,” the male viewer can dominate the female as an object of erotic desire. And yet, the “castration threat” is always intertwined with “the woman as icon”; thus, voyeuristic “pleasure” is extremely fragile, a paper-thin image that could easily be torn aside to reveal the “anxiety” of the “unpleasure” of castration (21). According to Mulvey, “cinematic codes create a gaze, a world and an object” through the illusionistic manipulation of time and space (25). Through technology, movement, and editing, female actresses are “coded for strong visual and erotic impact...to connote *to-be-looked-at-ness*” (19). However, this “to-be-looked-at-ness” also always contains the “threat of castration” that cannot be controlled or eliminated, revealing the instability of traditional cinematic illusion.

Mulvey emphasizes, however, that the cinematic gaze is not inherently voyeuristic; the cinematic gaze can shift and morph, with the possibility to free the image of woman from patriarchal voyeurism. The cinematic codes that control cinematic time and space “and their relationship to formative external structures...must be broken down before mainstream film and the pleasure it provides can be challenged” (25). Mulvey centres her analysis of cinematic voyeurism around the destructive power of analysis: once the voyeuristic gaze is analyzed, then

it is destroyed and fully negated. Pleasure, “satisfaction,” and “privilege” must be destroyed, in its traditional voyeuristic form (26). In traditional cinema, the intentional invisibility of the camera encourages the spectator to meld with the images on the screen, to form a surrogate relationship with the male actors. To counter this pleasure-filled yet highly dangerous process, Mulvey states that film must “free the look of the camera into its materiality in time and space and the look of the audience into dialectics and passionate detachment” (26). The physicality of the camera and the editing process must be foregrounded “to break the spell of illusion,” to destroy the unstable voyeuristic pleasure that thrives on the objectification of other people, primarily women in classic Hollywood films.

In *Afterimages: On Cinema, Women and Changing Times* (2019), Mulvey extends her analysis of the “gaze” in cinema, complicating our understanding of the gaze by bringing in specific filmic case studies “on the dislocation of time” (10). In the preface, Mulvey writes that the title *Afterimages* suggests a reworking of her previous feminist work on the cinematic gaze, focusing on “the woman as spectacle” and “the figuration of the mother in patriarchal society” (9). This new study is concerned with a cyclical, nonlinear sense of time, returning to and revising previously researched ideas. Mulvey’s *Afterimages* expands her cinematic canon to consider non-linear film texts that foreground a “dislocation of time.” Referring to the filmic case studies in Part II, Mulvey states, “But the progressive concept of time is no longer tied to the linear pattern: temporalities fold back and interweave past, present and future” (14). Just as Mulvey rethinks and reworks her previous feminist ideas, the films about motherhood that she analyzes in Part II present a “confusion of time and space” (13). Time moves forward and folds back on itself, exposing a “complicated temporality” while remaining grounded in history (95-96). Mulvey identifies Peter Brooks’ concept of the “mute text” (93) as a site of immense

possibility to challenge patriarchal linear time and “public speech” (96). Using “non-verbal” expression (or “non-linguistic speech”) in film, such as a look, an action, or a slight sigh, can voice the “‘unspeakable’ of women’s lives” (94). Mulvey is now tracing a slight sigh, a sly look or glance, instead of a dominating voyeuristic gaze. The traditional weighty heterosexual narrative of the silent, passive, objectified woman that Mulvey analyzes in “Visual Pleasure and Narrative Cinema” is complicated and even destroyed by the slight sighs and gestures in films such as *Under the Skin of the City* and *Jeanne Dielman, 23 quai du Commerce, 1080 Bruxelles*. Mulvey’s analysis of non-linear, lyrical expression and speech in the modern moving image goes beyond the limited, vocal speech and expression of patriarchal film.

Mulvey extends this un-silencing to issues of race in film, including “racial fetishism.” In the introduction to Part I, Mulvey refers to bell hooks’ statement that “Hollywood’s all-encompassing whiteness had never been addressed by white feminist film theory,” echoing her claim that black women used “an investigative or ‘oppositional gaze’” before white feminist critique (19). In “Visual Pleasure and Narrative Cinema,” Mulvey’s primary focus was the point of view of a heterosexual male in the cinema and gendered film criticism, and she admits that she only became aware of “racial presence and absence” in Hollywood cinema later on. Mulvey writes that “the female star as fetish, deflecting the male gaze from those aspects of the female body that provoke anxiety, condenses with a white fetishism, deflecting with glamour the anxiety provoked by racial difference” (19). Responding to bell hooks’ critique of early feminist film theory, Mulvey later adopts an intersectional approach, combining race, gender, and class in her filmic case studies. For example, she analyzes the “intense whiteness” of Marilyn Monroe’s image, an artificial “glamorous” and “commodified” image that was desirable in the final period of traditional Hollywood cinema (20-21). Mulvey paraphrases James Snead’s cinematic

analysis of race and gender: “While representations of gender were so obviously on the surface of Hollywood studio-system cinema...alongside the stereotyping of black people on the screen, Hollywood’s phobic relation to race is manifested through absence: the almost complete erasure of African American presence on the screen” (19).

The psychoanalytic analysis of the ‘mute text’ does not (or should not) merely extend to oppressed and exploited white women. For Mulvey, “the muteness of motherhood can be used as a figure for and extended to all groups of the culturally oppressed” and this complex “maternal time” can “be used as a figure for and extended to a re-imagination of temporalities” (14-15). This complicated, interwoven, folding-back, non-linear time challenges sexual, racial, and class oppression. Past, present, and future intricately intertwine; simple binaries of active/passive, male/female, voyeuristic/non-voyeuristic, and power/weak are thrown into confusion in this new complex “maternal” temporality, this “necessarily confusing time” (14). In *Afterimages*, Mulvey reworks these fairly uncomplicated binaries established in “Visual Pleasure and Narrative Cinema.” Mulvey writes, “The ‘afterimage’, evoking the lasting nature of the image left on the eye by the impact of the real, is in *Afterimages* a metaphor for women’s use of cinema to offer, not simply to women but to everyone, stories and images thought through this poetic and political film-making” (15).

On the surface, the simple dichotomy of the passive female gaze and the active male gaze seems to translate to the power play of the doctor and the patient. The doctor actively probes the patient’s body to discover abnormalities and signs of disease, and the patient (usually) submits to having their body examined, often in a passive role in which they bow to the physician’s expertise. This comparison is heightened in the case of the pathological anatomists who dissected physically inert cadavers, exploring the inner depth of their bodily cavities and organs. However,

such a comparison might lead to undue assumptions about the medical gaze. I am not drawing this comparison to stigmatize the medical gaze as a patriarchal voyeuristic gaze that explores the human body for pure pleasure. The medical gaze is necessary for diagnosis and treatment of disease. Like Mulvey's exploration of complicated temporalities in *Afterimages*, and her complication of simple male/female and active/passive binaries, one must also re-read and complicate the medical gaze. Time, space, gender, race, and class all interweave in phenomenological investigations involving the gaze. In 1970, only five years before Mulvey's essay on the "male gaze" in cinema appeared, John Heron published "The Phenomenology of Social Encounter: The Gaze," arguing that one should understand "mutual touching" and "mutual gazing" as an intertwined "interpersonal encounter" (243). But the gaze is often orchestrated by larger social structures. The directed gaze, whether structured by a particular type of filmic editing and camera angles or by the lens of an endoscopic scope as it slides into the body's interior, is structured medically, socially, culturally, and economically. Pathological anatomy and medical imaging extended the medical gaze, and yet it is still limited: the medical gaze is not all-seeing and all-knowing. It is also structured epistemologically, sociologically, medically, and in many other ways. As Mulvey writes, "the 'unspeakable' of women's lives" are often "unable to find expression in the transparency of day-to-day language" (94). Complicated temporalities challenge the prevailing myth of absolute transparency in objective scientific/medical language, or even "day-to-day" language.

As Lisa Cartwright, Foucault, van Dijk and other scholars have emphasized, the medical gaze has changed/evolved over the past centuries. The question remains: Can there be a medical afterimage or how could one phenomenologically and critically deconstruct the medical gaze or find the same inherent "possibility" to shift "the emphasis of the look" and the connotations

associated with that look (988)? In the following section of this chapter, I turn to literary, artistic and filmic case studies to subvert the medical gaze in the same spirit as Mulvey analyzed the patriarchal voyeuristic cinematic gaze; the myth of transparency will be foregrounded, understood, and ultimately destroyed.

### **Case Study 1: Trethewey, “Knowledge”**

In *The Birth of the Clinic*, Michel Foucault argues there is a change in the relationship between language and object, the visible and the invisible that is introduced with the birth of the clinic and the “careful,” empirical gaze of “[m]edical rationality” (xiv). According to Foucault, the individual human being becomes a subject-as-object under the rationalizing medical gaze (xv). In the clinic, rational medical discourse has to find new ways to scrutinize and understand the thick, corporal body. The formerly “reductive” gaze under classificatory medicine shifts to a gaze that preserves the “individual in his irreducible quality,” leading to the strange and liminal space of simultaneous subject and object (xv). In her poem “Knowledge,” Poet Laureate Natasha Trethewey examines this complex subject-object space of the human body in academic inquiry, particularly medical inquiry. A chalk drawing by J.H. Hasselhorst (1864) (Fig. 1) depicting four medical professionals examining a dissected female cadaver bathed in a “pyramid of light” accompanies her poem. Trethewey describes this bright triangular light as “a temple of science over which the anatomist presides,” lyrically foregrounding the illuminating gaze of the anatomico-clinical gaze that Foucault describes, the light of life that death brings to medical knowledge. Trethewey interprets the “pyramid of light” not as illuminating mysticism, but as an edifice of scientific observation, representing the artist’s attempt to avoid his viewers interpreting the scene as a moment of “sacrilege.” Trethewey writes, “Perhaps to foreshadow / the object



she'll become: a skeleton on a pedestal, / a row of skulls on a shelf. To make a study / of the ideal female body, four men gather around her." Trethewey's focus on foreshadowing indicates that the "young and beautiful and drowned" woman has not yet been transformed into a pure object; she is still floating in between the positions of subject and object. Once her skeleton and internal organs are fully exposed and preserved, then she will have become merely an object of medical study. In this drawing, the anatomist "lifts a flap of skin beneath her breast as one might draw a sheet," barely exposing the tissue and muscle underneath. Thus, the skin enveloping the body is integral to the human body being viewed as a partial object: she is an object of medical investigation but still a "young and beautiful and drowned" woman (subject).



**Figure 1:** J. H. Hasselhorst, *The dissection of a young, beautiful woman directed by J. Ch. G. Lucae (1814-1885) in order to determine the ideal female proportions*, chalk drawing, 1864.

Trethewey refers to Hasselhorst's image as a "translation" of dissection; the "step by step parsing" of the anatomical procedure/ "study" is not shown but hinted at with the skeletons looming in the background. Trethewey also extrapolates a voyeuristic/fetishizing element of the drawing. In the beginning and middle of the poem, Trethewey emphasizes the woman's "lips," "long hair," "nipples," "breast," and "the down of her pubis" as the four men (five including the artist himself) stare at the drowned woman on the table. The tension between the active male gaze and the passive female body as spectacle that Mulvey identifies in her 1970s essay on the gaze in cinema can be palpably felt in this image and is even more clearly and poignantly represented in Trethewey's poetic interpretation of the chalk drawing. According to Trethewey, the "cold" instruments, books, skeletons, and particularly the triangular light (symbolizing the light of knowledge and discovery) are added to avoid the categorization of this image as "sacrilege." The anatomist and the three observers are dissecting a cadaver for the good of humanity, to learn more about the "ideal female body" for medical anatomical purposes. And yet, as Trethewey implies, the drowned woman has not yet transitioned completely into an object: she still occupies the liminal space of subject-object and is in the process of becoming to-be-looked at or an object of objectification. Considering this drawing was created in the late nineteenth century, the woman undergoes a double objectification. As a woman, she is considered lesser than man, the weaker sex. In that sense, she has already been objectified socially by the men surrounding her. But she has not yet become fully objectified in the scientific/medical sense because she is still a whole body (a subject in a sense). Paradoxically, her skin and female anatomy that are subjected to the physicians' patriarchal objectification is what keeps her identity partially "in tact," although she will gradually dissolve under medical objectification as the dissection progresses and she is preserved for scientific purposes.

The cadaver under the eye of the anatomist is a heightened example of the subject-as-object that Foucault discusses in medical discourse and the medical gaze, particularly in clinical and anatomico-clinical medicine. The inert deceased body does not appear to have any agency, unlike the active gazes of the male medical professionals. This discussion of subject-as-object echoes Hannah Arendt's discourse on "what" versus "who" in *The Human Condition*. Arendt writes, "The moment we want to say *who* somebody is, our very vocabulary leads us astray into saying *what* he is...his specific uniqueness escapes us" (181). The "intangibility" of each unique person, the "who," our individual essence, evades description. The moment language is relied on, the person's essence is objectified into a "what." The rationality of medical discourse is particularly prone to this process of objectification through language and description. In clinical medicine, the patient or the cadaver's body is treated as the site of illness, and yet the human body (whether alive or dead) is still not treated as a unique, intangible "who." Foucault writes that in the clinic "the individual in question was not so much a sick person as the endlessly reproducible pathological fact to be found in all patients suffering in a similar way..." (119). Although the tangible volume of the body became increasingly important in clinical and anatomico-clinical medicine, the patient was still treated as quantifiable medical phenomena, compared to other patients to increase medical knowledge and data. Even though Arendt states that the essence of "*who* somebody is" cannot be expressed adequately through language, Foucault does not even attempt to mention the "who" of patients, indicating that this was not of primary interest in clinical medicine. In Trethewey's poetic interpretation of Hasselhorst's chalk drawing, she similarly foregrounds the primacy of the "what" of medical study and discourse: "Mary or Katherine or Elizabeth / to corpus, areola, vulva." The unidentified drowned woman could possess any or none of the names that Trethewey lists, and her sense of personhood is

further discounted because she is dead. This line also illustrates the progression of the woman from person (subject) to an object of medical study, from a first name to a body of flesh and organs to be dissected. And yet, within the transformation from subject to subject-as-object to purely object, Trethewey's description of the woman's body remains in the liminal space of subject-as-object. As the poem continues suddenly Trethewey herself as subject lyrically slips into the role of this woman, looking up at the males in the anatomical theatre: "In the drawing this is only the first cut, / a delicate wounding: and yet how easily / the anatomist's blade opens a place in me, / like a curtain drawn upon a room in which / each learned man is my father / and I hear, again, his words—*I study / my crossbreed child*—a misnomer, / the language of zoology, natural philosophy."

Not only commenting on gender and pathological objectification, Trethewey's own lyrical entry into the anatomical scene and poem also exposes another form of objectification: racial objectification. Trethewey's poem "Knowledge" is part of her book *Thrall*, which she argues "is 'the book that is actually most about race that I've ever written'" (qtd. in Hall xix). Trethewey further explains, "'Even when I say that it's me taking on race in a direct way, I realize that what I'm still taking on is not even exactly that. It's more about knowledge'" (xix). This "knowledge" refers to Enlightenment knowledge of the "'codification of racial difference'" as "'natural'" (xix). For Trethewey this Enlightenment knowledge in her poem "Knowledge" is linked to her father and one of his poetic references to her as his "*crossbreed child*" as "taxonomy, the language of zoology." Trethewey is a biracial child; her mother was Black, and her father was White. However, as Nagueyalti Warren notes, the "Mississippi records... lists her mother as 'colored' and her father, 'Canadian'... To legitimize a link between Black and White in the public record was illegal" (220). Trethewey's poetry engages with historical and poetical

memory, essentially “restoring facts, either unacknowledged or erased” (Warren 217, 224). In “Knowledge,” Trethewey excavates the wound of her father’s words, “*my crossbreed child,*” through lyrically meditating on the scene unfolding in Hasselhorst’s drawing. In an interview with Marc McKee, Trethewey writes, “I look to the imagery of art to help me understand something about my own place in the world” (qtd. in Hall xv). The gazes of the men gathered around the inert body of the drowned woman, guiding the first strokes of dissection, speak to Trethewey, opening up an avenue of reflection as she ponders her relationship with her father and his “Enlightenment” thinking about a biracial child.

In fact, Trethewey conflates the “learned” men in Hasselhorst’s drawing with her father: “Here, / he is all of them: the preoccupied man— / an artist, collector of experience, the skeptic angling / his head, his thoughts tilting toward / what I cannot know; the marshaller of knowledge, / knuckling down a stack of books; even/the dissector – his scalpel in hand like a pen/poised above me, aimed straight for my heart.” Preoccupation, skepticism, knowledge, and dissection are attitudes and actions that Trethewey associates with her White father. Even though her father’s words continue to wound her, Trethewey states in an interview that her father’s poem “is ‘really loving, it’s sweet’” (qtd. in Hall xix). However, Trethewey states that “[t]here’s still an edge and a blindness” (qtd. in Hall xix). This “blindness” of her father traces back to the prevalence of Enlightenment knowledge and the use of race as a form of categorization and segregation. Warren states that “DNA reveals the ridiculous construction of race,” and yet, as in the case of Trethewey and many other biracial people, “appearing Black” or “[b]eing Black and looking white produces a variety of experiences” (220). The systemic colonial mindset of Enlightenment knowledge and categorization still oppress and exploit people of color, both intentionally and unintentionally. In the case of Trethewey’s father, Trethewey believes her

father's use of the racial phrase "*crossbreed child*" was not intended to cause her pain; yet, it was one moment among many that showed how his White privilege "blinded" him to issues of race. As a biracial person, Trethewey, and the narrator of her poem "Knowledge," traverse the liminal space between Black and White culture.

In her poetry, Trethewey also engages in non-linear narrative, echoing Mulvey's "complicated temporalities" (95-96). In relation to *Belloq's Ophelia* and *Native Guard*, Trethewey states, "So many of the formal decisions I made are about circling back, so the narrative circles back in on itself and simply can't proceed in a linear fashion" (qtd. in Hall xvii). This "subversive strategy" (Hall xvii) also translates to her poem "Knowledge" in *Thrall*. The ekphrastic poem interweaves two narratives, past and present: the narrative depicted in Hasselhorst's drawing (as told by the narrator) and the narrator's biracial narrative that surrounds and punctures the poem. The two narratives merge when the narrator imagines herself underneath the "anatomist's blade" as the words "*I study my crossbreed child*" echoes in their mind. The period of Hasselhorst's drawing, the narrator's memories, and the narrator's current experience of pain swirl past and through each other in this temporally rich poem. Trethewey refuses to adhere to traditional narrative techniques, blending past, present, and future experiences and emotions into a common thread of reflecting on personal and historical events.

In "Knowledge," is the deceased woman still a subject-as-object to the four men observing her in the drawing? Or is she merely a subject-as-object to the viewer (or more specifically, the modern viewer)? Has death and the first cut of dissection transformed her wholly in the eyes of the anatomists/doctors in the room? It is impossible to know for certain. In the larger context of Foucault's history of medicine and the anatomo-clinical medical gaze, it is likely that the medical professionals in the drawing were focused on the woman's corpse as an

object of science, an opportunity to advance medical knowledge. At the time of Hasselhorst's drawing in 1864, anatomical dissection was one of the only modes available to medical professionals to explore the interior organs of the human body. Until Wilhelm Roentgen discovered X-rays in 1895, anatomo-clinical doctors relied on corpse dissection to expose a "visible invisible" (Foucault 114). Corpse dissection allowed doctors to view the human body as "a land, a mappable territory, a subterranean" terrain; one could use dissection to map the organs in relation to other organs and surrounding tissues. Unlike modern medical imaging through which doctors can view life unfolding in the present moment, the anatomo-clinical gaze paradoxically required death to reveal human life processes. Foucault states, "the presence of the corpse enables us to perceive it living" (183). The pathological medical gaze extolls the "brightness of death" (180) and "the life/disease/death trinity" allows the anatomist to achieve a semblance of transparency (195). The corpse is not thought of as a patient, but as a medical object required for the experimentation and exploration of life's processes.

In *The Transparent Body*, Jose van Dijck discusses the myth of bodily transparency within modern medical imaging. Van Dijck argues, "looking into the body" is never innocent (8). This argument recalls Foucault's description of the "violence of the dissected corpse" that is subjected to the anatomo-clinical gaze (102, 195). The "violence" of the medical gaze in Trethewey's poem is at work both physically and metaphorically: the drowned woman is undergoing violence to her body as the anatomist slices and lifts a flap of her breast. "Knowledge" also documents the violence of the medical gaze probing her body. She is dead and cannot feel (physically or emotionally) the violence of the scalpel or the medical gaze, but the reader/viewer can. When Trethewey's poem transitions from ekphrastic description to personal narrative of child-father trauma, the "anatomist's blade" not only exposes the breast tissue of the

drowned woman, but it also reveals the deeply buried trauma of the narrator's strained relationship with his/her father. According to van Dijck, medical and cultural interpretation cannot be separated in our current highly mediated culture (8). The poem's narrator adds a phenomenological third dimension: the personal/emotional. Medical, cultural, and personal interpretations are highly intertwined; we in turn bring our own knowledge base, history, and feelings to the poem, and the reader can interpret and feel the narrator's emotional pain.

Trethewey collages and collapses myriad gazes: the 'objective' empirical anatomo-clinical gaze of Hasselhorst's time, the modern medical gaze and patriarchal look of the narrator's time, and her own gaze back at the distant male doctor/father.

### **Case Study 2: *Fantastic Voyage***

In *The Transparent Body*, Jose van Dijck argues against the prevalent myth of the transparency of the human body that has risen with the increasing reliance on medical imaging (both medically [imaging] and culturally [media]). She insists that the "transparent body" is a mediated "cultural construct," arguing that the human body is "everything but transparent" (3-4). Van Dijck disrupts the idea that the interior organs and everything contained within the body are entirely visible through medical imaging. Even medical images such as X-rays and endoscopies require interpretation and cannot completely map the body's entire interior. In addition, the increasing use of medical imaging of mediated bodies in cultural media makes the concept of transparency even more complex. The levels of mediation range from the medical professional's gaze and the medical imaging device/screen to the type of media which portrays the images (e.g. TV vs. an art exhibit). Van Dijck identifies this "myth of total transparency" as a Western ideal that connects visualization with "curing" illness, perpetuating the idea "that peering into the body



is an innocent activity” (6). Conflating visualization, innocence, and pathology signals an implicit “trust” that most people have in the “mechanical-clinical eye” (7). As van Dijck argues, “looking into the body” is never innocent (8): the medical meanings of medical imaging are always interconnected with cultural meaning. Medical and cultural interpretation cannot be separated in our highly mediated culture.

As Lisa Cartwright also argues in *Screening the Body*, modern medical imaging has “progressively destabilized” the “sensory perception” (primarily sight) which dominates Foucault’s “history of empirical techniques of diagnosis” such as “palpation and auscultation” (10). Medical imaging pictures, produced by the endoscope or CT, are always mediated images: the doctor or technician looks at the internal organs through a lens or on an enlarged screen. With the rise of the X rays, van Dijck emphasizes that the body and its representation were “separated” (98); the new “mechanical-clinical eye” (7) that created “an illusion of unmediated, objective reality” of the body as “transparent” was in fact a highly mediated medium. Van Dijck writes, “The body – made transparent by a host of new mechanical instruments – is anything but an objective object of study. On the contrary, X-ray pictures, like other mechanical reproductions, always yield mediated perspectives, as their meanings are always shaped by the knowledge and feelings of their interpreters” (99). The common “dichotomies between instrument and observer, between object and representation, and between science and art” must be examined and overturned to comprehend the “illusion” of the “transparent body” and to understand medical images as mediated images (98-99). Medical imaging is often viewed as objective in the scientific community, and yet, doctors and technicians need to interpret the images, to view them from a pathological standpoint. Interpretation of medical imaging requires highly skilled professionals, and even then, sometimes the results are inconclusive or contested.

Van Dijck also emphasizes the role of cultural mediation, particularly “media’s insatiable appetite for visuals” and “spectacle” (4-5, 12).<sup>2</sup> Mass media not only helps fashion the “transparent” and “high visibility of the interior body in modern-day culture,” but it also creates specific associations with certain types of medical imaging “outside a clinical context,” such as associating the term ‘ultrasound’ with pregnancy, PET with schizophrenia, and MRI with cancer (12). Although these types of imaging are used in many different diagnostic areas, the cultural associations are strongly reinforced through mass media, such as medical dramas and medical documentaries. Van Dijck wants to disrupt the objective-subjective and scientific-art binaries to show that interpretation, mediation, and representation are active in science and medicine just as much as they are prevalent in art and media. The connection between art and science is often brushed aside, but the two are inextricably connected and have a complex history.

Representation and art are intertwined in the history of scientific medical imaging. Cartwright attests to this interconnection when she examines “historical instances of the use of the cinema in medical science to analyze, regulate, and reconfigure the transient, uncontrollable field of the body” (xiii). She describes the cinema “as a part of a social apparatus through which the cultures of Western science and medicine shaped and built the life they studied, and how individual subjects and cultures aided, confounded, or resisted Western medical science’s normative life-building projects” (xvii). According to Cartwright, Western medicine and science use the cinema to help form and enforce normative constructs. However, Cartwright also asserts that the “historical context” of “contemporary medical imaging technologies” reveals that they “cannot be simply demonized as the optical tools of medical surveillance” and cannot be simply

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<sup>2</sup> On the new X-ray technology and spectacle, see Lisa Cartwright’s *Screening the Body*, Richard M. Swiderski’s *X-Ray Vision: A Way of Looking*, Janelle Blankenship’s “Arno Holz vs. Thomas Mann: Modernist Media Fantasies,” and “The Roentgen Rays: X-Ray Spectacles, Now: Edison Invents a Portable Screen for Surgeons” in *Guy’s Hospital Gazette* (1896).

dismissed as patriarchal, voyeuristic, and harmful (169). Medical imaging is important for quicker, less physically invasive diagnoses, helping extend many patients' lives and improve their quality of life. However, van Dijck argues that medical imaging must be used in combination with other diagnostic modes, such as "anamnesis" (patient's account of their medical history) and blood tests. Van Dijck writes, "I had put such trust in the diagnostic visual evidence (gastroscopy and ultrasound) that I was ready to deny my own experience of pain. Thanks to my gastroenterologist, who relied more on anamnesis and the sheer number of blood tests, I am able to tell this story today" (x). Diagnostic imaging does not always tell the full narrative, and this implicit "trust" in the power of the visuals of imaging can lead to dangerous consequences. Van Dijck "challenges" the "simplified notion that new imaging technologies lead to more knowledge and thus lift the veil from the interior body," and she agrees with Cartwright "who equally considers medical and media technologies as representational tools, producing meanings at a particular historical moment" (16).

In the fourth chapter of her study, van Dijck describes endoscopic/laparoscopic procedures and complicates the myth of the "transparent body," suggesting a different level/type of mediation for the patient as opposed to the surgeon. She writes, "To a layperson, video endoscopy creates a strong sense of the body's transparency, yet for surgeons this technology means less, rather than more, access to the patient's inner layers. The surgeon is no longer looking directly at the insides of a real body and its organs and intestines laid open through an incision in the skin, but [sees] a *mediated* body – mediated by the camera and video display hanging over the operating site" (69). While both the patient (lay viewer watching a medical drama) and the doctor view a mediated image, the doctor experiences/faces a highly mediated body and a partially blocked view. There is limited transparency of the interior organs.

According to van Dijck, “the endoscopic gaze provides an inherently constrained perspective on the interior of the body.” Working with “miniscule openings,” the surgeon needs strong “hand-eye coordination” because they are guiding their instruments into the body solely “through the video viewer and its electronic display” (69-70). Unlike “open surgical procedures” where the surgeon is “looking from the outside in” (67), the endoscopic procedure allows the surgeon to view organs from within the interior of the body. The surgeon metaphorically enters and explores a portion of the patient’s body from within, completely bypassing and diving below the skin envelope that remains mostly intact. This shift of “the clinical endoscopic gaze” from “*the outside in*” to the “*inside out*” to “*the inside in*” (with the development of 3D virtual endoscopy) transforms the viewer’s relationship “between interior and exterior” (80), particularly the lay viewer’s consumption of mass media dissemination of endoscopic images/films. In mass media, Van Dijck writes, “the viewer is seduced into disregarding the boundaries between interior and exterior, between looking and cutting, and between the real and the virtual body” (80). Viewing from “*the inside in*” changes the viewer’s relationship between medical procedures and the body, and it veils the fact that it is not an innocent endeavour (80, 8). Although the endoscopic gaze remains “complex and opaque,” media portrayal of endoscopy promotes the myth of “transparency” and innocence - an “untainted body” (79). Medical technology and its portrayal in mass media has changed people’s relationships to their bodies and other’s bodies, signalling a phenomenological and epistemological change. The “fantasy” of the ‘transparency’ of medical imaging leads to an erroneous “ideal of a body that is malleable, perfectible, transparent, and fully understood” (142), in short, a “conceptualization of the permeable body” (66).

According to van Dijck, the 1966 science-fiction movie *Fantastic Voyage* mirrors the development of endoscopic technology (65) and embodies the spectator’s deep desire to see,

expose, and reconstruct everything subcutaneous while leaving the outer body ‘untouched’” (79). Scientific illustrator and animator Frank Armitage (who also did animated educational films, many for Walt Disney), produced set designs and animations for the film, which won an Oscar for Best Art Direction. Armitage famously stated in the voice-over to his short documentary *Anatomical Animation* (1970) “I feel there can be great beauty in medical art. A beauty that goes hand-in hand with science, as we explore the infinite inner spaces of the human body.”<sup>3</sup> Drawing a direct parallel between cinema and medical imaging technology, van Dijck argues that scientific and surgical “body voyage” in *Fantastic Voyage* self-reflexively catalogues the development of endoscopy technology (65). In *Fantastic Voyage*, four men and one woman are shrunk in an “experimental submarine” (1966) and are injected into the bloodstream of a wounded scientist who is suffering from a blood clot in his brain. According to the doctors, the blood clot is inoperable through surgical means without damaging surrounding tissue. The only way to access the clot is through “the arterial system,” and it must be “dissolved with a laser beam” (1966). In the mission brief, the doctors reveal that there is an hour time limit, and once the submarine begins to grow again, antibodies will attack the vessel (as well as “other unknown factors,” revealing the interior body to still be an uncharted territory). When the crew is injected into the blood stream, strange and discordant (almost triumphal) music swells as a lava lamp-like pink and green light show flows around their vessel (Figure 1). An unexpected “current” in the artery, the first “unknown,” carries the submarine into the veinous system through an arterial-veinous fistula, which is “too small to show up in the test” completed prior to their embarkation. This small “unknown,” undetectable from the outside, can only be discovered from within the

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<sup>3</sup> On Armitage’s scientific illustration also see Amy Mednick, “Disney Animator Practices the Fine Art of Medicine” in *Los Angeles Times* (1986), and Oliver Gaycken, “Through the Body with Laser Gun and Camera: *Fantastic Voyage* and the Cinema of Exploration” in *Cinema of Exploration: Essays on an Adventurous Film Practice*.

body itself: from “*the inside in*” (van Dijk 80). The power of the internal medical gaze (the crew in the miniaturized submarine) illuminates previously undetectable issues, and yet the danger that the fistula poses to the submarine crew taints what is otherwise an unprecedented discovery.



**Figure 2:** *Fantastic Voyage* (Dir. Richard Fleischer, 1966), still, 38.30

In an essay in *Wild Science: Reading Feminism, Medicine and the Media*, Kim Sawchuk refers to the “anatomical entertainments” of “biotourism” when she discusses the science fiction genre of *Fantastic Voyage* (10). Sawchuk defines biotourism as “the persistent cultural fantasy that one can travel through the inner body, a bodyscape which is ‘spatialized’ and given definable geographic contours” (10). As Sawchuk argues, biotourism is based on a fantasy of harmless intervention, echoing the title *Fantastic Voyage*: “Biotourism is the fantasy that one can voyage into the interior space of the body without intervening in its life processes, with silent footsteps, without leaving a trace” (21). According to Sawchuk, “that representation can be without intervention is itself a wish, a fantasy” (21). Even if the body is not cut with a surgeon’s scalpel, making the invisible (or hidden) visible (an exploratory act, according to the scientific illustrator) is also an “intervention” and a “transformation.” Echoing van Dijk’s explanation of

the “fantasy” of the complete ‘transparency’ of medical imaging (142), Sawchuk connects the fantasy of biotourism to this ideal of transparency. Scientifically and culturally, the interior body in the long twentieth-century became a “new frontier” with the invention of high-powered microscopes, X-ray machines, MRIs, and endoscopes (among other imaging technologies) (Sawchuk 21). The biotourist fantasy of “the new frontier” involves “scale” and “space” (11). For example, the submarine is miniaturized and injected into the bloodstream of the unconscious scientist. This change in “scale” provides the necessary scope for the scientists, and by extension the viewers, to explore and marvel at the “panoramic point of view of a vast multi-hued vista from within,” at “the floating blobs of fluorescent psychedelic plasma” (13). Sawchuk argues that “[t]his transposition of scale...prepares us for the second moment within the fantasy: the spatialization of the inner body and its transformation into landscape” (13). The “bioscope” of the interior body further cements the cultural view of the transparent human body and the common misconception that filmic ‘non-invasive’ exploration of the interior body is harmless.

According to van Dijck, current endoscopic procedures leave only a “small scar on the patient’s skin,” and the development of “‘virtual endoscopy’...will purportedly turn science-fiction fantasy into surgical reality: surgeons predict that they will soon be able to move around and operate inside a body without penetrating the skin” (65). “Virtual endoscopy” should allow surgeons to visualize and manipulate the body’s interior without inserting laparoscopic instruments into the body. However, the science-fiction medical gaze portrayed in *Fantastic Voyage* charts out a different journey, unlike “virtual endoscopy.” “Virtual endoscopy” is imagined as a representation of the internal body on an external screen with the doctor/technician as spectator, outside the body *viewing in*, whereas the medical crew in *Fantastic Voyage* are *inside* the body, as embodied spectators. The primary difference is an outside gaze from “*the*

*inside in*” and an inside gaze from “*the inside in*” (van Dijck 80). The large windows in the submarine vessel resembling a screen displaying enlarged corporeal images like plasma both distance and direct the endoscopic gaze. The medical explorers are inside the patient’s body; as biotourists they view it as spectacle: they are still gazing from “*the inside in,*” but they also enter the body and swim through it, fighting antibodies.

When the crew enters the brain, Dr. Duval lyrically meditates on knowledge and enlightenment as the submarine drifts through a blue and grey cobweb-like environment with twinkling light brain synapses (see Figure 3). Dr. Duval quotes a mysterious poet or philosopher in wonder, “Yet all the suns that light the corridors of the universe shine dim before the blazing of a single thought...” Grant finishes this lyrical meditation (of unclear origin): “...proclaiming an incandescent glory: The myriad mind of Man.” While viewing this corporeal mystery, Dr. Duval enters the domain of mysticism; he turns to philosophical poetry to describe the scene before his eyes. “The myriad mind of Man” represents infinite possibility and mystery that is even more awe-inspiring than the many “suns” of the “universe.” Attempting to cut these poetical reflections short and to return to the safety of scientific objectivity, Dr. Michaels, the anti-religious cold-war spy, skeptically quips, “Quite poetic, gentlemen. Let me know when we pass the soul.” However, Dr. Duval retorts: “The soul? The finite mind cannot comprehend infinity, and the soul which comes from God is infinite.” According to Dr. Duval, the finite light of wisdom, “the blazing of a single thought” can’t comprehend the infinite soul and the wider mystery of God, but the mind itself is wrapped up in infinite mystery. This dialogue disrupts and complicates the biotourist myth of transparency, as explained by Sawchuck. Visualizing the interior of the brain does not lead to complete understanding of the mind, and it certainly cannot lead to an understanding of the infinite soul. The interior of the brain is anything but transparent



as the web-like curtains float around the submarine. Although the viewer visualizes what the brain might look like from the inside, the physical qualities of the brain bioscope do not render the intricate workings of the mind transparent. Dr. Duval’s mystical, humanist meditations subvert the cold medical gaze, requiring the viewer to engage in self-reflexive contemplation of the mind’s complexity.



**Figure 3:** *Fantastic Voyage* (Dir. Richard Fleischer, 1966), still, 1:27.25

The poetic “blazing of a single thought” reminds us of the illuminated triangle Trethewey describes in the dissection chamber in “Knowledge”: “the artist entombs her body in a pyramid / of light, a temple of science over which / the anatomist presides.” The “pyramid of light” symbolizes enlightenment and shrouded mystery, like Foucault’s description of “the brightness of death” of anatomico-clinical medicine (180). In the dissecting chamber or “temple of science,” the “light” which bathes the young woman’s corpse is infused with a similar mysticism. Like Trethewey’s own lyrical intrusion into the dissecting scene, Dr. Duval’s meditations on the “enlightened” human mind and soul complicate the cold medical gaze. As the myth of

transparency breaks down, there is a need to interpret and re-read the body and the universe. The lyrical meditation forces the reader/spectator to consider the mediation, mind and bodies behind the gaze. In *Fantastic Voyage*, Cora Peterson (Raquel Welch) interestingly does not participate in this metaphysical/poetic discussion between Dr. Duval and Grant as the submarine propels through the brain. Is Cora the female assistant merely a spectacle? Is she like the passive female corpse in “Knowledge” that is dissected under the male medical gaze? Perhaps Cora’s silent awe at the sight of the brain, like the nuance of the cinematic sigh and glance that Mulvey traces in *Afterimages*, is as powerfully demonstrative of the mind, soul, and infinity as the blatant philosophical musings of Dr. Duval and Grant. In this scene, the crew’s personal biases, cultural conceptions, and the physical barrier of the submarine windows mediate their visualization of the brain’s bioscape. Although they are within the brain itself, their image of the brain will never be unmediated.

No matter how close reality gets to “science-fiction,” medical imaging will always involve mediation. “Virtual endoscopy” is non-invasive, but that also means no biopsies can be taken if required and a separate biopsy procedure would have to take place.<sup>4</sup> Unlike the submarine crew inside the body fighting off corpuscles and dissolving the blood clot with a “laser beam,” “virtual endoscopy” would only provide an internal image of the desired organ and surrounding area. However, even without penetrating the skin, the endoscopic gaze, far from innocent, is still steeped in cultural and medical interpretations.

However, is the endoscopic camera a type of mediation that cannot be escaped? The lyrical flow of the dialogue between Dr. Duval and Grant about the mysteries of the mind as the submarine drifts through the brain might be read as a “filmic” meditation on Henri Bergson’s

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<sup>4</sup> Bradford J. Wood, M.D., and Pouneh Razavi, M.D. “Virtual Endoscopy: A Promising New Technology.” (2002)

“cinematographical consciousness” and his parable of time as unreeling, unfolding, flowing duration. When Dr. Duval states that soul that comes from God is infinite, Dr. Michaels retorts “yes, but our time isn’t.” The Russian saboteur Dr. Michaels represents discontinuous ticking scientific time that is part and parcel of the medical/surgical gaze when he interjects, abruptly reminding the viewer and biotourist of the medical task at hand. Does the endoscopic camera (a la Duval) like Bergson’s description of creative unwinding allow humans to view life as “becoming” and unfolding before their eyes? Or does the endoscopic gaze (a la Michaels) remain outside flowing duration, outside what we can read between the lines in Bergson as a more organic “cinematographical consciousness”? Bergson on the one hand uses the cinematographic metaphor to critique the “natural bent of intelligence” to “decompose” and “recompose” an “assemblage” of images, refusing to engage with true duration or “real time” (90), but in his writings he also embraces a creative language of cinematic mobility. Instead of seeing and sensing the flow of the continuous real time of duration *from within*, common intellect, he argues, views time externally and cannot conceive of a “real time” of continuity, of continuous creation in which “the past presses against the present” in the flow of duration (27), of unfolding “gradual preparation,” maturation and infinite change (19). A number of scientist-filmmakers and biologists like Jean Comandon and Alexis Carrel drew on Henri Bergson’s vitalist theory of duration to fantasize in the early twentieth-century that the cinema, endoscopic apparatus and screen give us a glimpse of “physiological time” and the unfolding of life’s biological processes.<sup>5</sup> Many avant-garde filmmakers argued that Bergson-inspired scientific film footage of nature and the human body also conjured up “accidental beauty.” For the French surrealist filmmaker Jean Painlevé and impressionist theorists and filmmaker Jean Epstein and Germaine

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<sup>5</sup> See Rosine Kelz, “Tissue Culture and Biological Time: Alexis Carrel, Henri Bergson, and the Plasticity of Living Matter.” (2022)

Dulac dramatic “close-ups” of the body, slow-motion and time-lapse rhythms were charged with "photogénie" (Bonjour 13).] The body pictured in these twentieth-century mediated moving images - as Dr. Duval lyrically reminds us in the 60s sci-fi film - is not transparent fact, but art - art that has to be read and re-read.<sup>6</sup>

### **Case Study 3: The Stoma**

The ostomy, intestine exposed outside the skin barrier, complicates historical and current discussions of the medical gaze and the myth of the transparency of the human body. The internal processes of peristalsis and unformed waste defecation are visible to the naked eye, no longer requiring medical imaging to penetrate the internal organs with X-rays or endoscopic cameras. In medical imaging, such as endoscopic films of the intestines, doctors and technicians view the intestines for a short period of time and review the footage to look for bodily issues. However, the ostomy makes the intestine readily available for viewing. Although often hidden under clothing, the ostomy can be easily accessed, and both doctor and patient can view the internal made external. The ostomy is only a very small part of the intestine that is visible, but it does lend itself as an interesting case study for discussing the medical gaze, medical imaging, and the myth of the transparent body.

Previously in this chapter on the medical gaze I examined Tretheway’s poem “Knowledge” as my first case study and explored the liminal position of the drowned woman as subject-as-object in the text of the poem and Hasselhort’s drawing. Another liminal space suspended in between two opposites is the stoma, where an opening in the abdominal wall expels

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<sup>6</sup> On vitalist processes and time-lapse in avant-garde film, see Janelle Blankenship, “Film-Symphonie vom Leben und Sterben der Blumen: Plant Rhythm and Time-Lapse Vision in *Das Blumenwunder*.” (2010)

waste into an external bag. An ostomy resides in a fluid liminal space that slips in between interior and exterior. The internal intestine is made external. During surgical intervention, the surgeon sews the edge of the intestine to the abdominal skin, and the two surfaces (external and internal) fuse together in the healing process. Is the stoma (the end of the intestine) still considered internal? The stoma is usually hidden underneath an opaque bag and layers of clothing, but the intestine is still exposed above the skin envelope. Subject-as-object and internal-as-external are intertwined in the stoma.

Although now ostomies are quite common surgical interventions, “[n]ot that many years ago, ostomy surgery was referred to as the ‘secret surgery’ and considered only an alternative to death for many patients (Turnbull, 2006)” (Wilson 242). In the eighteenth-century, the first stomas recorded were “fistulas that developed spontaneously following bowel perforation,” and surgeons decided to explore the “correlation between spontaneous fistula development and patient survival” (Doughty 34). However, surgery was still an extremely risky and painful intervention until anesthesia was developed in the mid-1800s (Doughty 34). Although colostomies (the large bowel forms the stoma) were developed in the early 1800s, colostomies became a more standard surgical procedure in the nineteenth-century. The first ileostomy (the small bowel forms the stoma) surgical procedure was recorded in the late nineteenth century, much later than the experimental colostomies; however, “severe skin breakdown and high morbidity and mortality rates” of ileostomy patients caused surgeons to consider ileostomy creation as a “last resort” surgical intervention (Doughty 36). To make matters even more complicated for twentieth-century ostomy patients, “there were no ostomy supply companies” until the 1970s, and patient ostomy management was a painful and frustrating life-long struggle (Doughty 35). Until the development of Enterostomal Therapist positions in the mid-twentieth

century (now the WOCN Society), ostomy patients were on their own and experienced pain and ostracization “with no one to turn to when they had questions or problems” (Doughty 37). This brief history of surgical stoma creation reveals a highly complex narrative of accidents, experimentation, and patient participation. What now seems like a common procedure for many illnesses was historically a very complicated procedure. The first stomas were “skin-level” and now they are raised above the skin. The intestine exposed above the surface of the skin through a process of maturation (Doughty 34) is visible and touchable due to the efforts of surgeons, nurses, and patients. To see the intestine exposed above the skin is quite wondrous.

The interior-exterior liminality of the stoma, simultaneously inside and outside, can be viewed as a “meeting place.” In *The Scar of Visibility: Medical Performances and Contemporary Art*, Petra Kuppers theorizes the scar as a “meeting place” between interior and exterior. She writes, “A scar: meeting place between inside and outside, a locus of memory, of bodily change. Like skin, a scar mediates between the outside and the inside, but it also materially produces, changes, and overwrites its site” (1). Not only is the scar a “meeting place,” but the scar is also “the place of the changed script,” both physically visible changes and changes in how one experiences their body (1). Ostomies also hold this unique, vacillating position between internal and external organ. Undergoing an ostomy surgery literally places an internal organ (the intestine) on the outside of the body, which is different from viewing one’s own organs tucked safely inside the confines of a medical image. Like a scar, the ostomy is a “changed script” that alters the skin enveloping the body. Unlike a scar, the ostomy opens into the interior body, a meeting place that remains under constant renegotiation between inside and outside. A scar implies that the interior of the body was once visible to some degree and is once again sealed over and out of sight. A stoma, on the other hand, is never ‘healed’ in the usual sense of the

word, which connotes a perception of the ‘normal’ body as dry and not icky, oozing, bleeding, or expelling waste. The ostomy can be ‘healthy’ or ‘unhealthy,’ but it can never ‘heal’ as a scar can ‘heal.’ The “changed script” of the ostomy site continues to evolve; it has ‘changed’ and is still changing.

The stoma: no medical imaging is required to see this small part of the intestine. Its peristalsis activity is available outside of the body for the ‘naked’ eye to see. In a sense, the patient can see a small portion of what the surgeons see when they perform endoscopic procedures. However, the stoma patient doesn’t require the mediation of a camera or screen. The only mediation is the personal, cultural, social, and medical experience that forms their embodied perception of their own body. Koppers emphasizes the “moments of strangeness” that occurs when a person touches his or her scar and “experience the sensation of touching yourself but feeling the touch as strange” (1). With the stoma, the wet, slimy, unclean inside becomes outside and inside simultaneously, clean and unclean, seen and unseen. Laying in a hospital bed preparing my ostomy appliance for the first time, my forearm brushed against the squishy wetness of the new, inflamed stoma protruding from my abdomen. In the brief moment of contact, my forearm skin felt the stoma shrink and expand, but the stoma (*my stoma*) could not feel my forearm. The intestines do not have nerve endings; the stoma cannot ‘feel’ and cannot ‘touch.’ The reciprocal aspect of touch in Maurice Merleau-Ponty’s famous example of the right hand touching the left hand is inaccessible in this particular moment or tactile encounter. Inside meeting outside, flesh meeting skin, non-touch meeting touch intertwine and shift between self and other. The strange otherness of this phenomenological encounter with my own internal body made external sets into relief the challenge of (re)embodiment as a disabled person. The stoma

that my arm brushed against was not yet 'my' stoma. Scars can have varying levels of feeling, but a stoma cannot 'feel' or return a touch at all.

This feeling of strangeness also extends to the medical gaze and medical discourse. I overheard two surgeons talking about a patient as they walked past the elevators. They commented nonchalantly on how easy the surgical procedure would be because the woman was skinny, less layers to cut through and spread apart to access her internal organs. She was a body to be operated on. I had been operated on few times. Did my surgeons sum me up by the thickness or thinness of my subcutaneous layers?



## Chapter 2: Embodiment and the Disabled (Extraordinary) Body

### Merleau-Ponty and Critical Disability Studies

Disability is a unique form of “perpetual embodiment” that is constantly shifting. This shifting of disability constitutes a presence rather than absence, which is a commonly held negative ableist conflation. Embodiment, in general, is a perpetual reworking and reshaping of our flexible body schemas, through which we encounter and engage with the world and other people. To understand the uniqueness of disability embodiment, in this chapter I will first discuss Maurice Merleau-Ponty’s theory of embodiment as inhabiting the world in *Phenomenology of Perception* and then draw on Merleau-Ponty’s theory of embodiment to analyze two artistic and poetic interventions into the “lived experiences” of the disabled (extraordinary) body. The importance of embodiment to disability cannot be understated. As Joel Michael Reynolds argues:

“[d]isability cannot be understood outside of the centrality of its narrative role for the lived experience of selfhood, social identity, and...our being-in-the-world” (243-44). The narratorial role of disability experience is subjective, but not subjective in the relativistic sense of complete isolation (Fielding, *Cultivating* 11). In Merleau-Ponty’s theory of embodiment, the subject is always the starting point from which location or position that subject opens onto the world and other people. The body and world participate in a chiasmic intertwining. Merleau-Ponty’s theory of “existence” as “a perpetual embodiment” (169) and embodiment as inhabiting or being anchored in the world provides an important background/horizon for a phenomenological discussion of disability and chronic illness. In an often-jarring jolt(s), disability, acquired or not, disrupts the flexible fluctuating flow of embodiment, and the “bodymind,” which usually remains unnoticed in the background, takes centre stage (Price qtd. in Reynolds 244). The shifting disabled body schema is forced to adjust to social, economic, political, and physical

barriers, and it can no longer operate smoothly in the background. Thus, disability embodiment is unique in that it requires a constant reflection on experience of the interconnectedness of body and world. Disability is the lived experience of a critical phenomenology.

Merleau-Ponty focuses on the reversibility of the human body, the flesh that perceives and senses that can also be perceived and sensed. This reversible fleshly body is part of the “corporeal schema structured through habit” that “is the ‘experience of my body in the world’” (Fielding “Habit” 155). The body schema is both temporally and spatially located, but it also has access to conceptions of past, present, and other worlds that influence the lived experience of the present. As an “indivisible” whole (Merleau-Ponty, *Phenomenology* 100-101), the “body schema is not merely an experience of my body, but rather an experience of my body in the world” (142). Fluid rather than static, the body schema is constantly reworked and renewed, particularly through the acquisition of habits (143). Since the body always inhabits the world, the body and world cannot be completely separated. This body of intertwining and enveloping interdependent organs inhabits, and even constitutes, space (104, 147): “[t]he body is our general means of having a world” (147). Without the body, which is constituted and constituting, no person would be able to inhabit the world, to have it.

Through habit, the body understands itself and its interconnectedness to the world. Habit is a pre-reflective, pre-cognitive “motor signification” that the body incorporates into its corporeal schema as a “moving body” (155). The whole body, the “bodymind” (Price qtd. in Reynolds 244), is a living, moving, breathing subject that experiences the world. Merleau-Ponty scholar Helen A. Fielding describes habit as “the body’s understanding of itself in the world...Our bodies sediment ways of understanding that become habits that anchor us in the world” (“Habit” 156). These habits shape, structure, and ground how we perceive the world and

other people. Yet, habit-structuring through the body schema remains imperceptible in the background (156). Shaping how we encounter and engage with the world, habits that form and shift in the background beneath the movement of our everyday lives traverse different levels, or worlds (156). For example, racialization, heterosexuality, and ableism are three interconnected levels (worlds) that undergird both individual and communal habits as natural or normative. These often-imperceptible backgrounds are what phenomenology, recent critical phenomenology in particular, aims to foreground and interrogate.

Within this world of habits and levels, between the background and the foreground, the body inserts itself as a “mediator” (Merleau-Ponty, *Phenomenology* 146). As a “mediator,” the body “is the always implied third term of the figure-background structure,” occupying an in-between space. The body as a corporeal schema is as imperceptible as the background between which it is situated. The body moves smoothly, incorporating new gestures as habits and allowing the body to be not just ‘in the world’ but also “toward the world” (103). Differentiating his phenomenology from Heidegger’s “being-in-the-world,” Merleau-Ponty argues that we are not merely “in” the world, we “inhabit” the world: reciprocally, we shape the world, and the world shapes us (141). This reciprocity is possible through the mediation of the body as the hidden “third term” that allows human beings to inhabit the world. We are our bodies, and thus, as Merleau-Ponty argues, we cannot achieve the purely objective thought of empiricism and the analytic thought of intellectualism (77-78). The material and phenomenal body cannot be bracketed in favour of a precise “thinking subject” or an absolute objectivity (Fielding, *Cultivating* 9). The relational body mediates and co-constitutes experience with the world and other people. However, it is precisely this mediation that is often forgotten, particularly in an age that still strives for objective unmediated knowledge.

The mediating, sensing, and perceiving phenomenal body that occupies the invisible in-between becomes noticeable when it clashes with the world, such as the built environment. In such an instance, the body experiences a “misfit” which is a contextual, relational, and mediational “juxtaposition,” or a “discrepancy between body and world” (Garland-Thomson, “Misfits” 593). Fielding describes this “rupture” as a demand on our bodies for “reflection” (“Habit” 157). The “motor signification” of habit grinds to a halt when the body-world reciprocity misaligns. The “habitual world that our bodies know and take up unthinkingly” slows down, requiring reflection (“Habit” 157). The corporeal schema which functions in the invisible in-between becomes highly visible; the phenomenal body and the environments (levels) in which it operates and mediates is foregrounded. This jarring “juxtaposition” is a common experience “[f]or those who live in between worlds,” which Mariana Ortega theorizes as living “on the margins and ‘in-between-worlds’” (qtd. in Fielding, “Habit” 157). The “ease of movement” which characterizes the able-bodied, normative habitual subject becomes inaccessible. For Merleau-Ponty, the “normal,” able-bodied person does not have to interpret daily, habitual actions; that person does not analyze every movement before they move their body. If I want to open the door, I reach for the knob, turn it, and pull it toward myself. But what happens when a disability prevents, or makes it significantly more difficult, to open a door? The disabled person might have to stop, evaluate, and interpret the situation. It is not as simple as opening a door. The door is a barrier.

Habits are not static. They can shift and change. Changing habits affect my corporeal schema, and in turn a shift in my corporeal schema affects my habitual body: “Our equilibrium can...be ‘reorganized’ since shifting one aspect of the structure shifts the whole” (Fielding, “Habit” 159). Fielding continues, writing that “[b]ecause the body is not an automaton, it is

capable of learning new significations and shifting the ones that exist” (“Habit” 158). However, for the jarring “juxtaposition” of a “misfit,” an “equilibrium” is unachievable because “those who live in-between-worlds experience a level as constantly shifting” (“Habit” 157). For bodies that “misfit,” the “‘I can’ of the habitual body” lingers behind the “I cannot” (157). Merleau-Ponty’s “I can” delineates “bodily intention” (Sterne 18) and what “allows us,” according to Fielding’s paraphrase of Helen Ngo, “to take up, inhabit, and engage with” the world (Fielding, “Habit” 158). The “I cannot” occurs when the “ease of movement” of the habitual body stumbles, forcing a moment of reflection. However, the “I can” and the “I cannot” is not a strict binary, and I will discuss the ambiguous in-between space of Jonathan Sterne’s difficulty to determine whether he ‘can’ or ‘cannot’ in more depth below (18).

In experiences of “the real” (Fielding, *Cultivating* 9), humans cannot fully synthesize all horizons at once, leaving “the object incomplete and open” (Merleau-Ponty, *Phenomenology* 72). This openness and incompleteness of a person’s horizons (milieus) allows for difference, uniqueness, and creativity. As Taylor Carmen explains, “The philosophical mystery that impressed Merleau-Ponty and guided his work, then, has two sides: that we are *open* onto the world and that we are *embedded* in it” (xi). This is how he challenges mind/body dualism, we are not minds inside object bodies; it is our bodies that reach out to the world, that perceive other humans and objects. This “mystery” signals the intentionality behind Merleau-Ponty’s use of the term “inhabit” to distance his phenomenological philosophy from the prevalent Cartesian mind-body dualism, as well as differentiating his embodiment theory from Heidegger’s “being-in-the-world.” The mind and body intertwine. Although “[t]he Cartesian tradition has taught us to disentangle ourselves from the object” (*Phenomenology* 204), Merleau-Ponty argues that the subject and object, body and world, are intimately intertwined and cannot be fully separated, just

as they cannot be fully merged. Carmen further emphasizes Merleau-Ponty's rejection of binaries and dualisms, stating that "[p]erception is both intentional and bodily, both sensory and motor, and so neither merely subjective nor objective, inner nor outer, spiritual nor mechanical" (xiii).

This intertwining of subjectivity and objectivity is clear when Merleau-Ponty discusses the continual possibility of objectification: "Insofar as I have a body, I can be reduced to an object beneath the gaze of another person and no longer count for him as a person... To say that I have a body is thus a way of saying that I can be seen as an object and that I seek to be seen as a subject" (*Phenomenology* 170). And yet, "I never fully become an object in the world... some intention is always sketched out" (168). Objectification is never a complete process; there is always an element of subjectivity that remains, girded with intentionality. In a similar way, "the body never completely falls back on itself" (168), emphasizing that the fluid intertwining of object and subject cannot be undone. A person cannot ever fully become an external object or locked within their own body's subjectivity. Existence, the body, and sexuality all "presuppose" each other, and "the equivocal milieu of their communication, the point where their boundaries merge... their common fabric" forms human existence as a unified, indivisible whole (169). The body is always open to the world, even in extreme illness: "even when it is cut off from the circuit of existence, the body never completely falls back on itself" (168). The intertwining of the body as subject and object; the indeterminate, incomplete, and open horizons that allow for uniqueness and creativity, and the anchoring of body as it inhabits the world inform the study of both able bodies and disabled bodies.

To live is to experience the phenomenal body inhabiting the world. Critical phenomenology, as practiced by Fielding, Ortega, and Reynolds, takes up Merleau-Ponty's

theory of habitual embodiment through perceptual experience and inhabitation and “mobilizes phenomenological description in the service of a reflexive inquiry into how power relations structure experience as well as our ability to analyze that experience” (Weiss, Murphy, & Salamon xiv). Focusing on situatedness, critical phenomenology acknowledges that every phenomenological description and inquiry begins from the “limitations and liabilities of its own perspective” (xiv). Following this call to disclose one’s locatedness to engage a critical critique, I am a white, Canadian, heterosexual female with both invisible and hidden disabilities. I come from a background of white, heterosexual privilege, which still, despite my best efforts, influence my research and writing. Yet, despite how ingrained my privilege is, critical phenomenology opens up “the conditions of possibility for new and unpredictable futures” (xiv). Critical phenomenology “disrupts sedimented patterns of thinking and perceiving” (xiv), foregrounding and addressing privilege and power. My white, heterosexual privilege will always be a focus area for self-reflexive critique, but my privilege does not have to determine how I think and perceive. I can change how I orient myself towards the world and other people. As I claim above, disability is the lived experience of a critical phenomenology. Disability forces a self-reflexive position, requiring the disabled person who experiences a jarring misalignment (bodily, environmentally, or socially) to pause for reflection, which in turn sparks a shift in their corporeal schema. For Reynolds, Rosemarie Garland-Thomson’s coined term “normate” is crucial for an embodied phenomenological critique “without which phenomenology risks the errors of ableism at every turn” (247).<sup>7</sup>

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<sup>7</sup> Although I don’t have the time to explore this essay in depth, complicating the discussion of normativity, Reynolds also provides a “*crip* reading” of Merleau-Ponty’s essay “Cezanne’s Doubt” in which the terms normality and normate are seen as separate (200).

In *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, Rosemarie Garland-Thomson critically examines disability, identity, representation, and embodiment. Coining the term “normate,” Garland-Thomson states that this “neologism names the veiled subject position of the cultural self” (8). The “normate” position is the taken-for-granted social background of the assumed majority in which minority and disabled bodies determine the “boundaries” of what is normal and what is “deviant.” However, Garland-Thomson indicates that very few people could truly be categorized as “normates” because it is mostly an unachievable representational societal expectation of liberal individualism (8, 42). Garland-Thomson defines the “normate” as “the constructed identity of those who, by way of the bodily configurations and cultural capital they assume, can step into a position of authority and wield the power it grants them” (8). Thus, the “normate” position is associated with power, defining a hierarchical social arrangement. A flattening takes place in the complex encounter between a disabled person and an able-bodied person (normate). With a visible disability, able-bodied people tend to judge the disabled person solely by their disability, as well as other often unfounded associations, thereby flattening their complex uniqueness to a one-dimensionality (10, 12).

As emphasized in her book *Extraordinary Bodies*, Garland-Thomson stresses the importance of the phenomenal body and embodiment in discussions of disability. She writes that “[d]isability...demands a reckoning with the messiness of bodily variety, with individuation run amok...Disability is the unorthodox made flesh, refusing to be normalized, neutralized, or homogenized” (23-24). The fleshly messiness of disabled bodies and the relatively unattainable “normate position” means that certain ‘normal’ bodies will “fit” and ‘abnormal’ or disabled bodies will “misfit.” For Garland-Thomson, the material, unstable, and flexible terms “*fitting*”



and “*misfitting*” help to “defamiliarize” and “reframe” (mis)understandings of the disabled body (“Misfits” 592). Rather than locating the source of the “misfit” within the disabled body, the issue of the “misfit” occurs within the interaction between disabled body and the world, or the disabled body and the able-bodied (593). Thus, to “misfit” is a contextual, relational, and mediational “juxtaposition,” or a “discrepancy between body and world” (593). According to Garland-Thomson, the concept of “misfitting” has crucial implications for disability justice because “it definitively lodges injustice and discrimination in the materiality of the world more than in social attitudes or representational practices, even while it recognizes their mutually constituting entanglement” (593). In other words, the “dynamic encounter between flesh and world” is emphasized above social considerations (592).

The “fantasy” of the “stable, predictable, or controllable” body is disrupted by the “experience of living.” Since almost everyone will become disabled at some point in their lives, whether temporarily or permanently, everyone will have some experience of “misfitting” in their lives. The medical model focuses on the disabled body rather than the surrounding environment, implementing an individualized plan to ‘fix’ or ‘cure’ the disabled body to “fit” with the “normate” able-bodied environment. And yet, as Garland-Thomson argues, the “experience of living” is a series of “fits” and “misfits”: “The misfits that constitute the lived experience of disability...is perhaps, then, the essential characteristic of being human” (“Misfits” 603). Often only the “misfits” are recognized because the “fits” are expected for able-bodied people. However, the fact remains that everyone, whether disabled or able-bodied, will experience a “misfit” at some point in their lives. Disabled bodies will experience more “misfits” than the able-bodied; however, “the fragility of fitting” means that “[a]ny of us can fit here today and misfit there tomorrow” (597). “Fitting” and “misfitting” is not a static binary in which bodies can

be definitively categorized as one or the other. It is a fluid continuum, constantly shifting from a privileged, social position of “material anonymity” to the disruption of an unprivileged position in which “material anonymity” is unattainable (596). According to Garland-Thomson, “[o]ne of the fundamental premises of disability politics is that social justice and equal access should be achieved by changing the shape of the world, not changing the shape of our bodies” (597). The ‘problem’ is not the disabled body.

This does not mean that the body should never undergo medical treatment. Life-saving surgeries are completed every day. Yet, using medical intervention to improve a body’s fit with an able-bodied world should be rethought. The US Disabilities Act of 1900 and its shift from compensation to accommodation also started to signal that the ‘problem’ lies in the environment and not the disabled body (*Extraordinary* 49). While compensation was rooted in the “twin myths of bodily wholeness and bodily lack,” the accommodation model of disability focuses on “restructuring the social environment to accommodate physical variety,” specifically that “disability is simply one of many differences among people” (49, 51). Difference rather than lack is one of the key tenets of “the logic of accommodation” (49).

The fluid concept of “fitting” and “misfitting” evokes Merleau-Ponty’s theory of embodiment, not simply in the world but *inhabiting* the world. The invisible interconnectedness between body and world can be disrupted by a “misfit,” when a person must shift from habit to interpretation and re-evaluation. However, a disabled body can often experience an overwhelming number of “misfits” in a world designed for the able-bodied, and the “fits” are few and far between. Accommodations are meant to foster greater accessibility, but they are often implemented on a case-by-case basis.

In “The normal, the natural, and the normative: A Merleau-Pontian legacy to feminist theory, critical race theory, and disability studies,” Gail Weiss examines how Merleau-Ponty’s theory of embodiment is helpful “because his work suggests that gender, race, and ability of bodies are not innate or fixed features of those bodies” (77). Weiss points out that many feminist, critical race, and disability theories focus on Merleau-Ponty’s “lack of attention to crucial gender, race and disability concerns” (78); however, in this article, Weiss complicates these critiques, arguing that “Merleau-Ponty can be a helpful ally,” particularly that markers of gender, race, and ability “are not innate or fixed” but are fluid and malleable features of a shifting body schema (78). Throughout her article, Weiss emphasizes Merleau-Ponty’s “embodied ‘I can’ as an originary lived experience that precedes the Cartesian ‘I think’” (78). Weiss references the “Spatiality” chapter in *Phenomenology of Perception*, stating that the “I can” “emphasizes that our primary orientation to the world as human beings is constituted by doing, not by thinking” (78-79). Whether we think about an action or not, every action that we make is meaningful in itself. Meaning does not come from thought but rather from the act of doing.

In the first section of her essay titled “Maybe I can and maybe I can’t: The challenges of doing,” Weiss introduces Iris Marion Young’s feminist critique of Merleau-Ponty in “Throwing Like a Girl: A Phenomenology of Feminine Body Comportment, Motility, and Spatiality,” specifically her insistence of an “I cannot” that accompanies women throughout their socially gendered lives, leading to an “inhibited intentionality” (79). However, as Weiss clarifies, the “I cannot” does not often “lead to an outright rejection of the ‘I can’...but rather, is most often experienced as a tension-filled seesawing between an ‘I can’ (with its associated normative implication that ‘I really should be able to do this’) and an equally strong feeling that ‘perhaps I cannot’ meet this challenge without risking injury or embarrassment” (79). Sterne also

experiences this “tension-filled seesawing” between the “I can” and the “I cannot”: “[Merleau-Ponty] is in control enough to delineate the line between ‘I can’ and ‘I cannot.’ I cannot” (18). The shifting, ambiguous in-between space of the ‘I don’t know whether I can or cannot’ reveals the “ambiguities, contradictions, fragments, webs” of a disability/impairment phenomenology. The disabled or impaired phenomenal subject is not always sure of itself and cannot be definitively categorized. Sterne’s blunt “I cannot” testifies to this ambiguity.

Although, according to Weiss, Young presents a “powerful critique” of Merleau-Ponty’s “allegedly neutral and universal experience of bodily transcendence, intentionality, and unity” that is oriented towards the dominant male gender of a highly patriarchal, white society, Young’s theory of “contradictory bodily modalities” does not include the complexity of and possibility for transcendence, intentionality, and unity for both males and females (80). Weiss argues that Merleau-Ponty’s theory of embodiment opens up these possibilities for both the male and female bodies, even if the bodily experience that Merleau-Ponty describes does tend toward a universal and generic white, male body.

This “lived tension” and “seesawing” between the “I can” and the “I cannot” corresponds to Garland-Thomson’s theory of “fitting” and “misfitting.” In fact, Weiss analyses Garland-Thomson’s famous essay “Misfits” in conjunction with Merleau-Ponty’s theory of embodiment, arguing that Garland-Thomson’s theory is “a distinctly Merleau-Pontian intervention into the field of disability studies” (89). Weiss connects the two theorists more explicitly, stating that “just as Merleau-Ponty concludes that neither the body nor the world is the source of perceptual experience but that it arises in and through their dynamic interaction, so Garland-Thomson maintains that disability cannot simply be attributed *either* to the body *or* to the environment but, is better understood as a “mis-fit” between them (91). A “misfit,” that “juxtaposition” between

body and world (or one body and another), cannot rest on a simple binary or duality (“Misfits” 593). It is not as simple as throwing the responsibility (often blame) on either the body *or* the environment; rather, the space of interaction in the “dynamic encounter between flesh and world” is where the “existential continuum” of “fitting” and “misfitting” occurs (Weiss 91; Garland-Thomson, “Misfits” 592). Therefore, two elements, whether body-world or body-body, are always in play.

If, as Garland-Thomson argues, “misfitting” is a “contingent and fundamental fact about human embodiment” (“Misfits” 598), then to “misfit” can be experienced universally. However, Weiss makes the important distinction that “a universal experience” does not equal “a generic experience because there are as many different ways to misfit (and to fit) as there are bodies, cultures, and environments” (92). Universality does not negate the uniqueness of one person’s “fit” or “misfit” compared to another person’s experience. Yet, Weiss explains how Garland-Thomson again complicates this universal, unique “fitting” and “misfitting,” writing, “what might look like a misfit to others, namely a non-normative body that engages with the world in non-normative ways, with the right support from others and from the environment, may actually be lived as a fit” (92). Sometimes, as Garland-Thomson states, ““prostheses,”” such as ““a white cane or brailed book,”” “ease the material divergences between bodies and their location, making misfits into fits”” (92). An experience that begins as a misfit does not necessarily continue as such. The fluidity of the continually changing, shifting body schema allows the incorporation of other instruments into the body schema. The “I can” for a disabled person might look drastically different from the “I can” of an able-bodied person. The site of interaction of the “fitting” and “misfitting” continuum will determine whether the person experiences a jarring “juxtaposition” that inhibits their intentionality/action, requiring adaptation of one or both elements, or whether

the person experiences an action that does not require a significant adjustment of their current body schema.

For Weiss, Merleau-Ponty's phenomenological theory of embodiment "challenge[s] our conceptions of what is normal, what is natural, and what can and should be normative," imparting "a future whose potential will be more fully realized when we embrace the possibility of 'singing the world' in ways that transform more misfits into fits" (92-93). Intertwining Merleau-Ponty and Garland-Thomson's theories, in the next section of this chapter I will explore a unique form of disabled embodiment: the ostomy. Not only do ostomies fall uniquely on the "I can" and "I cannot" and the "fitting" and "misfitting" continuums, but they are also usually 'hidden' and require theories of "passing" as well. A "misfit" might not be immediately apparent or highly visible, but the 'hidden' "misfit" will experience a change in their body schema and engagement with the world and others through their embodiment.

### **Case Study 1: Ostomy Art**

Between 2003-2011, visual artist Carol Chase Bjerke created a series of installation pieces centering around ostomies called *Hidden Agenda: ARTiculating the Unspeakable* (Bjerke website). Her first *Hidden Agenda* exhibition was held at the International Museum of Surgical Sciences in Chicago from November 6, 2009 – February 19, 2010. Two more *Hidden Agenda* exhibitions were on display from February 20 – April 9, 2011 at the Marian Gallery in Milwaukee, Wisconsin, and from March 1 – April 14, 2013 at The Cooler Artisan Gallery in Paoli, Wisconsin. On her website, Bjerke explains the personal motivation behind her long-term project:

Hidden Agenda is a large-scale multi-faceted project about living with an altered body in the aftermath of colorectal cancer. This work is intensely personal and provocative. It is also thoughtful, informative, tasteful, and surprisingly beautiful. It is about the relentless repetition and inconvenience of an ostomy and its care. It is about the passage of time as measured in medical supplies and their packing materials. It speaks of issues around self-image, privacy, a reluctance to talk about these things, and a need to talk about these things. And yes, it is about rising above all of this with lightness and humor.

Bjerke describes her installations as a “dialogue” about “an otherwise unspeakable topic.” Her art about her “altered body” with an ostomy opens a conversation about a different way of embodied living, particularly surrounding uncontrollable defecation and necessary medical supplies. Time gains a physicality/materiality in her installations as the medical supplies and packing materials continue to amass. The “passage of time” connects to a medical abdominal appendage, linking her experience of time and connecting it with one specific part of her body: her ostomy.

Bjerke writes that her art “is intensely personal and provocative.” Yet, most of her ostomy art focuses on a very specific, small, rose-bud ostomy shape, the generic type of ostomy shown in informational pamphlets to avoid ‘grossing out’ readers. This uniform, rose-bud ostomy shape appears in “Misfortune Cookies” (Figure 4), “Rose-Colored Glasses” (Figure 5), “Stoma Wallpaper” (Figures 6, 7, 8), and “My Card (the luck of the draw)” (Figure 9). Made of red polymer clay, the ostomy “cookies” in “Misfortune Cookies” are journal entries written in the second-person voice that erupt out of the stoma opening. The long white pieces of paper with varying lengths of black text arch up and out of the stoma opening, curving gently until they reach the neutral-coloured surface of the table. The statement about this piece states that the

entries “are transcribed into the familiar second-person voice as a way of communicating information and feelings.” However, the second person “you” also asks the viewer/reader to attempt to identify with the strange looking, puckered, red clay blobs on the table. Bjerke is both communicating her feelings through the journal entries and is inviting her audience to delve into her personal narrative in a very intimate way. Although Bjerke does not explicitly state this, the expulsion of the pieces of paper from the stoma opening mimics the (usually) steady flow of ostomy output (excrement), which is a unique and personal experience. The pieces of paper are less messy than actual ostomy output; unlike output that varies in colour and consistency from meal to meal, the paper pieces are clinically white and are uniform and defined in shape. Even though the writing on the paper pieces is personal and provocative, the presentation of them spewing from the clay ostomies is, perhaps, calculated to reveal the medicalized nature of the ostomy.

In *Hidden Agendas*, Bjerke quotes several notes written on her “misfortune cookies,” requiring the reader to imagine the reality of having an ostomy:

You will be walking across the carpet when your pouch clip lets go and drops down your pant leg, followed by the excrement it had been containing.

You will have cleaned the area around your stoma and are drying the skin before attaching a fresh appliance. Excrement emerges from the stoma and soils the skin so you have to repeat the cleaning. And repeat. And repeat. And repeat.



You will find that changing the appliance too often is hard on your skin, and not changing the appliance often enough is hard on our skin. And there's no way of knowing whether it is time to change the appliance without actually changing it.

Although these are frustrating and embarrassing moments, as a person with an ostomy, I find these repetitive instances humorous and exciting to read because they are messy and raw and real. People with ostomies can identify with these "misfortune cookies" that, unfortunately, reveal all too common daily occurrences. Although people without ostomies cannot identify with the second-person voice, they are forced to imagine life with an ostomy. Giving us phenomenological glimpses, Bjerke's "misfortune cookies" raise awareness of ostomies, but they also unite people with ostomies who have similar experiences. These phenomenological glimpses, unlike the cold objective medical gaze, personalize the everyday experiences of people with ostomies.



**Figure 4:** Carol Chase Bjerke, *Misfortune Cookies*, polymer clay "cookies," about 1" x 1" x 1", 2004 - 2005.

Another piece that features a similar rose-bud ostomy shape is “Rose-Colored Glasses” (2005) (Figure 5). The text underneath the image on Bjerke’s website reads, “Reminder for those who want to look through rose-colored glasses.” Five pairs of reading glasses are featured in the photograph of this installation piece, each with a pair of “stoma-shaped plastic additions” plastered on the glass lenses. The Oxford English Dictionary defines the figurative use of the words “rose-coloured” as “[c]haracterized by cheerful optimism, or a tendency to regard matters in a highly favourable or attractive light” (OED). Often its usage implies that people who look through rose-coloured glasses have an unrealistic view of the world; everything appears idealistically rosy. The ostomy stickered reading glasses reminds people who tend toward an unrealistically optimistic view of the world that some things cannot be painted rose-coloured and be given a positive spin. Highly invasive, life-changing surgical operations such as ostomy formations are violence to the body. One cannot simply dismiss this violence with a trite “At least...” phrase and all the physical (and financial) hardships melt away: “At least you’re alive. At least you can hide it. At least you can eat solid food again.”



**Figure 5:** Carol Chase Bjerke, *Rose-colored glasses*, reading glasses with stoma-shaped plastic additions, 2005.

Reminder for those who want to look through rose-colored glasses.

In her artist statement, Bjerke mentions the “active, overjoyed, and smiling” ostomy models in advertisements: “There is no question that many of us living with ostomies routinely do enjoyable things. But this image of extreme ebullience seems insensitive to individual situations, and to the nature of the subject in general” (34). Attempting to show how their ostomy products allow ostomates the freedom to live happy lives, these supply companies tend to dull the gravity of the life-long struggle inherent with an ostomy. In *Extraordinary Bodies*, Garland-Thomson writes about the importance of “the messiness of bodily variety” to critical disability studies (23). This “messiness” can include bodily pain and discomfort. Bjerke’s “Rose-Colored Glasses” confronts viewers with the constancy of the ostomy, which is sometimes a temporary surgical measure but is often a permanent change to the body. Challenging normate viewers, the rose-coloured ostomies reflect a new lens through which the person with an ostomy views the world.

“Stoma Wall” (Figure 6) is a particularly impactful example of the same rose-bud stoma shape as in the previous two art pieces. On her website, Bjerke writes,

The United Ostomy Association has estimated that 75,000 ostomy procedures are performed each year. This translates to an average of slightly over 200 each day. In March 2005 I began a year-long project to recognize the myriads of anonymous individuals with ostomies and the seemingly mindless acceptance of this practice on the part of scientific, pharmaceutical and medical communities. Every day I used a hand-carved rubber stamp to print 210 stomas acknowledging those who were undergoing various types of ostomy surgery that day. At the end of the year I had seventy-nine 18" wide by 72" long strips of paper - a total of more than 75,000 stomas with which to paper

the walls of the Hidden Agenda installation. The "Stoma Wall" is a poignant reminder that even though not much is said about this barbaric practice, it is a fact of life for a significant number of us.

In the installation (Figures 7 & 8), the long sheets of paper with thousands of stomas stamped onto its neutral-coloured surface line the walls, framing the exhibit and providing a dotted pink/red background for the rest of the installation (including the two previous art pieces). In fact, these sheets simply look like patterned pink wallpaper, until up close one sees the individually stamped stomas (with varying colour densities) appear and confront the viewer with their strangeness. Although the stamp is uniform and exact, the individual stomas that dot the paper strips are slightly uneven at points, some closer together and some further away. This regularity and irregularity of the stoma stamps creates a mesmerizing, almost moving pattern. For Bjerke, the "Stoma Wall defines the installation area, and is a meditation for the myriads of anonymous individuals living with ostomies" (31). The repetitive red ostomy stamp covering the sheets of papers draped on the installation walls directly references the thousands of ostomy surgeries performed each year. One ostomy stamp becomes lost in the thousands of stamps beside, above, and below it; it becomes lost in a sea of red.

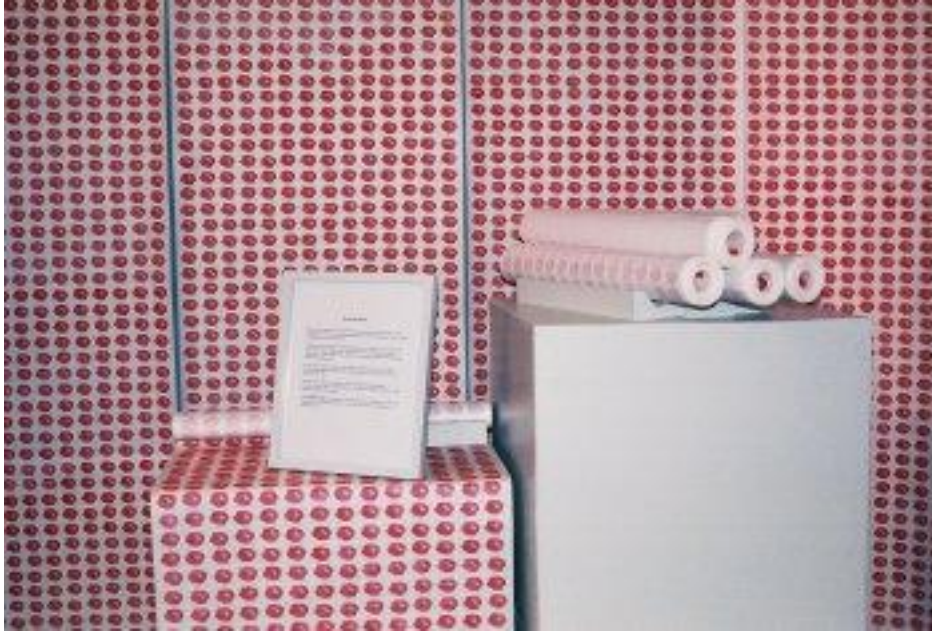


**Figure 6:** Carol Chase Bjerke, *Stoma Wallpaper*, seventy-nine 18" wide by 72" long strips of paper, 2005-2006.



**Figure 7:** Carol Chase Bjerke. Detail of *Stoma Wallpaper*, 2005-2006.





**Figure 8:** Carol Chase Bjerke, installation view, 2009.

Not only does “Stoma Wall” reveal or document the thousands of ostomy surgeries that have changed people’s lives over a few years, but the repetitive generic ostomy shape also comments on the medical/surgical cookie-cutter ostomy formation procedures. In her “Stoma Wall” statement, Bjerke draws our attention to the anonymity of many ostomates as well as “the seemingly mindless acceptance of this practice on the part of scientific, pharmaceutical and medical communities” (28). Bjerke calls the ostomy a “crude and outdated procedure” (xii) that is both “barbaric” and “traumatic” (28). Instead of continuing to accept ostomies as “standard treatment for a variety of gastrointestinal diseases,” Bjerke hopes that “increased awareness will ultimately lead to new solutions” (xii-xiii). As mentioned above, stoma surgery can result from many different gastrointestinal diseases, including colorectal cancer, Crohn’s disease, and Colitis, among others. When non-surgical treatments fail, the stoma is often the next step and the last resort for most patients. Every surgery is a violence to the body; it is a traumatic (both physically and psychically) event in which the body is cut while the patient is unconscious and

has no control over their body or the surgical team's actions. An ostomy is a "permanent wound" (Bjerke xii). Hopefully, in the future, further non-surgical options will be available. However, as Bjerke recognizes, thousands of people are living with ostomies around the world, and the phenomenological experience of having an ostomy and dealing with the pain, discomfort, messiness, and embarrassment that often accompanies an ostomy should be acknowledged and not simply washed over or diminished. As Bjerke emphasizes, an ostomy is not just a physical procedure, it also affects people psychologically (19).

The treatment of the reality of ostomies as "unspeakable" experiences is one of the primary themes of Bjerke's *Hidden Agenda* installation (19). In this way, ostomies present a phenomenological experience of hidden "misfitting" (Garland-Thomson, "Misfits" 598). The "misfit" is not often immediately apparent, since the ostomy is hidden under clothing. The physical transformation of the abdomen to include a newly formed opening with constantly "exposed fecal-lined tissue" (Bjerke 40) rearranges the trajectory of the intestinal arrangement and the progression of fecal matter through the body. Serious complications including dehydration, blockage, twisted bowel, and skin deterioration can make a person with an ostomy hyper-aware of their abdomen and stoma site. One of the misfits is lack of control. Often, in normative society, people are expected to control their bowels and wait for an appropriate time to excuse themselves to go to the bathroom. However, with an ostomy (especially an ileostomy), the fairly constant flow of fecal matter makes bathroom predictions difficult. The sense of physical defecation urgency is replaced with a purely emotional anxiety since the waste has already left the person's body and is in the pouch. The phenomenal body is crucial for Merleau-Ponty's theory of embodiment; it is the "third term" of the "figure-background structure" through which perception and inhabitation of the world is possible (*Phenomenology* 103). The

importance of the body as our way of inhabiting the world means that any change to our body will restructure how we inhabit the world. With an ostomy, that vulnerable piece of flesh exposed above the skin envelope becomes a central focal point.

The body as a “mediator of a world” means that a person always sees from somewhere (*Phenomenology* 146). This openness and incompleteness of a person’s horizons/milieus that is grounded through their body schema allows for difference and uniqueness (*Phenomenology* 72). The fluidity and malleability of a shifting body schema that structures and restructures repeatedly reveal the intrinsic universality of the “lived tension” between the “I can” and the “I cannot,” between “fitting” and “misfitting” (Weiss 78, 89). What might be an “I cannot” one day might become an “I can” at a future point in time. Or, as Weiss emphasizes when she engages with Garland-Thomson’s theory of “fitting” and “misfitting,” a “misfit” for one person might be “lived as a fit” for a different person (Weiss 92). In normative society, an able-bodied person might say that they would rather die than have a permanent ostomy, but a disabled person with an ostomy adjusts their engagement with the world through their shifting body schema to incorporate the stoma into their embodied existence.

The “misfit” does not have to be an explicitly physical “misfit” with the world; it can be a socially normative “misfit” that causes a person to re-evaluate what it means to have a body that is not the ‘typical’ body. Unless other pre-existing disabilities are present, an ostomy does not restrict activities such as climbing staircases, walking, opening doors, swimming, driving, and shopping (to name a few normative examples of expected independent, able-bodied existence). Yes, those activities are more difficult when recovering from the initial operation, but patients with new ostomies are assured by many nurses and doctors that they will be able to lead ‘normal, healthy lives’ with an ostomy. Passing with an ostomy is comparatively easy. There is a physical



stoma that requires diligent daily care, but one is also at first intimidated by the fact that a part of one's insides are on the outside, exposed and vulnerable. A sense of control is also lost, as Bjerke references in one of her installation pieces titled "Our Lady of Perpetual Defecation." The normative sense of complete independence, control, and physical normality are subverted in the case of the ostomy.

In July 2019, I had my ileostomy surgery after months of suffering with an autoimmune condition, failing medication after medication until there were no other options left. My colon was too diseased to save, inside and outside. The wet, slimy, unclean inside becomes outside and inside simultaneously, clean and unclean, seen and unseen. Laying in a hospital bed preparing my ostomy appliance for the first time, I felt my forearm brush up against the squishy wetness of the new, inflamed stoma protruding from my abdomen. My forearm skin felt the stoma shrink and expand, but the stoma (*my* stoma) could not feel my forearm. The intestines do not have nerve endings; the stoma cannot 'feel' and cannot 'touch.' Everything that I learned about my body and sense perception was transformed in that moment: my fingers could feel the wet, soft surface of the intestine, but I did not feel the touch of my finger on my ileum. Here binary distinctions break down: inside meets outside, flesh meets skin, non-touch meets touch - all intertwines and shifts in the strange otherness of this non-reciprocal touch. During surgical intervention, the surgeon sews the edge of the intestine to the abdominal skin, and the two surfaces (external and internal) fuse together in the healing process. Unlike Merleau-Ponty's chiasmic structure of embodiment in which two intertwining threads remain distinct and never fully merge, the fusion of skin and intestine of the ostomy expands the chiasmic concept: inside and outside fuse yet also remain distinct surfaces.

As Merleau-Ponty argues, there are no binaries or dualities. The most prominent binary that Merleau-Ponty argued against was Cartesian mind-body dualism. For Merleau-Ponty, the mind and body are intricately intertwined just as the body and the world are always interconnected but never fully merged. The “perpetual embodiment” of life is the ambiguous entanglement with the world of “existence” (*Phenomenology* 169). This continual (re)engagement and (re)structuring of our embodied selves in the process of inhabiting a world with other human beings eliminates the possibility of strict binaries and dualisms. Subject and object; self and other; body and world; mind and body; and inside and outside are fluid, intertwining threads of existence. As in Merleau-Ponty’s explanation of the chiasma, these individual threads never fully fuse together, but they require each other (interdependent) through the flow of life.

The strange otherness of my forearm brushing against my nerveless stoma creates a tension for binary systems of thought, such as normative, patriarchal, and heteronormative concepts of able-bodied and disabled, weak and strong, male and female. The inside is now outside; the intestine forms a stoma outside the skin layer, exposed and continuously expelling waste. Does the intestine become part of the outside of the body once it is sewn to the skin as a stoma? Or is the inside simply still the inside but on the outside? Is there a strict binary between inside and outside at all? Merleau-Ponty’s theory of embodiment and his rejection of binaries presents the option of a non-binary idea of the bodily interior and exterior. The body is not simply made up of inside organs and outside layers of skin. It is a complex interplay between all elements of the body (and the mind) in unison. A rearrangement of the intestinal system to expel waste from a stoma is different from the ‘usual’ form of defecation, but the fluidity of the body schema means that I can (re)adjust my form of embodiment and engagement with the world and

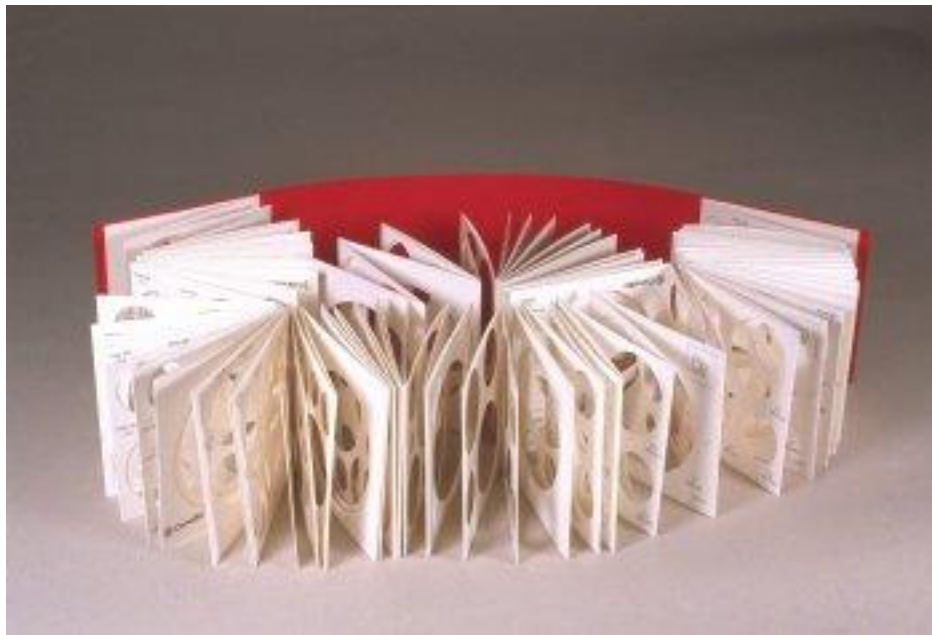
my own body. This does not negate the physical and psychical pain and suffering that occurs after a surgical intervention. I will address the still prevalent stigma surrounding difference in normative society in the next chapter because it is one of the important horizons that informs a disabled person's embodiment, specifically how they view themselves, others, and the world.

Even if bodily difference can be medically (and socially) categorized, such as the umbrella term ostomy, many different types of ostomies exist, such as ileostomies (end or loop ostomies), colostomies, and urostomies. Within those subcategories, some stomas protrude, some retract, some have more peristalsis, some are large, and some are very small. Every stoma is unique. The beautiful little rose-bud shape is not always what a stoma looks like. Bjerke addresses this difference in stoma size in her piece "How Long Can I Make It?" (Figure 10). Beginning in 2003, Bjerke continued to attach the circular "templates for custom-fitting an appliance" to a piece of red paper in an accordion manner (8). Spread out, the viewer can appreciate the various ostomy sizes which the templates accommodate from 10mm to 76mm. The small red stamp that she used for "Stoma Wall," representing the quantity and rate at which surgeons create ostomies, must be reevaluated upon viewing the size range of the stoma templates. "Stoma Wall" acknowledges and represents the thousands of anonymous ostomy procedures done each year, while "How Long Can I Make It?" takes the viewer deeper into the phenomenological realm of the experience of having and taking care of an ostomy. The "permanent wound" that never heals is a constant preoccupation, which requires (as many illnesses/conditions do) that those with ostomies are hyper-aware of a specific part of their abdomen (Bjerke xii, 12). Thus, the constant bodily awareness of an ostomate presents a unique form of embodiment: an inside-outside bodily experience. Even though, as Merleau-Ponty writes, the body is the only way that we can engage with the world as an integral part of it, the

phenomenal body itself as a “mediator of the world” (*Phenomenology* 146) remains the “implied third term of the figure-background structure” (103). The body is not foregrounded; it is “implied,” until something ‘goes wrong’ with it.



**Figure 9:** Carol Chase Bjerke, *My Card (the luck of the draw)*, 2005.



**Figure 10:** Carol Chase Bjerke, *How Long Can I Make It?*, 2008.

## Case Study 2: Dissonant Disability Poetry

In “Chronically Ill, Critically Crip?: Poetry, Poetics and Dissonant Disabilities,” poet and professor Emilia Nielson uses crip theory and critical disability theory to lyrically meditate on the instability of chronic illness, the intimate violence of surgery, and embodied experience. Citing select poems from her collection *Body Work*, Nielson describes “how poetry provides a critical site to explore” questions of (lack of) symptoms, chronic illness, identity, and disability “through crip experience and embodiment” (2). Nielson powerfully turns to the term “dissonant disabilities” from Driedger and Owen’s *Dissonant Disabilities: Women With Chronic Illnesses Explore Their Lives*, to explore disability as “site of tension” and complexity: “Can women with chronic illnesses identify as people with disabilities all the time or only sometimes?” (8)” (2). Stating that she has an autoimmune illness without specifying a diagnosis, Nielson states, “Given that I was living in dissonance, simultaneously well and unwell, I had a new awareness that I had as much to unlearn about disease as I did to rethink how illness and disability were now an ongoing part of my life” (3). For Nielson, chronic illness is a “dissonant disability” because it simultaneously intertwines two terms of a normative binary: well and unwell. Destabilizing, even destroying, this binary, Nielson finds dissonance “pleasing in its incongruousness and discordant sensibility,” particularly to resist “biomedical language” and normative binaries (5).

In *Dissonant Disabilities*, Driedger and Owen explore the fluctuation, instability, and resulting uncertainty of chronic illnesses in women and discuss how chronic illness fits (or misfits) with current disability and feminist movements. They write,

for people with chronic illnesses, since the disability movement tends to devalue us and society devalues us, this notion of being ‘sick’ as not being normal or desirable needs to change. The feminist movement has also adopted these attitudes about illness and

productivity. It is difficult to be a feminist with a chronic illness as the women's movement prides itself in working hard and this is a badge of dedication to the cause...

(7)

Driedger and Owen identify chronic illness as a liminal "in-between" space which does not quite fit anywhere. The disability movement appears to reject the term "sick" because "this is the ultimate devaluation in our society" and feminists do not want to appear weak (7). Addressing ableist demands of compensation and overcoming, Driedger and Owen state that "women who live with chronic illnesses and unpredictable bodies are neither 'superwomen' nor victims" (8). Ableist society feels the need to either praise extraordinary bodies or reject them all together: there is no allowance for unpredictable bodies in between. Eli Clare's beautiful, raw prose encapsulates this experience: "They approach me with prayers and vitamins, taunts and endless questions, convinced that I'm broken, special, and inspiration, a tragedy in need of cure, disposable" (7). Clare's cerebral palsy is part of his identity: "I have no idea who I'd be without my trembling and tense muscles, slurring tongue" (6). Disabilities, impairments, and chronic illnesses are often intermittently, or even perpetually, unpredictable. Disabled bodies cannot be relied upon to act or respond in the same manner every day, or even every minute. Clare's assertion "I'm not broken," is hard for able-bodied people steeped in ableist traditions to comprehend. It does not compute. Clare's direct statement is important for the conceptualization of disability, impairment, and chronic illness as valid forms of engaging with the world. This liminal space of misfitting with chronic illness as a valid form of embodiment is the space that Nielson explores in her poetry collection *Body Work*.

Nielson's poem "Surgical Diary" focuses on two seemingly unrelated/dissonant themes: skin and buttons. For Nielson, this poem on surgery and postoperative healing meditates on the

fact that “skin seeks to repair” usually without achieving the “false promise of ‘cure’” (10). The merging of skin in the form of a scar is, as Kupperts theorizes in *The Scar of Visibility*, the “meeting place” between interior and exterior (1). However, this reparation quality of skin does not, as Nielson emphasizes, signal full healing or a ‘cure.’ More importantly, Nielson’s “poem resists the notion that surgery fixes imperfect bodies because it cherishes imperfect things: a sweater without a button and a person that cannot sew the button back in place” (10). “Surgical Diary” embraces and examines bodily differences that medical institutions deem “imperfect.” At the same time, Nielson acknowledges that surgical interventions also do not transform the ‘natural body’ into an unnatural one. By treasuring “imperfect things” such as a missing sweater button, organs that do not fully function, or skin with scars, chronically ill people can learn to accept their bodies through the flares and remissions, weight gain and weight loss, surgeries and scars. Just as Garland-Thomson shows “misfitting” is universal, even though each experience of “misfitting” is unique, bodily imperfection is also universal. Celebrating imperfection does not diminish the hard, often painful reality of chronic illness, but it does allow the chronically ill to avoid the medicalized problematic terminology of surgical “fixes” (10).

The section titled “Note 4” in her “Surgical Diary” engages with presence and absence; knowing and unknowing; simultaneously addressing the bodily self and other. Nielson writes:

I will stitch the button back to  
 where its absence is clearly marked:  
 palimpsest. My body is dissolving  
 the threading that will remain  
 (un)knowable to me. This skin,  
 matrix-building. This body, that

is – and isn't – me, restructuring.

Nielson equates bodily “absence” after surgery with a missing button, which can be stitched back on. The “dissolving,” disappearing threads which have sewn her body’s skin together represent another “absence” and tie back to the button sewing imagery in the first two lines. However, the word “palimpsest” right before the line “My body is dissolving” reveals that there are still “clearly marked” visible traces of the presence preceding the absence. The line “My body is dissolving,” when separated from “the threading” imagery, connects intimately to the final two lines: “This body, that / is – and isn't – me, restructuring.” Not only are the stitches slowly dissolving as the surgical site heals and a scar forms, but her previous conception of her body is also dissolving. Her body, as the skin is “matrix-building,” physically restructures her skin as two cut planes of skin fuse. However, she also experiences a “restructuring” of her embodiment, which includes psychological restructuring. Nielson writes that her body “is – and isn't – me”; her body fluctuates between self and other.

“Note 5” focuses on the surgical removal of one of Nielson’s organs. The image of the button returns, and Nielson writes, “That I function well without an organ / but don't have the know-how to stitch / a button back in place.” Beginning “Note 5” with “That,” signals the finishing of an incomplete thought. The reader does not know the beginning. Starting in medias res, in the middle of a sentence compliments or reminds us of Nielson’s adoption of the term “dissonant disability” for chronic illness, particularly the shifting back and forth in the liminal space of simultaneous wellness and illness. The “organ” is absent, but she admits that she can “function well.” The problem remains her inability to “stitch a button back in place.” The second half of “Note 5” enters the surgical theatre, the “theatre of incise / and create.” Nielson follows the surgical steps of organ removal from start to finish: “divide, separate, divide, mobilize, /



divide, identify, identify, divide, separate, / remove, reapproximate, reapproximate; / close skin with subcuticular stitch.” The repetition of “divide,” “identify,” and “reapproximate” creates a lulling, methodically lyrical effect, and the semicolon semi-permanently separates the “subcuticular stitch” closure. The surgeon stitches the surgical site closed, and Nielson laments that she cannot “stitch a button back in place.” She does not know how to make her “imperfect” body perfect again, or at least the previous imperfection. After closure, her body is “restructuring,” and she undergoes a further “restructuring” of her embodied sense of self.

Nielson’s corporeal schema undergoes a loop of jarring, shifting, and reapproximating. She grapples with the illusory perfection of the “normate” material body. The surgical changes to her chronically ill material body affects her corporeal schema, which must shift as she learns to accept her new imperfections.

The continual restructuring of embodiment before and after surgery intertwines Bjerke and Nielson’s artistic narratives. However, where Nielson experiences the merging of skin as her wound heals and scars, forming the “meeting place” between interior and exterior that Koppers theorizes (1), Bjerke’s ostomy is a “permanent wound” that remains open and unhealed (xii). A different kind of “meeting place,” Bjerke’s ostomy is the bodily interior erupting above the skin barrier, entering a liminality between interior and exterior. These two case studies, like disability in general, point to a unique form of Merleau-Ponty’s “perpetual embodiment” that shifts and requires a hyper-self-reflexive state. The flow of “perpetual embodiment” is interrupted in jarring moments before, during, and after surgery. As the body schema changes, this shifting and reapproximating is sudden and interrupts the everyday flow of life. Disabled bodies are forced to adapt to these abrupt corporeal schema changes.

## Chapter 3: Critical Disability Studies and the Ability-Disability Continuum

### **Models of Disability: Medical Model, Social Model, and “Complex Embodiment”**

Disability is a complex concept and identity that evades precise definition. The very foundation of disability is difference from social norms, an intersectional ‘other,’ and a rediscovery of finitude. Fluctuating in a marginalized space of liminality, disability is inherently unstable, just as the whole of life is inherently unstable. How can we talk about disability if it is constantly shifting and changing form? Accepting that variation, difference, and change (and ultimately, finitude) is unavoidable in an ever-changing world, we will approach or engage with the world (socially, economically, politically) as flexible embodied beings. This flexibility towards life will open avenues of being and discourse that no longer uncritically adhere to ableist, sexist, homophobic, racist, and classist ideologies. Difference will be accepted. This does not mean that there will cease to be a difference between ability and disability; these terms will not disappear altogether. No longer the stigmatized ‘other,’ disability will become a positive identity, one that embraces impairment not as lack but as a valid form of embodiment. Visualizing disability and ability as a continuum rather than a strict binary allows the complexity of disability and ability to flourish unfettered by ableist assumptions and stigmatizations. For example, Tobin Siebers’ “theory of complex embodiment” (25) theorizes disability and ability in a non-binary way, combining concepts from previous models to fully appreciate the intricacies of disability. Although critical disability studies and scholars such as Siebers primarily engage with new complex theories, in broader contemporary culture, the medical model and the social model are still prevalent.

There are two primary models we use to understand the term disability: the medical model and the social model. The medical model pathologizes disability as an “individual defect” (Siebers 3-4) locating the source of the “problem” solely in the disabled body (Bones et al. 6). In *Disability Theory*, Tobin Siebers writes that the medical model views disability as “a defect that must be cured or eliminated if the person is to achieve full capacity as a human being” (3-4). Siebers addresses an important issue within disability studies and theory: the treatment of disabled people as a non-human “other” and, therefore, lacking social, political, or economic value. In the medical model, the disabled body has no value. Value comes solely from an able productive body, which the ableist ‘kill or cure’ mantra exemplifies. Jay Dolmage imagines what an “image” of the medical model would look like: “it would be a picture of an individual in which the head is out of frame, while the medical ‘abnormalities’ of the body are centred, are the singular focus” (94). This image both dehumanizes the disabled body as a “problem” to be fixed and reproduces the Cartesian mind-body split that continues to prevail in twenty-first-century medicine. The head is separated from the body; the psychological from the physical; and the rational human from the irrational non-human. The language of the “problem” suggests that there is a solution, a cure that will return a body to its natural, not defective states of health and wholeness. As the social model reveals, however, “fixable” issues are not solely locatable in the disabled body.

A sharp turn away from the pathologizing medical model, the social model emerged from the Disability Rights Movement in the 1980s, differentiating “impairment (the medical condition) from disability (social barriers and attitudes about impairment)” (Bones et al. 6). A critique of naturalism, the social model “challenges the ideal of defective citizenship by situating disability in the environment, not in the body. Disability seen from this point of view requires not

individual medical treatment but changes in society” (Siebers 73). The language of “individual defect” is replaced with an examination of the “social and built environment” (Siebers 25, 73). However, the language of the ‘problem’ persists. No longer located in the body, the ‘problem’ is the social environment. Socially constructed, disability is “the product of social injustice,” and “the social and built environment” needs to change, not the disabled body. This social constructionist model identifies and analyzes systemic “exclusion and oppression” of disabled minorities, and “social justice” replaces “medicine” (Siebers 3-4, 54). A picture of the social model of disability would show a built, inaccessible cityscape in which the human body is out of the frame altogether; the disabled body (and head) is the unseen impetus for the model but remains floating just outside of the picture frame. Siebers addresses this lack of embodiment in the social model (25), while acknowledging the importance of the “socially constructed” body for disability politics, justice, and identity (54, 73). To completely turn away from the medical model’s sole focus on the body, the social model overcorrected and eliminated the body almost altogether. The disabled body became a lightly implied piece of the disability puzzle, and the important issue of lived embodied experience was thrown to the side. Although the social aspect of disability is important, eliminating the body from disability discussions does not acknowledge the physical and psychological pain and suffering that are often a part of disability experience. Taking up this issue of embodiment, current critical disability theories aim to insert the physical body back into the disability equation.

Accounting for both biological and social factors of disability, Siebers’ “theory of complex embodiment” intertwines “social representations and the body” as a part of “the spectrum of human variation” (25). The body and the social environment are balanced, allowing lived experience to guide social justice. Complex embodiment complicates the simplistic binary

between the medical model and the social model; both social and bodily factors “need to be considered in tandem” (25). In *Diminished Faculties*, Jonathan Sterne also emphasizes the trajectory of current disability theory to shift “beyond the split between a medical and a social model of disability” (19). This complex intertwining of the social and bodily aspects of disability addresses the bodily experience of disabled people while still confronting the systemic social environment of “exclusion and oppression” (Siebers 3-4). Other new combined models include “Social-Relational Theory” and “Resistance Theory” (Bones et al. 7-8). These theories, like Siebers’ “theory of complex embodiment,” call for the integration of the medical (biological) and the social aspects of disability. Complex embodiment focuses on the “lived experience of the body” which is balanced with “awareness of the effects of disabling environments” (Siebers 25). This physical living, breathing, fluctuating embodiment is now at the forefront of critical disability studies, and the starting place of disability embodiment theory is the inconstant messiness of the human body.

Theorizing ability and disability as a “continuum” (Jackson 195), current critical disability models actively refuse to adhere to the able/disabled binary of the “ideology of ability” (Siebers 8). Unlike ableist ideology where “the preference for able-bodiedness” favours a binary that delineates a stable, able-bodied category and an unstable, disabled non-human category, ability and disability here are not opposing binary forces. Equating able-bodiedness with “humanness,” ableist ideology is based on the medical model: disabled bodies should be cured, hidden, or eliminated (Siebers 8). In ableism, disability is a negative word, the dark flipside of ability that should remain hidden in the shadows; disability is the “invisible center” of ableism (Siebers 8-9). However, the fluctuating differences and changes that govern the finite lived experience of humanity reveal the fallacy of the stable able-bodied position. Disability is “a

reality of the human condition” (Siebers 6); everyone will become temporarily or permanently disabled at some point in their lives. Thus, “[a]ble-bodiedness is a temporary identity at best” (Siebers 5), crumbling the fantasy of ableist ideological stability. The “death-fearing world” (Sterne 19) attempts to erase any signs of finitude and constructs an ideology that suffuses a false sense of stability and rigidity into an ultimately ever-changing unstable world. To be human is to change: physically, emotionally, spiritually. For Sterne, “[t]he ground for phenomenology – and perhaps for all descriptions of experience – is more like sand than a floor” (20). The image of numerous tiny particles of “sand” constantly shifting and rearranging is an apt description for disability experience. And, if disability is “a reality of the human condition,” as Siebers argues, then the lived experience of humanity, individually and communally, shifts unpredictably as well. If the human body and lived experience is at the forefront of current critical disability theory, then all discussions of disability and ability will inevitably shift like sand. This flexible theory allows accounts of lived disability experience to destabilize the strict disability/ability dichotomy of the ideology of ability; to question ableism’s negative significations of disability; and to acknowledge disability as a valid way of being in the world. A shifting, experiential theory of disability allows this “invisible center” to take the spotlight, which will illuminate all areas of the ability and disability spectrum.

The concept of “normal impairments” is yet another contradiction in the ideology of ability that destabilizes an ability/disability binary. Sterne defines “normal impairments” as “a set of impairments that are coded and experienced as normal, expected, and even desirable in some settings...Normal impairments cut a transversal across concepts like debility, disability, ability, and capacity because they are a rare case where an incapacity may be socially preferred or even advantageous in some settings” (119). Here, Sterne introduces the terms “debility” and

“capacity” into the ability and disability continuum. Julie Livingston uses the term debility to describe a “dynamic” process in which “experiences of disability, aging, and illness” are negotiated and renegotiated through “ongoing physical and social processes” (28). Thus, debility, like Siebers complex embodiment theory, intertwines biological and social aspects of disability. Debility acknowledges the fluctuations of chronic illness and aging, which sometimes do not quite fit into typical disability definitions. Debility encompasses illnesses/disorders that swing back and forth between well and unwell. As Livingston uses it, debility is a more inclusive term, which includes disability as one of its manifestations. The concept of “normal impairments” dances around the disability, ability, and debility continuum; a “normal impairment” is treated as an “advantageous” disabling/debilitating ability in some contexts. Using examples of auditory “normal impairments,” Sterne lists concerts, restaurants, and even loud hand dryers in public washrooms (123). Sterne introduces his coined term “*audile scarification*” which is “*the consensual transformation of the capacity to hear*” (119). In this discussion, Sterne requires his readers to disperse with typical associations of “loudness and hearing loss” as “undesired and undesirable”; in fact, in certain public spaces, “audile scarification” is preferred and “advantageous,” providing “access to spaces and communities unavailable to the nonscarified” (122).

In a society deeply rooted in the ideology of ability, hearing loss as advantageous seems incompatible with Western medicine’s axiom “that it is better to be fully hearing than hard of hearing and that it is better to be hard of hearing than deaf” (120). This medical and scientific hierarchy of hearing loss greatly oversimplifies the complexity of the “variety of hearing impairments” (120). The true contradiction surrounding hearing loss (a medical term) is found in “medical writing,” which presents hearing loss as “both preventable and inevitable” (120). The

inevitability of death and loss spurs medical and scientific research to come up with cures. Searching for cures does often yield new treatments for ill/disabled people to lead less painful lives. However, the search for cures is also highly problematic because illnesses and disabilities are still viewed as problems to be dealt with. Disability is encased within layers of loss and fear. The medical language of “loss” has led to the inversion “*Deaf Gain*”; however, even the term *Deaf Gain*, as critiqued by M. Remi Yergeau, is still rooted in a capitalist value system of human productivity (121). To advance “beyond a model of impairments as nothing more than undesirable deficits,” Sterne asks his readers to consider this question: “What if hearing loss is not necessarily a loss?” (119).

Rather than using terms of “loss” and “gain,” studies of the ability and disability continuum should focus on phenomenological embodiment as a fluctuating, shifting presence that intersubjectively grounds people in the world. Audile scarification is one type of social participatory impairment that not only acknowledges that “normal hearing is a construct” and “challenges existing understandings of compulsory able-bodiedness” (Sterne 125-26), but also moves discussions of impairment beyond the medical terminology of “loss” and “declining abilities” (124). According to Sterne, “Hearing loss implies a unity of hearing from which people diverge. Audile scarification points to the essential plurality of hearingness” (134). This “plurality” breaks down the idealistic “normate” and confirms the importance of human variation and difference (Garland-Thomson). In Merleau-Pontian terms, the plurality of horizons which make up the background of existence and experience leaves “the object incomplete and open” (Merleau-Ponty 72). These incomplete, open, and indeterminate horizons allow for infinite generative, creative possibilities for human beings to inhabit the world. Mind and body, subject and object, disabled and able-bodied are all woven in a chiasmic web, always intertwined but



never completely merging. Viewing the body schema as a fluctuating, ever-changing presence eliminates the need for strict dichotomies and allows human beings to embrace difference and change as a positive manifestation of embodiment. From this viewpoint, disability is no longer simply the negative of ability, not simply “loss” and defectiveness; disability becomes a valid, positive form of embodiment.

Viewing bodies through “plurality” (Sterne 134) and “instability” (Dolmage 96) complicates, destabilizes, dismantles, and eventually reassembles the popular conception of disabled/different bodies, viewing it no longer as an invisible negation but as a valuable part of human existence. Only through acknowledging, addressing, and foregrounding the historical and current erasure of disability experience, keeping in mind the intersectionality of other marginalized and silenced groups/identities with disability, can the unstable, ever-changing “partiality as multiplicity” of existence overturn the ableist fantasy of the stable, static, singular idea of the ‘normal.’ However, this reconceptualizing of disability as valuable is not a straightforward linear path. Ableism is so deeply ingrained in society that even with an intense overhaul of society and a concerted effort to be mindful of ableist assumptions in everyday life, ableism will continue to surface and resurface.

Intentionally or unintentionally, even disabled people themselves reproduce ableist assumptions and actions. Living with a chronic illness, some days I am unpredictably fatigued. Instead of accepting that my body needs rest, I barrage myself with ableist logic: You were fine yesterday, so you should be fine today; you’ve pushed through worse, you can push through this too; you’re lazy; you’re just not trying hard enough; other people work eight-hour days, and you should too, etc. My use of the second-person voice instead of first-person reveals the disconnect that I feel from my body. My body is not cooperating in a predictable manner, and it deserves to

be reprimanded. Using “you,” I am reproducing ableist assumptions, as though I have an ableist side trying to squelch my disabled side down into submission. Using “you,” someone else seems to be telling me how to feel and act, but that someone else is myself: myself that has been expertly crafted to adhere to be a productive part of ableist society. My body rebels, just wanting to lie down, but my ableist mind keeps me upright trying to ‘just act normal.’ Struggling with “the reality of chronic illness,” Emilia Nielson describes her “own dialogue of self-worth...as unwittingly ableist,” which she must “unlearn” (3). Nielson’s direct confrontation with her ableist “self-conception” excites me. Reading her article was the first time that I thought about exactly how *deeply rooted* ableism is: even disabled people can be ableist. Having a chronic illness or disability does not automatically exempt you from reproducing ableist assumptions and actions towards yourself or others. Everyone needs to become more aware.

According to Bones et al., “Disability isn’t a bad word” (15); however, the ableist assumptions and structures that have determined what disability means in the past still need to be questioned, dismantled, redefined, and reframed. This non-linear process is riddled with ableist pitfalls. For disabled people, redefining and reframing disability as valuable happens both within and without. Disabled people start at a different place than able-bodied people because they have lived experience to inform their engagement with ableist society. For Bones et al., whatever theoretical model, or combination of models, one chooses to employ, one must recognize the importance of a model for meaning-making created by disabled people themselves to “inform non-disabled people” (9). Disabled voices need to be heard to instigate systemic societal change. Recognizing the ableist inside all of us will help everyone reach a place of informed nonjudgement.

## Visible, Invisible, and Hidden Disabilities

In critical disability theory, the terms visible, invisible, and hidden are linked to themes of societal expectations, acceptability, accessibility, legitimacy, identity, belonging, disclosure, and stigmatization. In *Disability, Self, and Society*, Tanya Titchkosky examines her own dyslexia as it intertwines with her partner Rod's blindness. Titchkosky writes, "Unlike blindness, dyslexia is not readily observable" (11). Whereas Titchkosky's disability is not readily apparent to other people as she moves through the world, Rod's blindness is highly visible as he engages with the world in conjunction (and through) his guide dog, Smokie. However, visible/invisible is not a strict binary. In *Redefining Disability*, visibility and invisibility are not mutually exclusive categories; Bones et al. acknowledge that disabilities can be "both, depending on access needs at the time" (4). The unstable, fluctuating nature of disability is particularly prevalent with "hidden (or less visible) symptoms of chronic illness" which often "follow a relapse-remitting pattern and are not always easily apparent to others" (4). Hidden and invisible disabilities are not identical, even though many sources use the terms synonymously. Even visible disabilities fluctuate as life progresses, often moving from less visible to a more heightened visibility. Titchkosky writes, "The blind person who is going blind is living testimony to the radical inadequacy of simple dichotomies" (81). Although Rod was already legally blind before, he was given the social identity of blindness when Smokie (a visible sign of blindness) became his guide dog: "With Smokie, Rod was seen as blind...Through these interactions, Rod was given the identity – blind person" (82). Rod's experience complicates the "dominant inclination to frame sight and blindness as opposites" (81), just as Sterne argues that hearing and deafness are not a dichotomy.

The concept of "passing" - a term popularized during the Harlem Renaissance to refer to African-Americans living as Whites in the United States - in critical disability studies

foregrounds the complexity of the visible-hidden-invisible continuum, which can be viewed as a continuum within the larger ability-disability continuum. Although passing is often associated with hidden and invisible disabilities, passing also refers to the attempt to pass as ‘less disabled’ despite having a visible disability. Before Rod adopted Smokie (a visible signifier of his disability), Titchkosky explains how Rod “passed” as a sighted person, and often Titchkosky helped him to pass. Discussing cultural maps, Titchkosky refers to “Passing as a Map of Normalcy”: “Learning about sight and its topography allowed Rod to imitate it. He imitated the ways in which sight makes an appearance in culture” (66). Passing “involves playing roles” which requires “an intimate knowledge of human ability and its everyday definition” (Siebers 117). However, interpretation and imitation are not simply “copying.” As Titchkosky discusses, passing is an intricate, creative process that requires “knowing” the explicit and implicit expectations that sight guides every part of life (Titchkosky 70). Thus, passing requires intimate knowledge of societal expectations and behaviours, a sort of creative interpretation and performance of ‘normal’ ways of being. However, the skillful interpretation, adaptation, and creativity of passing also involves an “incredible amount of work” (Titchkosky 68) and can be emotionally draining (Siebers 118). Behind the motivation for passing the “ideology of ability” looms which “makes a powerful call on everyone in society to embrace uniformity” and to “be able-bodied as possible” (Siebers 117, 107). If a person is not able-bodied, then they are still expected to act like they are. The norm of able-bodiedness (ability) “appears unmarked and invisible” (Siebers 102-103), whereas the otherness of disability is thrown into a paradoxical visible invisibility, a “liminality” and a “between-ness” (Titchkosky 69). Even though there is an ableist expectation to act able-bodied, disabled people who pass as able-bodied are sometimes accused of being deceptive. From this impossible expectation another ableist contradiction

emerges: act able-bodied but do not misrepresent yourself. Whether a person pushes through chronic fatigue or uses a wheelchair when needed, they should not be devalued as liars.

Sometimes passing is easier than constantly explaining one's invisible or hidden disability with the result of either stigmatization or delegitimization. In "Finding Empowerment in the Middle: Navigating Hidden disabilities in Academia," Summer M. Jackson explores the "double-edged sword" of her chronic hidden disability and explains how the "ability to pass as a non-disabled person provides me with the power to control my identity and minimize...the impact of what could potentially be a stigmatizing label" (193). However, as Titchkosky and Siebers acknowledge, the effort of passing can be both physically and emotionally draining. The "double-edged sword" of a hidden disability lies both in the issues of legitimacy and disclosure: "The positives are that I do not have to disclose my disability if I chose not to, which I often do not...However, having a hidden disability often makes me feel the need to "prove" myself when I need assistance" (Jackson 192). Unlike visible disabilities with 'clear' signs of disability, such as a guide dog or a wheelchair (although, even these instruments might not be used all the time), a hidden disability is often questioned because, as Jackson writes, "How I look – physically – and how I feel – internally – dramatically differ" (193). In this sense, some disability writers with visible disabilities refer to their sense of privilege because their disability is questioned less. Yet, people with hidden disabilities have the privilege of choice: to pass or not to pass. Despite the possibility of privilege for both visible and invisible disabilities (depending on one's point of view), the fact remains that, in an ableist society, neither way of being in the world is valued.

Most disability literature treats the terms 'invisible' and 'hidden' as synonymous. However, Bones et al. make an important distinction between 'invisible' and 'hidden.' In the introduction, they state that "[d]isabilities can be either visible or invisible (or both, depending

on access needs at the time),” and then they include a definition of “hidden” disabilities as “less visible,” usually relating to “chronic illnesses” (4). This definition places hidden disabilities closer to the invisible end of the visibility/invisibility continuum; however, the possibility for simultaneity of both invisible and visible disabilities makes this continuum non-linear. In “Diagnosis Limbo,” Danielle Barber uses “hidden” instead of invisible, specifically connecting the term to chronic illness: “A hidden chronic illness can be defined as a health condition or disease that is experienced long term, and the associated symptoms are not always readily apparent or visible to others” (120). Hidden chronic illnesses are often hard to diagnose, leaving the person in “prediagnostic limbo.” Intertwined with the complicated nature of hidden disabilities/illnesses is the issue of disclosure and stigma, especially disclosure without a diagnosis (120). Both Bones et al. and Barber encourage “self-diagnosis” as a valid form of diagnosis; however, Barber does acknowledge the “relief” that comes with a diagnosis (120).

Examining the experience of university students with invisible disabilities, Mullins and Preyde refer to Matthews and Harrington’s distinction between hidden and invisible: “‘non-visible’ or ‘hidden’” suggests that “the disabilities can become visible” whereas “invisible implies that the disability cannot be seen at all” (148). Matthews and Harrington list “dyslexia, mental health disorders, and attention-deficit hyperactivity disorders” under the term invisible. For these disorders, they argue, “the cause of the disability cannot be seen,” even though symptomatic behaviors might surface (148). Thus, the primary difference, they conclude, is that hidden requires a visible (at times) physical manifestation of disability, while invisible concerns internal disorders, such as mental health. Bones et al. and Barber both expand on Matthews and Harrington’s definition of the umbrella term “invisible” to include chronic illness.

Again drawing on some of the case studies and authors considered in this thesis, Titchkosky's dyslexia is considered an invisible disability. Rod's blindness, especially with his guide dog Smokie, is considered a visible disability. Bjerke's ostomy, as represented in her art installation *Hidden Agenda*, is considered a hidden disability. A more complicated case is Nielson's autoimmune condition, which she discusses in "Chronically Ill, Critically Crip?" and her poetry collection *Body Work*. According to Bones et al. and Barber, Nielson's chronic illness is an invisible disability, although Nielson expresses the "dissonance" of chronic illness as a "site of tension" because the fluctuating nature of the illness tended to misfit with disability studies.

Nielson's "Surgical Diary" poetry embraces surgical incisions, stitches, and scars, including the surgical removal of one of Nielson's organs. In a sense, Nielson's invisible chronic illness becomes visible after surgical intervention. Through the "meeting place" of the scar, which Koppers theorizes in *The Scar of Visibility*, the interior and exterior body merge at the site of the scar (1). Thus, invisibility and visibility are also intertwined in Nielson's case. Personally, I identify as having both invisible and hidden disabilities. My chronic illness is invisible to the naked eye. During flares, visible signs emerge, such as drastic weight loss, but most of my illness remains below the skin. However, when I required surgical intervention to remove an organ, my invisible illness also became a hidden disability. My ostomy is hidden beneath an appliance and layers of clothing, but removing all that, my reddish pink pulsing intestine is visible as it involuntarily eliminates liquid waste. Before and after my intestinal surgeries, nurses and doctors were quick to assure me that an ostomy was easily concealable. No one would even know I had one if I wore the right clothing. Although the possibility of hiding my ostomy was supposed to be comforting, I suppose, it also perpetuated the ableist assumption that I would *want* to hide it.

My quality of life increased tremendously, and I was happy that I had finally gotten the surgery. Was I supposed to be embarrassed? Should I keep it a secret?

With these distinctions between visible, invisible, and hidden, it might be tempting to return to a Cartesian mind-body split; the visible is the body, the invisible is the mind, and hidden is an ambiguous extension of the physical/bodily visibility. However, understanding and theorizing disability experience itself (Titchkosky 17-18) requires that dichotomies are replaced with fluid continuums and that disability (and all of life) engages with the Merleau-Pontian phenomenological body schema in which the mind and body are intricately intertwined in lived experience. Aurora Berger uses the term “bodyminds” to engage with this wholistic idea of the body schema in relation to crip theory (51). According to Carrie Sandahl, ““The term cripple, like queer, is fluid and ever-changing, claimed by those whom it did not originally define... The term crip has expanded to include not only those with physical impairments but those with sensory or mental impairments as well”” (qtd. in Berger 51). Exploding beyond the simple ability/disability binary, new concepts such as impairment (Sterne 34-35), debility (Puar xv; Sterne 34-35), and crip theory (McRuer; Berger 50-51) help to increase the fluidity of disability as a valid, varied identity.

The concept “dynamic disability” incorporates a fluid, fluctuating aspect to the ability-disability continuum. Referring to B. Benness’ 2019 article “My disability is dynamic,” Jackson states that her chronic condition with its fluctuations and “inconsistency” is a “dynamic disability”: “A dynamic disability is best described as being unpredictable in both presentation and severity of symptoms” (193). Chronic illness as a “dissonant disability” in Emilia Nielson’s poetry collection *Body Work* also exemplifies this unstable, shifting “between-ness” of a “dynamic disability” (Titchkosky 69; Jackson 193). For Nielson, her chronic autoimmune illness



simultaneously intertwines “well and ‘unwell” (3), disrupting the normative well/unwell binary. This liminal “in-between” space of chronic illness (and other fluctuating illnesses/disabilities) creates a space of misfitting (Dreidger & Owen 7): people with dynamic disabilities do not fit into normative ableist society nor into some disability communities. Jackson addresses this struggle of being “in the middle,” stating, “I also struggle with an internal dialogue of not being ‘disabled enough’...I feel like a fraud who should leave discussions on disabilities to those who are visibly disabled” (192). A dynamic disability cannot be forced into the normative able/disabled binary because it occupies a space in-between, which is why redefining disability as a continuum is important. Jackson writes, “We tend to view disability as either/or, all the time or not at all. However, like with other forms of identity, this does not account for the breadth and depth of disability identity. Hidden disabilities are fluid and nuanced. They are complex and not always apparent to the observer” (196-97). Therefore, while those with invisible and hidden disabilities have an inherent choice when it comes to disclosure or nondisclosure, this “middle” space remains a confusing place to navigate.

Livingston also uses the word “dynamic” to define “*debility*” as a term that encompasses “disability, aging, and illness” (28). In a similar way to “dynamic disability,” Sterne refers to Livingston’s concept of “*debility*” to explore the “ambiguous space” of ability and disability, specifically “the uneasy relationship between disability and chronic illness” (35). For Livingston, and Sterne, the concepts of debility and impairment allow for more inclusive discourse within disability studies (34-35). While some people with chronic illnesses assume a disability identity, others are hesitant to claim disability. Debility opens the realm of ability and disability to include people who do not identify as disabled but who have debilitating conditions that affect their everyday lives. In *The Right to Maim: Debility, Capacity, Disability*, Jasbir K. Puar also

distinguishes debility from disability as “the slow wearing down of populations instead of the event of becoming disabled. While the latter concept creates and hinges on a narrative of before and after for individuals who will eventually be identified as disabled, the former comprehends those bodies that are sustained in a perpetual state of debilitation precisely through foreclosing the social, cultural, and political translation to disability” (xiii). Puar uses “debility” to disrupt the “ability/disability binary” and to create an ability (capacity)/disability/debility triangle to include people who are not “recognized as or identify as disabled” (xv). The concept of debility also reaches beyond state discourses of what constitutes a disability to include racialization and poverty. Addressing the racialized violence in the United States, especially police brutality, Puar questions the “familiar cant that tells us we will all be disabled if we live long enough.” For some people, geographical location, “resources,” “traumas,” skin colour, access, and type of work will determine whether they live long enough to even become disabled: “we will not all be disabled. Some of us will simply not live long enough, embedded in a distribution of risk already factored into the calculus of debilitation” (xiv). Disability and debility are often used as forms of biopolitical power. Puar’s triangulation of ability, disability, and debility reveals the importance of intersectionality within disability studies.

The term debility is still steeped in a language of loss and gain; weakness and strength; and negative and positive. Personally, I prefer the words “dynamic disability” to describe my hidden and invisible disabilities rather than debility. However, I recognize the importance of debility as an inclusive concept for people who do not identify as disabled. Perhaps my resistance to the word debility stems from the fact that it has not yet been fully claimed and reframed in the way that the word disability has.

Even though not everyone will become disabled, as Puar points out, everyone has a relationship with disability (and debility) in some capacity. Titchkosky comments on the social construction of disability through the complex intersubjective interaction of able-bodied and disabled people:

Everyone, disabled or not, who interacts with disability is engaged in producing its meaning and its social identity. A ‘disability identity’ does not belong strictly and only to those of us who are identified as disabled...It is impossible to experience disability outside of our relations with others. (4-5)

For Titchkosky, Rod’s blindness and her own dyslexia are intertwined in a complex experiential, comingling relationship (3). Examining the “mapping of maps,” Titchkosky notes the implicit cultural landscapes and expectations that govern cultural ideas of ability and disability, especially through “the ideology of ability” (Siebers 8). Often normative cultural maps are implicitly enforced and followed without anyone questioning the mapping of the maps themselves: the process of map-making becomes a cultural blind spot. Explaining her “passing project” in which she passed as blind, Titchkosky describes this experience as a shared “sighted-blindness” with Rod (71-72). This passing experience allowed Titchkosky to notice “background” normative cultural maps, in which “an unexamined position of normalcy is the unmarked viewpoint from which deviance is observed” (148). Passing as blind brought normative “background expectancies” to the foreground, revealing disability to be much more complex than “simply the doing or the non-doing of things” (15-16). The experience also led Titchkosky to compare visible and invisible (or hidden) disabilities. She is “rarely ever seen as dyslexic” and “[t]he sets of background expectancies that dyslexia disrupts are not the same ones that blindness does. Dyslexia, more so than blindness, can often appear *only* as an ordinary

mistake” (16). Just as there are “normal impairments” versus not normal impairments (Sterne 119), there are also ordinary “mistakes” versus “extraordinary” mistakes (Titchkosky 17). The disruption of ability, such as spilling a glass of water, is common, but it must be a brief ‘normal’ disruption of normalcy. Titchkosky emphasizes that she and Rod experienced this commingling of sightedness and blindness “from very different perspectives” (72). Her experience of Rod’s blindness as his partner and her experience of passing as blind are very different from Rod’s daily experience of blindness. Rod can never avoid ableist “inscription,” such as “[b]latant avoidance,” “blindness as lack of knowledge,” “blindness as excessive disruption,” and “blindness as inability and/or poverty,” among others (92). Titchkosky’s “blind-sightedness” with Rod appreciates the complex interaction and “interrelatedness” of sightedness and blindness (54, 64). This “blind-sightedness” as a site of critical examination of background expectancies and cultural maps of disability further illustrates the inadequacy of ableist binaries.

Again, visibility, invisibility, and hiddenness are not mutually exclusive categories (Bones et al); they can function simultaneously depending on the context. Complicating the relationship between disability and visibility and invisibility, Titchkosky writes that a visible sign of disability, such as Rod’s guide-dog Smokie, does not necessarily mean that people will change how they interact with a disabled person. Often, people with visible disabilities are still treated as though they are able-bodied, or there is the assumption that they should try to be as able-bodied as possible. In Rod’s case, although “sighted people now have a marker of blindness,” “[m]aking blindness obvious does not necessarily change the cultural inclination to treat disabled people *as if* they are not,” which can easily lead to dangerous situations (83-84). The ableist stance of sightedness as ‘natural’ (“signs of the hegemonic hold of sight”) creates blindness as opposite and ‘unnatural,’ and blindness becomes a “spectacle” to be stared at rather

than understood as a different way of engaging with the world (84). For example, someone opens a door for a blind person and watches the blind person groping for the door without saying anything or a friend waves at Rod with Smokie from a distance (Titchkosky 110). In these common scenarios, these people are attempting to ‘help’ with “an *unworkable* conception of disability” (110). Titchkosky writes, “The door to the building remains open, but the door to any interactional development of what it means to be blind remains closed tighter than ever” (111). An encounter between an able-bodied person and a non-disabled one comes with a host of cultural maps and preconceived ideas of what ability and disability are (108). The examples provided above also exemplify what Titchkosky refers to as “the inequality between disabled and non-disabled people,” specifically the issue of “choice” (65). Sightedness is so taken-for-granted that “seeing” is performed as though it “involves no effort, no decisiveness” (65). Sight is treated as “natural,” and, in ableist terms, blindness becomes the opposite: “unnatural.” Although both disabled and non-disabled people “engage in the projects of seeing and embodiment,” their different levels of privilege are influenced by deeply ingrained cultural maps which determine the intentionality of environments (such as public spaces), particularly regarding accessibility (65).

In “Cancer Isn’t Like a Movie, But If It Was It’d Be a Horror Flick,” Terri Juneau Eklund writes about the invisibility that accompanies a visible disability: “It’s not just about invisible disabilities sometimes. It’s about becoming invisible with a disability too. Like when that professor showed that silent film when we had a blind student – she didn’t matter. He forgot she was even there (with her dog)” (237). Eklund experiences the “quicksand” of “sinking into cancer” as she moves from visibility to invisibility. Thus, invisibility is not just experienced by persons with invisible disabilities, and it is not a static state. Often with a visible disability, not

just the disability is ignored, but the whole person is treated as invisible or infantilized. The doctors only talk to her husband, and Ekland writes, “it’s like I’m invisible now” (237). The simultaneous visible-invisibility reveals the invisible and visible continuum does not follow a linear pathway from visibility to invisibility, but it is a circular space that folds back on itself, compresses and expands. Just as time is fluid in the experience of illness, visibility and invisibility are also fluid.

Everything discussed in this section should be viewed in the context of intersectionality. Ability, disability; visibility, invisibility, hiddenness; intentional and unintentional passing; disclosure, identity, legitimacy, stigmatization, and accessibility; these issues cut across gender, sex, ethnicity, race, and class. Each marginalized group experiences ability and disability differently. Emphasizing the need for intersectionality in disability studies, Cassandra Lovelock states that “[t]here is no established mixed-race disabled identity” (40). Existing in a “messy, changeable” liminal space between White and Black, “the mixed-race disabled experience requires its own axis of understanding” (42) rather than requiring a mixed-race person to choose a “master status” (41). Lovelock writes, “Disability movements tend to be dominated by white (passing) people who can easily fit into the already perceived narrative of disability and whose experiences are difficult to relate to as a mixed-race person” (41). My thesis is written from a position of white privilege: I am a disabled, white, heterosexual woman. My “positionality” influences what I write and how I choose to write it (Evans 730). Being a white, heterosexual woman, I possess two unmarked “norm identity traits” (Lovelock 41) and my hidden and invisible disabilities allow me to pass as able-bodied. I am unfairly exempt from having to choose a “master identity.” Staying with disability experience itself requires that all aspects of intersectionality are explored (Titchkosky 17-18).

## **Hidden from whom?**

As previously discussed in this thesis, the term ‘hidden’ implies a visible disability that is concealed, such as an ostomy. Hidden also suggests that the disabled person has agency, a sense of choice: to reveal or conceal, “[t]o pass or not to pass” (Siebers 96). However, this agency is often only possible in non-medical society. To receive help for a hidden disability/illness, as well as invisible disabilities, a person must disclose their impairment and/or disability to doctors, nurses, technicians, hospital staff, and caregivers, among many others. Mandatory disclosure is unavoidable in the medical realm; one cannot conceal their disability/illness if one wants to reach a better quality of life.

Discussing disability, impairment, passing, and disclosure as she researches autobiographical accounts of 12 participants with “non-apparent” acquired impairments, Heather D. Evans identifies three types of disclosure: confessional, pragmatic, and validating. Confessional disclosure “can bolster internalized notions of disability stigma,” such as “revealing impairment to justify asking for services or to apologize for perceived deficiency in one’s performance” (727); pragmatic disclosure is practical, such as “using disclosure to enlist others in reducing barriers to productivity in built and social environments” (743); and validating disclosure “legitimizes disability identity, signaling a political identity that resists or calls out systems of oppression against a shared, minority status” (743). These three types of disclosure are not mutually exclusive and can bleed into one another at times; one scenario can contain two types (or even three types) of disclosure. Disclosure is intimately connected with the development of a disability identity, especially validating disclosure which “legitimizes disability identity” as a valid different way of being and moving in the world (Evans 743).

According to Evans, people with acquired “invisible impairments” or “non-apparent” (hidden) impairments/disabilities “have the widest possible range of options open to them for managing stigma and negotiating disability identity” (729), including passing which is often not available to people with visible disabilities. However, as Anabel Moriña argues, having more options is not necessarily better; invisible and hidden disabilities come with their own “challenges” (Moriña 13). Passing also involves an “incredible amount of work” (Titchkosky 68) and can be emotionally draining (Siebers 118). Moriña writes that non-disclosure of a disability is “not a neutral decision,” especially within a university context because “it has consequences for retention and success...as well as personal impact” (9-10).

Yet, as “a person with multiple hidden disabilities,” Shanna Hollich argues that passing is not always a decision; she introduces the concepts of intentional and unintentional passing (99-100). She writes, “Passing, much like disability status and other markers of identity, can itself be a liminal state...passing is not always all-or-nothing, and it is not always deliberate. Because my disabilities are hidden, I frequently pass even when I do not intend to” (99). Often considered “solely as intentional” or a “premeditated decision,” Hollich challenges this prevalent view of passing, introducing unconscious and unintentional passing as an important concept for hidden and invisible disabilities. Along with a disability-ability continuum and an invisible-visible continuum, there is also an intentional-unintentional continuum. It may be possible to extend Hollich’s concept of unintentional passing to the issue of disclosure. Does disclosure always involve conscious decision-making? Is intentionality inherent to disclosure? Unintentional passing returns to how deeply the ableist ideology is ingrained in our way of being in the world. I am fatigued, moving about the house in an exhausted haze. But as soon as I step into a public place, I straighten my posture, open my eyes wider, and smile as though I am not about to



collapse on the spot. The hard sidewalk begins to look like a comfortable place to take a nap, but I shake my head and tell myself that I am just being lazy. My ostomy itches to the point that I want to rip the appliance off, but I talk and smile as though I am entirely comfortable. I am so accustomed to assuming this new able-bodied posture when in the presence of other people (who I assume are able-bodied) that I am often not aware that anything about my way of engaging with the world has changed.

Unlike most other social situations, people with hidden and invisible disabilities must disclose their impairments to receive medical care to improve quality of life. However, a concept of mandatory disclosure implies that the person who is suffering has *something* to disclose. This mandatory disclosure in medical settings is complicated when a person lacks a definitive diagnosis. In “Finding My Way in a Society Where I Don’t Fit,” Jill Richardson writes about her experience navigating the health care system before she was diagnosed with a “somatoform disorder,” which is “a real physical disease with psychological origins” (61). Richardson refers to an article by A. Jutel (2019) when she states, “Patients without a diagnosis don’t just lack the proper treatment, they also lack a way to explain themselves or legitimize their disease” (63). Commenting on the medical gaze, Richardson argues that the “prevalence of somatoform disorders” reveals Cartesian dualism to be “imaginary” (64). Before her PTSD diagnosis, Richardson was passed back and forth between doctors, who focused on the body, and psychologists, who focused on the mind, showing the prevalence of Cartesian dualism in the current medical system (64). Richardson emphasizes the connection between “diagnoses and power” (65). Receiving a diagnosis “is empowering”: social empowerment and self-empowerment. A diagnosis makes it easier to “explain yourself to others” (65). However, “[o]nly certain people and institutions have the power to license people to diagnose patients, and to

define and classify diseases” (65). The power of a diagnosis stems from licensed medical practitioners; once a diagnosis is given, then a disabled person can take that diagnosis and form a sense of social and self-empowerment, connecting with a specific community of people with similar diagnoses. Without a diagnosis, a person suffering from a debilitating hidden or invisible illness/disorder/condition will remain powerless and misunderstood, including “disability accommodations, treatment, and insurance reimbursement” (65). A diagnosis legitimizes pain and suffering, whether mental, physical or emotional; unexplained pain and suffering that eludes diagnosis creates a stigmatizing loop of delegitimization and judgement.

Richardson writes that “[i]n our society, doctors are supposed to know how to diagnose and treat illness. Mine didn’t know how to help me. My doctors believed I was telling the truth about my pain, but they had no idea what was wrong” (62). In Richardson’s experience on her road to diagnosis, her doctors believed that her pain was real even when they could not explain it. Oftentimes, unexplained pain is dismissed as a psychological issue, something that is separate from the physical body. In an age of medical imaging and an ever-growing range of tests, doctors are treated as all-knowing, and the human body is “seemingly transparent” (van Dijck x). However, as van Dijck and Cartwright emphasize, the “transparent” body is an “illusion” (van Dijck 98-99). Medical imaging is not objective, as popularly thought; instead, medical images are always mediated images. Mass media co-creates and reinforces the “transparent” and “high visibility of the interior body in modern-day culture” and allows stigmatizing associations with certain types of medical imaging to flourish (van Dijck 12). The artificially constructed objective-subjective and scientific-art binaries must be disrupted and dismantled because all images, whether scientific or artistic (or both), are mediated. Cartwright shows the historical interconnection between scientific medical imaging and cinema (xiii), particularly how Western

medicine used the cinema to create and enforce normative constructs. As discussed in the first chapter, providing a specific example of this interconnection, van Dijck and Sawchuck explore the inside-outside, outside-inside, and inside-inside medical gazes in *Fantastic Voyage* (1966), an example of the “anatomical entertainments” of “biotourism” (Sawchuck 10). The dream of being able to enter an “optical unconscious” (Walter Benjamin) or travel through inner bodily spaces and processes without any outside consequences is the “fantasy” of a transparent body created through modern media, medical imaging and minimally invasive endoscopic procedures, a main theme in *Fantastic Voyage* (van Dijck 142).

This cultural expectation that medical imaging, among other tests, provides doctors with the data that they need to accurately and objectively identify and diagnose illnesses and disorders leaves people who suffer from unexplained pain in a state of delegitimization. Thus, undiagnosed hidden and invisible disabilities/illnesses/disorders further complicate issues of passing, disclosure, and stigmatization. Hidden and invisible disabilities are still often treated with suspicion, even with diagnoses and medical documentation. In academic settings, students, professors, and staff must prove “the legitimacy of their disability” to receive necessary accommodations (Moriña 13-14). Without a diagnosis, people suffering from “non-apparent impairments” are even less likely to be believed (Evans 726). Barber’s “relief” after receiving a diagnosis stems from this cultural tendency to doubt experiential accounts of pain and suffering until a medical professional puts it into writing. The “prediagnostic limbo” is even more ambiguous than the diagnosed liminality and delegitimization of hidden and invisible disabilities. “With no diagnosis,” Richardson writes, “patients feel like other people think they are lazy or crazy” (63). Before her dyslexia diagnosis, Titchkosky recalls being viewed as “lazy, slow, and stubborn” (33). As E.J.K. Bremner and R. McGuire write, “a diagnosis is not what makes

someone disabled, but the search for answers, no matter how successful, is an experience that unites many disabled people” (23). To increase the inclusivity of disability studies, many scholars argue that “self-diagnosis” should be viewed as “a valid claim to disability” because it can be hard to get an official diagnosis (Bones et al. 2).

### **Embracing disability as a valid form of embodiment**

As argued in this thesis, living with a disability presents a different way of embodiment, a constant renegotiating of one’s disabled body and its engagement with the world. Again according to Bones et al., “Disability is simply a state of being, and it’s fine” (15). The “dynamic nature” of disability requires a “broad approach” to include people with diagnoses, without diagnoses, and those “who may not label themselves ‘disabled’” (Hollich 95, 98). To counteract the negative cultural connotations surrounding disability, Evans views disability as “different” rather than “diminished” (738). Disclosure, especially “validating disclosure,” “can play an important role in asserting impairment as a different way of being, rather than a diminished state of being” (738). Disability as a positive identity is formed through the negotiation of different types of disclosure, and it is cemented when disabled people practice “validating disclosure” and “assert disability as a legitimate, integrated identity” (727). I am trying to reach a place of incorporating “validating disclosure” into my life, but it takes practice to achieve a sense of peace with permanent bodily changes.

Through the experience of disability, a disabled person is not only negotiating and renegotiating new bodies and forms of embodiment; they are also negotiating and crafting a social, political, economic, and self-identity. Sterne writes, “One common trope of acquiring a disability is that you wake up in a different body. But the process of negotiating that body is

more like a process of awakening than one that happens in a particular instant” (29). Whether a person is born with a disability or acquires it, the constant “process of negotiating” one’s body in an ableist society remains the same. With my ostomy, I eliminate waste differently, I eat differently, and sometimes I sleep differently. I am more aware of my abdomen, and the safety of my ostomy factors into conscious and unconscious decisions. My orientation toward the world has changed, and continues to change, but this change is not a position of lack. Sterne theorizes disability as presence, not just absence. Discussing chronic fatigue, Sterne writes, “While industrial managers and sports scientists imagine bodies in terms of energy stores and their expenditure and replenishment, for the chronically fatigued subject, it is not an absence of energy. Fatigue is presence” (163). Disability as I mention in this thesis often is used “to refer to bodies for which something has gone wrong or is missing, or to bodies that lack,” giving “people a map of disability through a series of negations” (Titchkosky 50-51). Contemporary critical disability studies scholars, however, argue against disability as negation or absence.

To conclude my chapter on critical disability studies and the ability-disability continuum, I would like to reference Samuel’s concept of “crip time”: “When disabled folks talk about crip time, sometimes we just mean that we’re late all the time...But other times, when we talk about crip time, we mean something more beautiful and forgiving. We mean, as my friend Margaret Price explains, we live our lives with a ‘flexible approach to normative time frames’” (qtd. in Sterne 184). This flexibility of “crip time lies in shaping the world for the subject rather than bending the subject to the world” (Sterne 185). For Titchkosky, this is a pedagogical principle: “Disability as teacher...is only possible if we suspend, even momentarily, the need to fix disabled persons or fix up society’s treatment of us” (28). Disability is not simply “an obstacle” to be avoided or overcome; it is a way of being that should be acknowledged and valued as a

valid way of being in the world, “a way of experiencing” (Titchkosky 30). “[S]taying with disability experience” and allowing “crip time” and other ways of being to flourish without judgement or stigma can be a new basis to move beyond stifling binaries and accept disability as a valuable presence (17-18).

## Conclusion

Impairment phenomenology takes the “I can’t” and “I don’t know” of protention as seriously as the “I can”

Jonathan Sterne, *Diminished Faculties* (155-56)

Is continuum the right word to describe the intricate interwoven relationship between ability and disability? Evading precise definition, disability itself is a fluid ambiguity that shifts and morphs over time, affecting and being affected by the corporeal schema and its horizons. A continuum is more flexible than the strict ableist ability/disability binary, but is it flexible enough? For analytic purposes, a way of categorizing is essential to determine boundaries and limits that lead to disability policy making. But disability does not have any firm boundaries; disability explodes beyond analytical categories that try to contain and explain it. But how can ability and disability be understood without any marked boundaries (or at least a few signposts) to distinguish one from the other?

Understanding disability does not come from definitions. I have tried that route, and became more confused than ever. Understanding disability comes from narratives woven into prose, poetry, visual art, dance, song, and many other experience-driven forms. I return to Reynold’s poignant statement: “Disability cannot be understood outside of the centrality of its narrative role for the lived experience of selfhood, social identity, and, in a word, our being-in-the-world” (243-44). Subjective disability narratives of lived experience are what bind the

strands of critical disability together, weaving these threads into a discipline that explores different ways of knowing and understanding embodiment. Understanding is a feeling, an uncomfortable and exciting journey through a maze of first-person disability accounts that eschew the traditional academic third-person voice. But understanding is also a journey that always remains incomplete. I will never arrive at a destination with a flashing neon sign (or even a faded dilapidated wooden sign) that reads “You have reached the town of Understanding.”

This incompleteness, this indefinite journey is like Sterne’s “I don’t know,” which hovers uncertainly between Merleau-Ponty’s “I can” and the “I can’t” (155-56). I lay in bed fatigued, caught in a space of “I don’t know” whether I can force myself to get out of bed or not. Disability is a series of in-betweens that shift with the changes of individual corporeal schemas and the world. The liminality of disability positions it as a unique avenue to critical phenomenological inquiry. The “juxtaposition” of “misfitting” (Garland-Thomson, “Misfits” 593) in an ableist world jolts disabled bodies out of the comfort of the “ease of movement” (Fielding, “Habit” 157), illuminating the usually invisible/implicit background and corporeal schema. These jarring jolts lead to the fecundity of disability experience. John Hall’s description of blindness as “*a world-creating condition*” can be expanded to include all disabilities and impairments (qtd. in Reynolds 246). Disabilities and impairments are “*world-creating condition[s]*” that “undermine the effect of the normate” (Reynolds 246).

In this thesis I argue that dismissing the “hegemonic phantasm of able-bodiedness” frees disabled bodies to celebrate their lived experience as different and valid forms of embodiment, not as “worth less or even worthless” (Reynolds 245-46). Dispelling the restrictive ableist binaries and connotations allows disability expressiveness to flourish not as a marginalized, closeted, resistance-oriented form or expression, but rather as an integral, accepted part of

society. However, it is important to note that Merleau-Ponty's "I can" and "I cannot" is "constituted by one's environment and the future it affords" as well as one's bodily experience (Reynolds 245). To discard the "hegemonic phantasm of able-bodiedness" requires extensive systemic intersectional societal, political, and economic change.

Sterne's "I don't know" (155-56) and his "inaccessible-to-myself-self" (40) linger in my mind as I continue to reflect on the interconnectedness of ability, disability, and debility, as I continue to contemplate visibility, hiddenness, and invisibility; well and unwell; subject and object; body and world. An interlacing web or a matrix is perhaps a more apt depiction here than a single continuum, even if it is nonlinear. However, no matter how open or precise the language, the sensual nature of disability must be explored through mediums that engage all the senses. The four case studies explored in this thesis are just a few samples taken from a vast tapestry of literature, visual art, and film, among other art forms, that explore the perceptual intertwining of ability, disability, and debility. Bjerke's ostomy installation exhibit enters the domain of tactile art, using the tactile nature of a stoma to mold the "misfit" and make the invisible or hidden visible. Other corporeal case studies incorporated into my thesis foreground/further complicate visual/optical engagement with embodiment and the scientific/medical tactile reach, such as the sci-fi film *Fantastic Voyage* and Tretheway's poem "Knowledge." The endoscopic-like biotourism of *Fantastic Voyage* and the clinical anatomical dissection described in "Knowledge" highlight the power of the highly mediated surgical gaze, which operates within an ableist visual regime. Nielson's poetry *Body Work* turns to intimate descriptions of visual perception, tactile explorations, and auditory experiences to contemplate the dissonant complexity of surgical intervention, chronic illness, and disability. In this thesis, I augment these case studies with my own phenomenological analysis of my own embodied experience, arguing that embodied



experience intertwines our senses, almost inextricably, when we perceive the world. Not every body has all five senses at its disposal, and each body senses differently. As I discuss in this thesis, new theoretical investigations in critical disability studies need to explore the full range of disability embodiment as a unique engagement with the world and also address the lived critical phenomenology of taste and smell.

My research has primarily centred on visible, hidden, or invisible *physical* disabilities. But Merleau-Ponty's dismissal of the Cartesian mind-body dualism usefully complicates the picture and introduces new categories we could also use to more holistically consider mental health disorders and disabilities. Viewing subjective narratives and lived experiences of disability invites us to engage all our senses. In this thesis I draw on corporeal case studies in the arts and humanities, my own experience and theoretical approaches taken from critical disability studies, and critical theory and critical phenomenology, including Merleau-Ponty's theory of embodiment, Garland-Thomson's theories of the "normate" and "misfitting," and Sterne's "audile scarification" and "I don't know," as well as Foucault and Cartwright's archeology of medical perception to weave a new tapestry of disabled artistic expression and identity.

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## Curriculum Vitae

### Education

Western University, London, ON, Canada  
MA in Theory and Criticism  
2021 - present

Trinity Western University, Langley, BC, Canada  
BA English Honours  
2016 – 2019

Simon Fraser University, Burnaby, BC, Canada  
2015 – 2016, 2020

### Awards and Honours

Western Graduate Research Scholarship,  
2021 – 2023

Social Science and Humanities Research Council  
(SSHRC) Grant, 2021 – 2022

English Department Literary Award,  
2018 (Trinity Western University)

President's Scholarship  
2017, 2018 (Trinity Western University)

Dr. Barbara Pell Scholarship  
2017 (Trinity Western University)

### Related Work Experience

Editor-in-Chief, [spaces] Literary Journal  
Trinity Western University  
2017 – 2019

### Publication

“Portraiture and the Convergence of Social Classes in *Bleak House*.” *The Oswald Review*, vol. 22, no. 1, 2020, pp. 57-78.