

FITS AND MISFITS: RETHINKING DISABILITY, DEBILITY, AND WORLD WITH MERLEAU-PONTY

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Much of Merleau-Ponty's thought centers around the idea that we find ourselves neither separate from the world, nor "in" it, but fully intertwined, caught up in a web of relations that shape experience through and through, bottom to top. Those relations are charged, which is to say, human experience is conducted through a *web of forces* in which we ever find ourselves "fitting" or "misfitting" relative to a given set and setting. We deploy the concept of "misfit" here to explicitly invoke Rosemarie Garland-Thomson's (2010) seminal article, "Misfits: A Feminist Materialist Disability Concept." Fits and misfits, in Garland-Thomson's sense, are everywhere once you know how to look for them: spatial, placial, architectural, equipmental, technological, economic, social, cultural, cosmic, and so on. For Maurice Merleau-Ponty and for Garland-Thomson, one could say that being human is a navigation project. Indeed, each and every one of our lives *just is* its project of journeying through the channels, paths, and alleyways that existence lays out before us.

Yet, in our highly modified world, fitting or misfitting is rarely a question of chance. More often than not, we encounter barriers or affordances due to things that have been built—materially, but also socio-culturally through sedimented norms, practices, institutions, and habits. What's more, given rampant inequity and injustice, many are actively *made* to misfit. One form of forced misfitting is described by Jasbir Puar (2017) as *debility*. For Puar, debility refers to the *making impaired* of individuals and groups through systemic harms, whether these be a result of police brutality, capitalist modes of production that immiserate workers, policies that bar many from accessing healthcare, housing, and employment, and so on. The concept "addresses injury and bodily exclusion that are endemic rather than epidemic or exceptional" (xvii).¹ Debility, on our view, helpfully names the many ways in which people are *made* to misfit. Debility is a crucial concept for critical phenomenologies of disability, which we understand as a method engaged in the "historically-grounded, quasi-transcendental study of particular lifeworlds" as well as in "(situated and interested) analysis

¹ See also Puar (2017, 13, 73).

of power” (Guenther 2021, 5). One can understand neither the meaning of disability, nor the complexity of fitting and misfitting, without appreciation of how affordances are allocated by means of power.

Merleau-Ponty’s observation in the “Freedom” chapter of the *Phenomenology of Perception* that “insofar as I have hands, feet, a body, and a world, I sustain intentions around myself that are not decided upon and that affect my surroundings in ways I do not choose” is all the more poignant when we understand it through the power relations that define experiences of (mis)fitting, (dis)ability, and debility (2012, 465). And yet, when we are forced to acknowledge that the world we live in is shot through with injustices, many of them deliberately inflicted upon innocent people, we must also contend with the fact that we often have more agency to address and remedy them than we might at first suppose. The articles in this special issue have been organized into four sections, each of which addresses different dimensions of misfitting, disability, and/or debility that are experienced in communicating with others (section one), caring for extremely ill loved ones (section two), adjusting or failing to adjust to temporal norms (section three), and responding creatively to the complex fabric of aesthetic and political life (section four).

Section one, *Challenging Communicative Norms*, fittingly begins (pun intended!) with Garland-Thomson’s contribution entitled: “What Misfitting Makes.” This article explores surprisingly generative (and sometimes comical) misfits (such as “Miss Fitz” or “Miss Fritz” for “misfits” and “Norm Mates” for “normates,” both the result of dictation software technology) that Garland-Thomson argues are capable of producing “disability gains” insofar as they “hold the potential for new meanings” (6). Drawing upon the powerful iconography of Michelangelo’s *Pietà* and its creative reinterpretations by contemporary artists, Garland-Thomson argues that the *Pietà* highlights “the fundamental misfit all humans share,” namely, the mortality of our flesh in a world that continues on without us (14). Susan Bredlau’s “Conversational Accessibility: Healthcare, Community, and the Ethics of Everyday Encounters” offers a critical phenomenological analysis of the communicative challenges that emerge in and through the interactions between patients and healthcare workers in the clinical context. Bredlau’s emphasis upon “conversational accessibility” calls attention to one of the most pervasive, yet at the same time under-theorized forms, that a lack of accessibility can take. Indeed, “how healthcare workers speak with patients—or even if healthcare workers speak with patients,” as Bredlau points out, “has a bearing on whether healthcare workers fulfill their responsibility to patients” (24). She concludes with a discussion of three strategies that have proven effective in improving conversational accessibility in a healthcare context: trauma-informed care, a narrative ethics approach, and a commitment to community-based participatory research.

Section two, *The Interworld of Intensive Caring*, explores how fit and misfit emerge in caretaking relations—or, in a different register, through what Eva Feder Kittay (1999) has called “dependency work”—and how such relations are shot through with both unique difficulties and also profound beauty. In “Being Touched by Wellness: Merleau-Ponty, Nancy, and the Intensive Care Unit,” Helen Fielding explores the rich, intimate contact that can occur in the Intensive Care Unit *despite* the cold, disconnected logic by which such a space operates. Drawing on her experience with her sister, Bronzino’s 1560 painting of

Noli me Tangere, and the work of Jean-Luc Nancy as well as Merleau-Ponty, she explores the meaning of wellness in light of our finitude and the role of both love and joy therein. Ann Murphy’s “The Spirited Interworld: Caregiving and the Liminal Phenomenology of Dementia” provides a moving account of her experience caregiving for her mother with advanced Parkinsonian dementia. Pushing against the clinical norm to “play along” with the hallucinatory landscape of such dementia, Murphy explores the ethics of dementia caregiving instead as “being-with,” a practice we desperately need to cultivate collectively.

Against the Clock: Misfitting and Time names section three of this special issue. David Morris analyzes time’s “normality” as well as the dynamic relationship between norms and time in “An-Archic Time: Melting the Clock as Hypernorm of the I Can—and Philosophy.” He argues that time is not transcendental, but quasi-transcendental, arising out of what he calls *deep change*. Crippling the clock, Morris draws out the cosmological implications of our relationship to one of the most basic ways we fit and misfit: seconds, minutes, hours, days, and years. Rachel Elliott’s “Sharing Time with Misfits: We-Experience Across Bodily Difference” takes up the question of sharing time between normates and misfits, between those who fit and those who don’t. She argues that it is shared body schemes, understood as emergent, bi-directional, and flexible, that provide the ground for a “we” even across otherwise significant differences.

In section four, *Who is a Misfit? On Aesthetic Creativity and Political Vulnerability*, Rebecca Longtin’s article, “Merleau-Ponty’s Cézanne As Misfit Artist,” exposes the false dilemma of viewing Paul Cézanne’s mental illness as either the source of his creativity or an obstacle to it that he needed to overcome. In her words:

[T]rying to ascribe a simple causal connection between Cézanne’s embodied particularities and his works of art is reductive and deflates the meaning we might find in them. Yet these embodied particularities are still significant for understanding the meaning of Cézanne’s art. It is not an either/or problem. (101)

Longtin argues that Cézanne’s work exhibits what she terms a “misfit optics” that is truer to our lived perspective than Cartesian optics, which privileges an ideal linear perspective, or a “God’s eye view,” that ultimately inhibits and restricts artistic creativity (102). In “The Politics of Vulnerability and the School for Peace: Insights from Butler, Merleau-Ponty, and Family Systems Theory,” Laura McMahan offers a critical phenomenology of human vulnerability, not as a trait we individually possess, but as an intercorporeal relation between two (or more) entities whose actions directly affect one another, as we see when one person, group, or nation’s attempts to eschew their own vulnerability produces increased vulnerability for others. McMahan draws upon family systems theory as well as Butler’s critical phenomenology to address the ethical, political, and intercorporeal implications of the heightened forms of vulnerability that have been produced since the 1948 founding of the state of Israel, including, most recently, the October 7, 2023 Hamas attack and its aftermath, Israel’s military assault on Gaza. By acknowledging “the empirical, systematic ways in which our vulnerabilities are intertwined one with the other in multigenerational, complementary, and cyclical manners that are always framed by

competing group narratives,” McMahon suggests, we can overcome the psychological rigidity of presuming that our own narrative is the only legitimate one, a perspective that inevitably does serious injustice to others (136).

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WHAT MISFITTING MAKES

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APOLOGIA

What you have here are some misfits. One might read this essay about misfits as itself a collection of misfits, attempts to fit some square pegs of content into some round holes of form. The essay here began as an academic paper that offered the critical concept of *misfits* and *misfitting*. From there, the concept expanded in response to my colleague Gail Weiss's entreaties into an eventual publication more than a decade ago in an academic journal (Garland-Thomson 2011). From there it migrated to a lecture at the bidding of my colleague Joel Reynolds at Georgetown University for a conference called "Fits and Misfits: Rethinking Disability, Debility, and the World with Merleau-Ponty." The genealogy of *misfits* arrives to you, Dear Reader, as perhaps the final version of the square peg of that in-person lecture fit here into the round hole of an open access online academic journal.

The pushings and pullings of this enterprise, the shovings and swearings of such a layered conversion, bear witness to the convergence of form and content my talk-turned-essay here reaches toward. My reach, unfortunately, may very well exceed my grasp. Invoking this hackneyed metaphor of one's reach exceeding one's grasp to signal excessive human ambition has always galled me. From the ancient didactic tales of Icarus or Pandora to the murkier lessons we now agonizingly extract from the egotism of Elon Musk or Vladimir Putin, our shared literary and philosophical tradition offers us a rich diversity of cautionary tales about the disasters that follow the persistent hubris of pressing beyond human embodied limitation. Everyone's reach eventually exceeds their grasp.

Many people with disabilities inhabit bodies that do not fit the received tales of wisdom or pronounced truths of the ascendant majority. Such is the case with me, your wise author who accompanies you through this essay. My reach, quite literally, exceeds my grasp. This situation is no case of hubris but rather one of disability. I get no moral benefit of hubris undone from the embodied experience of my perpetually graspless underreach. Let me explain. The human variation we now call congenital disability endowed me with what I

have come to call unusual, asymmetrical arms and hands. I've developed this self-description in response to the continual demand of interlocutors to know what I "have" or more rudely, "what is wrong with me." Over my many decades I have been obliged to give an account of myself, sometimes with words but more often with the visual inquisition of stares that range from sincere interest to creepy fascination, diagnostic expertise, maternal concern, and genuine human empathy (Garland-Thomson 2009). This situation unfolds out of the relationship between my embodied experience of the world and the normative rhetorical and material demands of the reach-exceeding-grasp cultural sagacity. I am perhaps, then, a phenomenological case study in the most fundamental sense: the particular form of my particular body in particular moments and places shapes my particular consciousness. In other words, my bodily experience of reaching and grasping in the world structures how I recognize, incorporate into consciousness, and act upon the received didactic narrative about the gap between an aspirational reach and its realization in the gratification of intention embodied in a successful grasp.

Like my phenomenological overreach, the misfitted jumble I offer you may seem perplexing, even incoherent. To continue the metaphor, the mess of pegs and holes comprising this essay fit together awkwardly, their clarity perhaps dim and elusive. You will find here much explication but little argument. You will also find some wonderful, compelling images available to you as links. If you spend time with print academic journals, you know that the images they present are almost always small, grainy, and unsatisfactory. In contrast, *Puncta's* digital format affords you access to the compelling images my presentation slide deck offered my in-person audiences and which are now available to you. As a scholar of literature and culture, my true reach is to open a portal to reveal an object's meaning-making work by explicating texts, images, and objects by "reading" them intently and creatively (Garland-Thomson 2015). This methodology of the literary scholar is the knowledge skill I bring to the enterprise of academic research and teaching.

What you have in this essay is a set of readings, explications of idiosyncratic objects, images, and texts drawn from my own experience and interests. To continue my embodied metaphor, I am reaching here to show you that these are instances of misfitting. My gentle assertion is that these misfits are not mistakes, violations of cosmic order, or random incoherence but are generative. These misfits, in other words, hold the potential for new meanings. What you have here then is a concatenation of misfits. Like my arms, this assemblage of words and stories strives to do my distinctive intended work in the world. And like my body in the world, this essay is an overreacher, attempting more than it can achieve, aspiring to more than it can fulfill.

Like my awkward reaching, misfits are often awkward encounters, graceless engagements between things in the material world that end in an incongruent relationship. In putting forward the critical concept of misfitting, I focused on materiality as an adjustment to the prevailing linguistic turn in social constructivist theory. As feminism did, I aimed to put some flesh on the linguistic turn in critical theory. I confess to you now that my lifetime of awkward reaches doubtlessly gave shape to the concept of misfitting. Little of the world was designed and built with my arms and hands in mind. And of course, this revelation is eventually shared by everyone over a lifetime, since the myriad misfits between body

and world come to all of us. Even though the fundamental human misfit is between flesh and world, I found suitable a perhaps more accessible metaphor to suggest the situation of misfitting. The futile attempt to fit a square peg in a round hole was my crude image to bring the dynamic material world into our focus. To consider how we might allow lives and communities to flourish for all, I proposed the situation of how human bodies engage with built material environments as a felicitous case study. What we think of as disability materializes both in experience and meaning when our body-minds encounter a misfit, when a secure and seamless relationship between embodied self and world breaks apart. To expand the image of misfitting, consider the metaphor of a wheelchair rolling up against a stair. Both scenes are vivid narratives of misfitting, easily available to the archive of human experience from which we individually and collectively take knowledge and make meanings that structure our understandings, actions, and relations to others. Such scenes and stories of misfitting, then, make up the ethical work my theoretical concept undertakes.

Misfits are situations of asymmetries in scale and shape. Round and square, large and small, intricate and gross, textured and smooth: misfits testify to the enduring hold of the immanent upon the transcendental. Nothing, it would seem, is itself a lone thing in the world; everything, it would seem, is in an awkward relationship with something else. The minute we shift our consideration from singularity to plurality, we run up against a misfit. Like my body, misfits manifest the principle of asymmetry rather than the ideal bilateral symmetry science deems to be the fundamental natural principle that organizes living things. Like my arms—or really, anybody's—in a gesture of relatedness, the two elements in relationship do not fit together with the elegant matching of the steepled hands of academic contemplation, the praying hands of supplication, or any other handed gestures of emphasis such as the tiredly repetitious side-by-side two thumbs up or the exaggerated double middle finger one often observes drivers recklessly aiming at their fellow commuters during a rush-hour backup. The virtue of asymmetry that a misfit manifests, then, is that it interrupts rather than affirms natural patterns. Misfits contradict the assumed evenness of the natural and social order.

Let me shift the concept of misfitting from what it is to what it makes, to what I have called misfitting's generative potential. Scenes of misfitting—the dynamic, lived human encounters between bodies and world—make meaning. We recognize our lived human embodied existence through the form we experience it, through making it into a story with the temporal and spatial dimensions of human experience. We observe, interpret, and know the world around us and our place in it by way of story, which is the epistemological organization of our sensory and cognitive engagement with the world. For knowledge to manifest into conscious and meaningful action, we translate raw human experience into narrative form with characters, setting, plot, and dialogue. In other words, representation structures reality, making narrative the fundamental epistemic form of human embodied experience. Making meaning from human embodied experience is what the medieval historian Caroline Walker Bynum (1999) elegantly expresses as shape (or body) carries (or structures) story (or

meaning).¹ What I am drawing from Bynum suggests that the particularity of human shape, our wondrous diversity often celebrated in human story, is most epistemologically apparent and ethically relevant when it comes into human focus through experiencing misfitting. My work converges with that of Bynum in that we are both narrative humanists, scholars who consider the meaning-making work of representation, of human-made language, images, and objects. This enterprise of story making endows the material world with coherence to make it usable for actions that reach toward human flourishing.

In the spirit of considering the ethical work of misfitting and what misfitting makes, I offer here two stories of the many instances of beneficial misfitting, of how a misfitting encounter makes a potential usable human good. One story is charming and personal and the other capacious and universal. These stories are of misfitting gain—to borrow from and allude to Deaf gain and disability gain, meaning a material situation that increases rather than reduces human flourishing.

THE ROMANCE OF NORM MATES AND MISS FITZ: A STORY OF MISFITTING GAIN

My first story shows how misfitting generates new language, how barriers to intentional human action can be remade into new paths opening toward human purpose. Misfitting, you will recall, is a materialist understanding of disability drawing from lived, situated experience in which the particularities of embodiment interact dynamically with their environment in both time and place. My misfit story begins with the primal scene—universal in some version to everyone—where our bodies encounter a machine, a man-made tool designed and marketed in today’s modern liberal capitalist social orders to make our lives better. All machines, or what we now call technologies, promise benefits that, when delivered, often at the same time impose harms. Think of atomic energy, cars, plastic, opioid medicines, and our computers. This clash of opposing substances—of organic flesh and inorganic material stuff—takes various forms over the time and place of our lives. This collision of body and world shapes our embodied selves and the journey that is our lives.

My misfitting story begins with the unusual shape of my hands and arms, a rare and distinctive form for which almost all tools are not designed. A simple implement like a spoon offers service to me; a typewriter is a mechanical nightmare. Both assume normative embodiment, movement, and pace, but a typewriter is much more demanding and less flexible than a spoon, especially an adaptive (often elegant) spoon designed to serve a wide range of hand shapes and capacities. With the ascendance of inclusive design that the disability rights movement and its accompanying regulations provided to the disabled and the disabled-in-waiting came accessible technologies of every kind designed to accommodate the widest possible range of human variation. The rigid, exclusionary machine that was a typewriter (now sentimentalized in lucrative retro forms) gave way to

¹ See Bynum’s (1999) Jefferson Lecture in the Humanities. Bynum uses the verb *carries*, rather than *structures*, in describing the relationship of stories to shapes. I have adapted her phrase by using the alliterative term *structures* rather than *carries*.

computers, more flexible and refined machines for the increasing text making demands of modern life and work. With the increased complexity of computers came the benefit of voice activated programs that liberated me from the misfit between the design of my body and the design of a keyboard-driven machine. Nevertheless, as the historian Susan Strasser (1982) has shown in her history of housework, aptly called *Never Done*, our modern liberal capitalist societies swamp us with products that both reduce and increase the demands they are created to alleviate. So even while the computer gave me more effective text input by taking my words out of my hands and putting them into my mouth, the demands for text output and manipulating this machine—which has increasingly become the center of our lives—outpaced any relief from misfitting that my dictation software program aimed toward turning into a good fit. My disability, my unfitness for the misfit between my body and my machine, thus became the cliched canary in the coal mine, warning of the inevitable escalation of misfits between bodies and machines that modern mechanized life demands of us.

Living with misfits can be isolating, even when we are surrounded by fellow humans quietly and often desperately struggling to achieve unattainable fits. Redemption from the frustrating sense of aloneness that often accompanies misfits came to me from a communal triad of disabled women engaged by necessity in the disability innovation that often emerges in inaccessible work environments. A richly elaborated communication relationship of novel workarounds and good humor evolved among two other disabled colleagues and me who use accessible technologies and communication preferences that at once complement and conflict with one another. One of us is a sign language using Deaf woman with two hands and sturdy fingers who communicates most comfortably and effectively by typing. Another of us is a blind woman who prefers spoken and haptic engagement with her computer. I prefer to speak to machines to create text communication through dictation or talk-to-text programs. In other words, for us to do our work, one of us touches her machines, another's machine talks to her, and my machine listens to me. We speak about our relationships with these machines in terms of our preferences rather than our limitations to emphasize our adaptability and resourcefulness. These machines were not made with us in mind. Each of us misfits with what our machines expect from us; yet each of us has created from that misfit both innovative ways of using machines and distinctive narrative and rhetorical forms that our embodied relationships with our machines generate. Our complex communication patterns with one another are gains, not deficits. Our misfits have made something good in the world (fig. 1).

The relationship between my computer and my body is a misfit that bonds me with my colleagues and is an occasion for creativity. Even when this misfit leaves me depleted and despairing, it simultaneously delights me with the vivid new language it provides. The inherent quirkiness of voice input, or what I prefer to call talk to text, is an enlivening poetics, a narrative creativity, and a knowledge enterprise that sterile mechanical typewriters could never extend to me or my interlocutors. One misfitting gain is a distinctive semantics of misfits between my body and my machine. This misfitting semantics emerges from the fluency I've developed over years of talking rather than typing into my computer; indeed, I am often garrulous enough to create this unintentional fresh expression in the



Figure 1. Three friends at the FDR memorial.

form of charmingly hilarious words and phrases. Talk to text technology relies on sound and prediction based on the words it has accumulated in one's personal vocabulary; it has no sense of actual meaning or any intelligence. So it makes sound-based, or homophone, errors that people who use spoken and written forms of language would never make. It's perplexingly hopeless with the small words that connect the primary meaning-making words of a language, like "by" or "an." I sent a message once, for example, intending to say that I would be "in touch by email" but my technology wrote that I would be "in touchy pie email." A fully hearing person native speaker would never make such errors, which is why they seem so novel. Deaf people, I have learned, often have no difficulty with the homonyms that plague hearing writers because they experience no conflict between the written and spoken version of words. Hearing people can laugh at ourselves via my talk to text poetics. Hasty enunciation on my part, for example, has rendered "humanities" into "you manatees." I favor the adjective "celebratory" which often gets written out as "Celebra Tori," vaguely suggesting a porn star name. The Mellon Foundation comes out regularly as "melon" or even occasionally "smelling foundation." Unintentional truths frequently

emerge, as if Freudian slips. I once sent my academic colleague an email in which I had intended to say that I would “craft a memo” about some tedious administrative issue, but my talk to text said that I would “crap a memo,” which my colleague immediately grasped as an oxymoronic accuracy about the situation.

Name crossing from talk to text is particularly creative. For example, my dictation often translates the name of the famous neurologist writer Oliver Sacks into “all of her socks.” The academic theorist Jasbir Puar becomes “jazz beer poo are.” The phenomenologist Merleau-Ponty becomes “Merlot Panty.” My professional dictation program Dragon NaturallySpeaking refuses obscenity, but the sassy Siri button on my phone swears like a sailor. Reminding my children in a text message to remember their grandfather on Veterans Day, I intended to note that he had fought in three wars, but my dictated iPhone message told them he had “fucked in three wars.” Technologies have cursing profiles that are apparently tailored to intended audiences. I had to use my one good finger to type out “fucked” in this document in which I am otherwise fluent. My Microsoft Word spellchecker, however, tells me that what I just keyed in “may be offensive to my reader.”

From this misfit semantics, my composition practice has generated not only engaging words and phrases but an entire Romance, a fanciful story elaborated among misfits about misfits. One day while quickly dictating a message, I spoke in a single sentence two words from the critical vocabulary I have contributed to disability studies. The words are “normates” and “misfits.” Instead of these critical terms that my dictation program might have recognized, onto the screen flew the characters of my new story: Norm Mates and Miss Fritz (I promise that I did not make this up!). A great name for a rock band perhaps, but soon enough I began to imagine these two misfits as a romantic couple. From this narrative prompt, I was reminded of the clever romance plot anthropologist Emily Martin (1991) offers in her classic analysis of the metaphor’s meaning making work, “The Egg and Sperm: How Science Has Constructed a Romance Based on Stereotypical Male-Female Roles.” Martin’s capacious rhetorical scrutiny shows us how culture shapes the ways biological scientists describe the natural world and human body.

Gender stereotypes, Martin shows, hide within scientific language considered objective and possessing truth value. The scientific explanation draws on a traditional cultural gender binary that characterizes men and women not just as opposites but as differentially valued antitheses. In other words, our supposedly objective knowledge system of science draws on patriarchal narratives of men and women to interpret human bodies and their functioning. According to what Martin identifies as the Romance narrative that science imposes on human reproduction, men produce enormous quantities of resourceful, energetic, and determined sperm, whereas women are born with a limited cache of rapidly deteriorating, listless, and static eggs that impassively await a date for the prom. Syntax, semantics, and grammar carry out the romance narrative to give cultural meaning to scientific description (Martin 1991, 489). In this story as science, passive verb constructions instruct us that the feminized egg “is swept” along her way in the process of fertilization, whereas active verb constructions “propel” or “deliver” sperm to “penetrate” their target. Even the egg’s active verb is passive: she “drifts.” Adjectives do similar gendering work. Sperms are “strong” and “streamlined,” propelled by “whiplash-like motion and strong lurches.” In contrast, eggs

sit primly and wait to be asked to the prom. We are firmly in the story of Disney's 1950s *Cinderella* and *Sleeping Beauty*, told in the rhetoric of medical education and scientific fact. What we see in this romance is fantasy shaping fact. This scientific fairytale of the romance between the sperm and the egg reveals that the cultural work of metaphor does the ideological work of verifying supposed objective scientific truth. In what Joseph E. Davis calls medical sciences' rhetorical production of "all pathology all the time," we see the narrative effect of switching from one rhetoric to another, of the meaning-making function of translating a scientific truth into a familiar romance story (2021, 1).

My point here is that the experience of misfitting makes things in the world. My misfit semantics generated an epistemological concatenation (the first try of this admittedly pretentious and obscure word produced "content an nation") on the meaning-making work of language. Norm Mates and Miss Fitz emerge as characters from my embodied misfit with technology; these novel characters invoke the possibility of an ironic romance; the meaning-making work of the misfit between science and patriarchy emerges; the cultural work of a romance plot beckons to me.

Thrilled with my misfit romance, I offered it up to my Deaf and my blind colleagues. Perhaps, I suggested, we could do something generative, even charming, with the auditory cousins Norm Mates and Miss Fitz. Touching the microphone icon lurking at ready in the lower right-hand corner of all my iPhone screens, I spoke the names into a text message to my blind friend so she could tell us what her screen reader voiced. The two of us—one blind and one sighted—engage in an ongoing experiment to see how the words and the emojis that I speak or touch into the text messages to her translate when she hears them via the phone application she uses to render texts into auditory language. I will often speak an emoji description, for example "bread emoji," then send it to see if the intended meaning in the communication chain from me to her through our technology reaches her intact. I will send a text or an emoji, and then call her on the phone to ask what her screen reader actually said to her. "Misfits" and "normates" are homophones, auditory cousins hard to tell apart. So, we were curious to know how my phone talk to text would translate into my blind friend's text to talk technology. To our amazement, when she spoke the semantic cousins into her phone, they translated perfectly into "normates" and "misfits" written out onto my screen.

Intrigued by the narrative potential of this unlikely couple, my Deaf friend spun out a new literary romance from the misfits, Miss Fritz and Norm Mate (fig 2). A *Jane Eyre* riff emerged as a video from my Deaf friend, which is an appropriate technology for deaf people who consider themselves "people of the eye" instead of being reliant on the ear for communication. In my friend's video, Miss Fritz becomes a principled governess fed up with the aristocratic buffoon Mr. Norm Mates, who is forever galloping across the heath astride his stallion with his flowing cape and spurred boots rather than attending to the derelict manor house Miss Fitz must manage. We generated together an archive of misfitting gain, linguistic and literary forms emerging from our literal crossing of perspectives, producing a network of what disability resourcefulness and delight offers.



Figure 2. Still image from “Miss Fritz and Norm Mate: The Love Story.” Brenda Brueggemann, Youtube, Oct. 12, 2021. https://www.youtube.com/watch?v=we_i0-BkvMc.

MISFITTING HARM

My misfit Romance is a gain because it makes a story that brings more benefit than harm, although disentangling those outcomes from any act in the world is complicated. Juxtaposing the misfit Romance of Norm Mates and Miss Fitz with the Romance of the Sperm and the Egg suggests the complexity of the work of story in the world. My story of misfitting gain should be taken as well as a cautionary tale about how representation carries out the cultural work of structuring reality that benefits or harms human communities. My misfit Romance benefits the enterprise of critical disability studies and promotes inclusive design development. Martin’s romance of the sperm and the egg reveals how the cultural work of representation can harm human communities.

In a 2020 paper about the metaphor of gene editing, I suggested that comparing microscopic surgical procedures performed on human biological matter to an everyday large-scale material process like editing text on a computer can lead us to believe that these medical procedures using the so-called tools of gene editing are much more stable, exact, and safer than they may actually be. Metaphors do the narrative work of assuring us that this biological process is a stable and predictable mechanical process, but they also shape the moral and ethical decisions we make. We need to recognize that the materiality of our human biology constitutes a constraint on our understanding. Such an acknowledgment of human phenomenological and epistemological limitation can, and perhaps should, lead us to an ethically necessary humility about the extent of human control over the consequences of medical scientific enterprises. And to honor human limitation in this way is also to honor the ethical commitment to humility enconced in the Hippocratic vow to *first, do no harm*. This first principle of medicine elevates the caution of nonmaleficence over the aspiration to beneficence (Beauchamp and Childress 2013, 149). Before we consider the benefits of our eager strides to develop and implement technologies that shape the outcomes of human lives and futures and the future persons included in our human communities, we may be wiser to carefully consider the harms.

MISFITTING GAIN

One way to characterize bioethics, the field to which I contribute now, is that this knowledge-making enterprise considers what harms and benefits come from actions taken in the name of medical science and healthcare. Although misfitting might cause harm, as with any action in the world, it has the potential for benefit as well, often benefit intertwined with harm. The experience of misfitting can teach us about being human. Misfitting forces us to recognize the fundamental distinction between flesh and world, and with it both the limits and possibilities of the human capacity to act and to be. The fundamental misfit all humans share is that we emerge from the sheltering womb into a material world that is indifferent to our individual existence. This is the tradition of humility expressed in the rhetorical forms of both *Vanitas* and *Memento Mori*. Misfitting witnesses a truth of human existence: our bodies are contingent and evanescent. One misfitting gain might be the human potential to develop an epistemological nobility born of this sobering phenomenological recognition of contingency, fragility, and the limits of what we take to be freedom and autonomy. We have a received and widely available narrative archive of humility gained from misfitting. Think of Oedipus, Icarus, or Jesus. Indeed, such cautionary tales are a predominant narrative genre in the literary archive, ranging from Aesop and Sophocles through F. Scott Fitzgerald and Gwendolyn Brooks. What I'm calling misfitting gain may also support the counterintuitive proposition I have put forward elsewhere that there may be benefit in conserving rather than eliminating the human variations we think of as disabilities, that witnessing, recognizing, and sustaining disability can be a source of human connection and virtue. As a bioethicist, I have made the case for disability as a resource to be conserved rather than a liability to be protected. Our disabilities witness the fundamental misfit between flesh and world, and

the lives we make with our disabilities witness the human capacity to endure, often with grace and compassion. Conserving rather than eliminating disability could offer the human community often unbidden opportunities for unexpected resourcefulness or flourishing that disability can present. The benefits of conserving disability are accepting people with disabilities who enter our lives as unexpected and often unwelcome gifts and valuing the inevitable growing into disability inherent in the human condition (Garland-Thomson 2012).

PIETÀS: MISFIT ICONOGRAPHIES OF CARE

My second story of misfitting gain is an application, perhaps an implementation, of the misfit knowledge I've described as a potential opportunity to witness human limitation. As I've made clear, my explication here of misfitting's generative potential draws on the methods of literary and cultural studies, of the meaning-making work of representation. I reach here to a received representational narrative—one of perhaps many misfitting case studies from the received and familiar cultural tradition of our time and place—to suggest the didactic potential of misfitting. My example here is a scene of misfitting that has great cultural authority in the Western tradition and that has been reiterated in multiple forms enough over the last centuries in the West to have become a generally recognizable story, composed in this case of an image that carries the cultural clout of the sacred.

The cultural work of representations that have didactic authority is the focus of several academic enterprises ranging from art history to semiotics, literary criticism, aesthetics, and museum studies, performance studies, and sociological inquiries such as social interactionism, among other traditions. What I offer in my concluding example of the generative potential of misfitting can only gesture to the kind of rigorous analysis these academic traditions offer.

With these caveats in place, I conclude this meditation on beneficial misfitting with the imagistic didactic cultural narrative of the story of misfitting depicted in the classical Christian sculptural tradition of the *Pietà*. Perhaps the most familiar iteration of the *Pietà* in our contemporary space and time is from the Renaissance sculptor Michelangelo Buonarroti whose 1498 marble sculpture of the Mother of God embracing her dead son, Jesus (link 1), represents one of Western tradition's central stories of human experience. This iconic choreography of lamentation from the Christian narratives of birth and death is a pictorial narrative, rather than a linguistic narrative like the ones my dictation offers.

My narrow reading here of the *Pietà* focuses on how the misfit between flesh and world I've described might be understood as generating a narrative that suggests the right ethical relations between persons. The strength of this image as a didactic narrative comes from its iteration in varying forms across time and space, in other words in the pervasive repetition, legibility, recognition, and familiarity that makes it available to be repeated in a way that strengthens whatever didactic work people intend or find in the imagistic narrative.²

² Think of the most generative reading of Walter Benjamin's (1968) *The Work of Art in the Age of Mechanical Reproduction*.

Michelangelo's *Pietà*, which I begin with here as the prototypical image in our cultural moment, presents a story told through the representation of two bodies, one living and one dead, in an embrace of bodily care. Drawn from the Christian narrative of human form made sacred through divine authority, this narrative scene presents the human condition rendered in great complexity. The mother here embraces her lifeless son to whom she gave life. The mother in this domestic scene holds her grown child on her lap. What I call this choreography of care parallels the many Madonna and child representations so familiar to the Western eye. These choreographies of care, ranging from the Madonna mother figure presenting the infant Christ to her nursing the child, all follow a choreography in which the viewer is asked to witness an act of maternal care that appears as an embrace of bodily care and comfort.

The familiar Madonna and Child images represent the bodily care necessary to sustain life at its beginning. The *Pietà*, in all its iterations, represents the bodily care necessary at the very end-of-life, not to sustain a new life, but rather to honor and properly care for the human body in its final pose of mortality. Both the Madonna and Child and the *Pietà* arrange the two figures in a holding embrace choreographed or arranged according to the size of the child and the adult that the maternal figure embraces.

In the *Pietà*, the maternal caretaking figure presents the body of the grown child as an offering to us to witness human mortality. She both displays and enacts the fleshly connection, this bodily entanglement between the two of them. Theirs is a duet, a *pas de deux*, an embrace, a holding that lightly refers to other iconic sculpture ranging from classical Greek mythology to the romantic era's Rodin's *Kiss*.

The *Pietà* is a story told through an image. The story is a secular choreography of care made sacred through the Christian narrative. Divine authority sacralizes the traditional work of body care assigned to women throughout culture. The didactic work of this story of human enfleshment, of mortality quite literally laid out before us, is a form of memento mori calling not to our terror of death but rather the tenderness of this embrace of bodily caregiving and care receiving. This sacred duet honors human mortality by presenting life and death as entanglements between and among humans. Our lives and our deaths are not solely our own but rather intimately entangled with others.

The story the *Pietà* presents is what we might call a cultural meme, reiterated in multiple variations from around the thirteenth century to our present moment. The perpetual presence of this scene of holding in the cultural imagination as an act of bodily care generates fresh versions that retell the story, reworking the characters, costumes, setting, and props for decades. But in every iteration, from every culture or time, the fundamental choreography of a caretaker holding the recipient of care remains the essence of the representation and the didactic core of these cultural representations. Each representation gains numinal resonance from its resemblance to the familiar icon of Michelangelo's and other *Pietàs*. These new iterations of the *Pietà* offer viewers a new meaning, a lesson to be read, through the allusion to the Christian *Pietà* so familiar in the received cultural imagination.

I offer here four contemporary *Pietàs* whose didactic work honors the human entanglements of care work. Although each of these *Pietàs* departs from this specific

Christian reference of the iconic *Pietàs*, they carry with them the cultural authority and the rich legacy of the Christian narrative of birth, life, death, and resurrection. The meaning-making work of *Pietàs* is to instruct their viewers in lessons about human mortality and our responsibility to care for human bodies and for one another at all stages of human life. The distinctive choreography of holding, the pose of the two entangled bodies, affirms this fundamental obligation of human attachment that enfleshment and mortality require of us.

The first *Pietà* I offer is a black-and-white photograph from 1990 of David Kirby on his deathbed, surrounded by family (link 2). This photograph carried out the didactic work of journalism in bringing awareness of the AIDS crisis to the American public. The realism of photography here adds truth value to the wrenching apart of human relationships that mortality brings. As in the duet of mother and child in Michelangelo's iconic *Pietà*, we witness the holding so fundamental to the human emotional attachment of familial love. However, the characters, setting, medium, and arrangement differ from the classic *Pietà*. The grainy black-and-white photograph suits the somber scene of senseless death that AIDS wrought on a community and a generation. The apparent hospital setting suggests the ascendance of medicine as both the explanatory template for human life characteristic of modernity, but also the withdrawal of redemption as a consolation for human suffering. Here, we witness raw grief and helplessness with no suggestion of consolation as the father holds his dying son while the mother holds her mourning daughter. Despite the despair of this AIDS *Pietà*, soft allusion to the redemptive sacred embrace of the traditional *Pietà* inflects the choreography of this scene of bodily care and attachment.

The second reiterative image of the familiar pose of the *Pietà* is the realistic sculptural representation by the Australian artist Sam Jinks (2007, link 3). This *Pietà* does its meaning-making work through a much closer allusion to the classic *Pietà*, inviting a focused didactic reading by substituting an ordinary twenty-first-century man contemplating a very old genderless figure cradled in his lap who we might read as the parent rather than the child of the caretaker figure. This arresting gender and age reversal of the traditional *Pietà*'s mother and child challenges the traditional obligation of women as caregivers for all humanity. The impassive and faintly perplexed expression on the man's face as well as his everyman demeanor, comments perhaps on the depletion of emotional attachment that masculine individualism has enforced upon many contemporary men.

The third *Pietà* also closely follows the bodily choreography of the Christian *Pietà* of lamenting mother and dead child, vividly bringing that scene to the violence of racism in America (link 4). In Tylonn Sawyer's 2018 American Gods series, we witness the *Pietà* as a choreography of protest rather than consolation. Here, a Black mother holds a dead Black boy in the characteristic hooded sweatshirt of Black American youth so vulnerable to violence. The American flag in the background both moves the scene of lament from the local to the national and witnesses the betrayal of promised equality Black people have endured. This *Pietà* of racial injustice re-choreographs the modestly lowered eyes of the traditional Christian Madonna into the fierce gaze of this mother as she glares with fierce accusation straight out at the witnesses, suggesting sorrow laced with rage at the layered wrongs this choreography recounts.

The final image I offer re-choreographs and recasts the *Pietà*'s iconic scene of human mortality in which the living behold the dead. In Robert Andy Coombs' (2019) color photograph "Cuddle on Couch" from the series Cripfag (link 5), we witness instead a tender reclining embrace between two nude men on a tattered sofa, each a living lover, one black and one white, one patient and one caregiver. The pose alludes not just to the classic *Pietà* but the sexualized repose of Manet's (mayonnaise) Olympia. The conventional erotica of this pose gives way as the unexpected juxtaposition of Coomb's G-tube protruding from his fleshly abdomen in this domestic scene overtakes our attention from the becalmed and modest penis, creating a visual dissonance that opens the opportunity for new meanings. This *Pietà* queers the traditional sacred dyad of bodily care between mother and child by rearranging the embrace and recasting maternal attachment as queer filial attachment. This domestic *Pietà* introduces the medicalized body as a subject of care, a merger of erotic and clinical attachment. This story of queer disabled domesticity renarrates what we have learned to think of as medical equipment and sexual attachment, inviting us to witness anew the human condition of fleshly finitude.

REPAIRING MISFITS

Mortality is the fundamental misfit of the human condition. Our urge to live is the essence of our bodily vitality, and our knowledge that we will die haunts that very vitality. The juxtaposition of these epistemological and phenomenological facts is the square peg in the round hole of human existence. Not only do we all die, but we know that we ourselves and everyone we care about will die, and we know that we must witness many of those deaths as well as our own. We also know that flesh is evanescent while world endures. Consequently, flesh emplaced in world is a relationship of misfitting. The *Pietà*'s sacred choreography might then be understood as both a witnessing of mortality as misfit and at the same time a repair of that misfit in the form of the fitting between two bodies that we witness in *Pietà* scene of holding.

These sacred choreographies of caregiving witness human mortality but at the same time offer us a narrative suggesting that attentive human care might ameliorate the sundering of relationships mortality insists upon. They answer Eve Kosofsky Sedgwick's call for generative and generous rather than negative, or paranoid, narratives to counter what Paul Ricoeur calls "the hermeneutics of suspicion" (Sedgwick 2003, 4). The emblematic act of embrace can be seen as what Sedgwick terms a reparative narrative. The metaphor of repair here suggests a stitching up of the world that gestures toward women's traditional handicrafts and the principles of cultural feminism and care ethics that recuperate and revalue the work of women that patriarchy has denigrated.

The imagistic duets of these *Pietàs* advance a Sedgwickian narrative that works toward repairing through mutually attentive caregiving and caretaking the necessarily broken world that human limitation and fragility bequeathed to us through our lived, embodied existence. Such a narrative of human embodiment these *Pietàs* offer overtakes the representation of sorrow and lamentation that such scenes of mortality depict.

In *Rethinking Repair*, Stephen J. Jackson lays out “broken world thinking” (2014, 221). The proper response to a broken world, Jackson suggests, is repair, what he defines as

the subtle acts of care by which order and meaning in complex sociotechnical systems are maintained and transformed, human value is preserved and extended, and the complicated world of fitting into the varied circumstances of organizations, systems, and lives is accomplished. (222)

The entangled embrace of the *Pietà*s suggests, then, that the relationship of misfitting that is human mortality might be repaired, perhaps rehabilitated, through attentive care work between and among human bodies. What is repaired is not the body itself but the relational connections amongst mortal humans. The care work the *Pietà* depicts is not a cure but rather a mutual stewardship of one another that the embrace of holding emblemizes (Piepzna-Samarasinha and Lakshmi 2018). If misfits are the manifestation of a broken world, the human relational gesture of holding might then be an act of repair, a transformation of misfitting into an altogether human fit.

The didactic work of these *Pietà*s is to elevate care as sustaining attentiveness that repairs bodies in the sense of abiding with mortal flesh. This attitude stands in contradistinction to the traditional aims of allopathic medicine but conforms more to the philosophy and practice of palliative care. These images both honor and call upon an ethics of care that asserts that there is moral significance in the fundamental elements of relationships and dependencies in human life. The bioethicist Jackie Leach Scully (2008) and the philosopher Eva Feder Kittay (1999), among many others, define care work as maintaining the world of, and meeting the needs of, ourselves and others. Care ethics asserts moreover that dependency relations can and should guide public policy about human equality. The care work of maintaining human life, making families, dying, illness, disability, and death has been the work of women across all patriarchal societies throughout recorded human history.

HOLDING AS REPARATIVE AFFIRMATION

I'll gesture briefly in conclusion to these winding speculations about what misfitting makes by drawing from the twentieth-century philosopher Hannah Arendt's (1958) ambitious meditation on the human condition, which she offers her fellow humans on the heels of the massive devastation of World War II and the accompanying Holocaust that humanity had devolved toward at the optimistic pinnacle of modernity. In finding humanity's desperately needed universal commonality upon which to forge the notion of shared experience and thus solidarity, Arendt gathers together the human community based on the common condition of our natality rather than our mortality. Arendt suggests that the primary human bond of birth rather than death might unite us in the work of living together in ethical relations with one another and building human communities. Human action begins in shared natality and emerges through shared plurality in a perpetual context of uncertainty.

This human solidarity amid diversity grounded in the shared experience of being born is crucial, Arendt maintains, for us to address “the frailty of human affairs” with practices such as forgiveness and promising and to counter the contingency and hostility of the shared world into which each of us is born (1958, 188).

The diverse *Pietàs* presented here can be taken as didactic narratives representing the promise of natality—understood in the broadest sense as abiding with and sustaining human embodiment—that Arendt finds to be the essence of the human condition. The reading of the *Pietà* here offers a choreography of holding that witnesses and sacralizes our embodied relations of caregiving and caretaking at both the beginning and ending of life. The *Pietà*'s reparative narrative of natality attending to mortality is modest rather than triumphant in its aspirations and generative in its varied iterations that have extended and reinterpreted its meanings across the centuries.

Finally, Arendt (1996) offers us an exhortation in her early work that we might imagine as the call that the holding figure extends to the reclining figure of care embraced in the *Pietàs*. The gesture of support and affirmation that the *Pietà*'s choreography of holding expresses is Arendt's ethical invocation that humans might offer one another, the restrained yet revivifying call: “I want you to be” (Latin: *volo ut sis*) (301). Arendt's active sentence is a beckoning into life, the human condition that Arendt concludes is the highest good. This invocation to life, to *be*, both witnesses and responds to our inherent vulnerability, frailty, and need for others. As the theologian Inger Marie Lid suggests, Arendt's refrain calling one's fellow human to *be* revivifies the human bond through affirming shared natality and prompting action (2022, 102). This summon to *be* is to both have life and to act from the distinctiveness of one's individual being. Imaginatively supplementing the *Pietà*'s visual narrative with the beckoning call to life of “I want you to be” strengthens the didactic work proposed here that the choreography of care the *Pietà* bestows on its centuries of witnesses.

What are you to draw from the concatenation of misfits I've offered here? I intend these scenes of misfitting and the accompanying images to suggest that misfits between bodies and world, especially bodies considered disabled, which of course will eventually include all of our bodies, can generate fresh meanings and renewed understandings. The first part of my essay offers a misfit romance to show how we might cobble coherence from what might first seem incoherent, similarly to the way disabled body-minds may seem incoherent to the normals but once recognized have an integrity and wholeness of their own. The middle, briefer, part of the essay suggests that in contrast to the technology that produces my misfit romance, the rapidly developing gene editing technologies that aim to normalize us all would reduce the number of people who generate distinctive gains or benefits to persons and worlds. The concluding part of my essay universalizes what we think of as disability by casting what we take to be the exception into the universal condition of human mortality. The final meaning making images of these *Pietàs* invoke not only mortality but, perhaps more significantly, they suggest natality as the shared common human condition of simply being born, of emerging from one human body into the collective arms of the human community. Presenting the *Pietàs* through Arendt's natality offers a model of being with and understanding one another in an attitude of care and love that might perhaps mitigate the awkward asymmetries of misfitting by opening

up the recognition that we are all misfits, that this fundamental misfit between flesh and world is the human condition shared by all. The repair that misfitting calls for is attentive care and love, an attitude of welcome and openness to all body-minds, whether expected or unexpected, whether fit or misfit.

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CONVERSATIONAL ACCESSIBILITY: HEALTHCARE, COMMUNITY, AND THE ETHICS OF EVERYDAY ENCOUNTERS

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The fundamental responsibility of medicine, the clinical ethicist David Schenck writes, is to care for people's bodies when they "can no longer [do so] themselves" (1986, 49). Fulfilling this responsibility, he argues, requires acknowledging "the texture of embodiment" (43). In this article, I begin by exploring the ethical significance of this texture of embodiment for interactions between healthcare workers and patients. I then focus on trauma-informed care and narrative ethics, arguing that both practices recognize the risk healthcare workers pose to patients' life-worlds, a risk that is amplified when healthcare workers fail to acknowledge their responsibility to these life-worlds. Both practices also recognize that open conversation between healthcare workers and patients is fundamental to fulfilling this responsibility. I then draw on Maurice Merleau-Ponty's conception of human agency as embodied and interpersonal to argue that conversations with others, much like physical spaces, are places whose accessibility is not guaranteed. Finally, I examine how issues of conversational accessibility are at play in the larger context of healthcare research and how we might rethink existing practices in light of community-based participatory research.¹

I. THE TEXTURE OF EMBODIMENT

Drawing on the work of Merleau-Ponty, Schenck identifies several essential features of the texture of embodiment: the body is the "reference point" in terms of which a person's

¹ I want to note that two of the terms I am using, "healthcare workers" and "patients," are not entirely unproblematic. With respect to "healthcare workers," I want to use a word that is inclusive of all the different people whose work is connected with healthcare: doctors and nurses, of course, but also nurses' aides, home health aides, respiratory therapists, x-ray technicians, and even, as I will discuss shortly, clinic receptionists. With respect to the term "patient," I would prefer a term that better emphasized the agency of those interacting with healthcare workers like "the people healthcare workers work with," but that just gets confusing so I am going to stick with "patient."

world is lived both spatially and temporally (Schenck 1986, 44, 47); the body is “intimate” such that there is “*seldom any distinction* to be made between self and body” (45; emphasis in original); and the body is “always in communion with the world,” both through physical activity and as “inherently socially expressive” (46). A person’s body must, in other words, be understood as a lived body, as fundamentally the subject who experiences and not merely an object that is experienced. As such, a person’s body is the foundation of her identity and agency: “it is only through the body that we are present in the world, only through the body that we carry out projects in the social and physical world, only through the body that we have a self” (50). Yet even as our bodies are fundamentally constructive of our way of being-in-the-world, they are also fundamentally disruptive.

Our bodies, through illness or injury, can become obstacles to the very worlds they previously made possible; since the body “maintains our entire life-world . . . a bodily crisis becomes, inevitably, a total crisis of that world” (43). There is, Schenck writes “a tensed duality” (43) at the heart of embodiment: “the possibility, and indeed inevitability, of the alienation of our bodies from our wills, our minds, our selves, is an essential aspect of embodiment” (48). Illness and injury threaten the very foundation of our identity and agency and render us unable to address this threat ourselves: “[i]n illness, I am unable to care for that which is most ‘my own.’” (51). The relationship of patients to healthcare workers, then, is one of profound vulnerability.

Patients, in placing their bodies in the hands of healthcare workers, are also entrusting them with their life-worlds: “in this new relationship with those who are now caring for my body, people most likely in our society to be total *strangers*, I have of necessity ‘given’ to these others extensive (even total) power over my embodied life” (52; emphasis in original). Moreover, patients entrust their life-worlds to healthcare workers at moments of their lives when they have little, if any, ability to prevent or remedy any betrayal of this trust. In patients’ relationships with healthcare workers, Schenck writes, “all those issues of trust and power and honesty that are the hallmark of every human relationship take on suddenly dramatic importance” (51).

The texture of human embodiment makes even routine interactions between healthcare workers and patients ethically significant; patients’ life-worlds are at stake in these interactions, and healthcare workers’ responsibility to their patients entails responsibility to these life-worlds. To be indifferent to or dismissive of the texture of embodiment, to treat patients’ bodies as if they were merely objects, is, in a critical sense, to mistreat patients. Furthermore, the texture of embodiment means that how healthcare workers speak with patients—or even if healthcare workers speak with patients—has a bearing on whether healthcare workers fulfill their responsibility to patients. From the patient perspective, Schenck writes, when “[t]hose who care for my body speak of it as though it were a machine, perhaps even handle it that way,” this raises a question for the patient: “[c]an I trust these strangers who cannot even speak properly of this ‘object’ closest to my self?” (52). When hospitalized following complications of a heart attack, Kevin Aho writes that

experiences of strength, confidence and vitality that were so much a part of my self-interpretation before the heart attack suddenly seemed foreign . . . And the detached discourse of the health care professionals only exacerbated the experience, turning me into a passive object and stripping away any sense of agency. (Aho 2019, 195)

Healthcare workers cannot, in other words, assume that, so long as they are not performing a medical intervention, they pose no risk to patients. Any interaction between healthcare workers and patients, including their conversations, poses the risk of further diminishing patients' often already diminished sense of identity and agency.

Bioethical considerations are not, in other words, confined to crises of the kind that summon hospital ethics committees but instead permeate everyday interactions within healthcare settings, including conversations between healthcare workers and patients. Nonetheless, the ethical significance of such everyday interactions—their amelioration or intensification of disruptions to patients' life-worlds—is not usually the focus of bioethicists. Even as bioethicists have become increasingly interested, for example, in trust as a key aspect of healthcare, researchers have primarily focused on trust as an “input” in the relationship between patients and healthcare providers rather than an “outcome” (Taylor et al. 2023, S3). Furthermore, there has been little attention to the ways in which healthcare workers' interactions with patients make them more or less worthy of patients' trust. Lauren A. Taylor et al., in their introduction to the Hastings Center Report, “Time to Rebuild: Essays on Trust in Healthcare and Science,” write:

[i]n working on this special report, we have been struck by the absence of studies that attempt to define and measure trustworthiness. It seems that the research focus in health policy and health services has been disproportionately on patients and their attendant attitudes, when researchers might learn as much, or more, by studying the behaviors of institutions and providers. (2023, S6)

To better understand, then, how healthcare workers can, in light of the texture of embodiment, fulfill their responsibility to patients, I will now focus on trauma-informed care and narrative ethics.

II. THE ETHICS OF EVERYDAY ENCOUNTERS

While research suggests that over seventy percent of people worldwide have experienced trauma, including, though not limited to, physical assault, sexual abuse, and exposure to combat, many healthcare providers remain unaware of these experiences (Kessler et al. 2017). Yet trauma can alter the structure of people's experience such that they encounter routine aspects of healthcare as highly distressing. Lying down on an exam table, for example, or being alone with an unknown healthcare worker can significantly increase the anxiety of a person who has experienced trauma (Raja et al. 2015). Furthermore, people

who have experienced trauma may cope with their increased anxiety by becoming angry or aggressive. When healthcare workers do not recognize patients' behaviors as symptoms of trauma, they may demand patients' compliance or attempt to physically restrain them, and in doing so retraumatize them.

Trauma-informed care begins with an awareness of how pervasive experiences of violence and abuse are, and it aims to design and deliver services and programs in ways that support, rather than undermine, a patient's recovery from trauma. Recognizing that even routine aspects of healthcare can be experienced by patients as threatening, trauma-informed care works to acknowledge this threat at the beginning of any interaction between healthcare workers and patients. Healthcare workers can ask patients if there are specific aspects of their interaction that worry them, such as "lying back, fear of not knowing what comes next, and the possibility of pain," and talk with patients about what might make them more comfortable: "[p]atients may have general preferences, for example, leaving the door slightly ajar or sitting closer to it" (Raja et al. 2015, 218). Trauma-informed care also works to diminish this threat by, whenever possible, offering patients choices about how their interactions with healthcare workers will proceed. It offers patients choices about how they will be physically examined, for example, giving them "the option of shifting an item of clothing out of the way rather than putting on a gown . . . or sitting in a chair rather than on the examination table for a respiratory system examination" (Raja et al. 2015, 218). Furthermore, when patients react to healthcare workers in unexpected or alarming ways, trauma-informed care seeks to respond in terms of the question of "[w]hat has happened to you?" rather than that of "[w]hat is wrong with you?" (Bloom 2013, 195). Trauma-informed care tries, that is, to gain insight into the person's experience, rather than simply concluding that they are unreasonable or hostile. Recent studies by Michael Sun et al. (2022) and Gracie Himmelstein et al. (2022) attest that healthcare workers do draw such conclusions and, furthermore, are likely to do so in racially biased ways. Black people's electronic health records are more likely than White people's to include stigmatizing or negative descriptions such as "not compliant" or "agitated."

Trauma-informed care recognizes, in other words, that every encounter in a healthcare setting, however seemingly inconsequential, has ethical implications. Every interaction can amplify or ameliorate a crisis in the patient's lifeworld; every interaction can cultivate experiences of safety, trustworthiness, choice, collaboration, and empowerment, or, instead, escalate conflict and reenact traumatic events. Because anyone working in a healthcare setting may interact with someone who has experienced trauma, and because the specific situations that a person who has experienced trauma may find distressing are unpredictable, trauma-informed care requires everyone who interacts with patients to acknowledge the ethical significance of these interactions:

all staff of an organization, from the receptionist to the direct care workers to the board of directors, must understand how violence impacts the lives of the people being served, so that every interaction is consistent with the recovery process and reduces the possibility of retraumatization. (Elliott et al. 2005, 462)

Beyond trauma-informed care, the ethical dimensions of healthcare workers' everyday encounters with patients have also been a focus of the narrative approach to biomedical ethics. While many approaches within biomedical ethics tend to focus on the questions that arise for healthcare workers, narrative ethics focuses on the questions that arise for patients and their families. As Arthur W. Frank explains:

Narrative ethics asks first what the problem might be for patients and their families, not for health care professionals and institutions. This shift in perspective does not devalue professional or institutional problems, but it does mark a need for a complementary form of ethics, proceeding from a different point of view. (2014, 16)

Furthermore, the primary focus of narrative ethics, Frank writes, is to “prevent situations from turning into cases” (16), that is, to facilitate communication between patients and healthcare workers so that full-scale ethical dilemmas, like the ones that summon hospital ethics committees and fill textbooks on biomedical ethics, do not actually arise.

Narrative ethics focuses on the power of stories for making sense of our lives and, more specifically, on how patients who have the opportunity to give an account of their lives and their experiences of illness are better able to navigate difficult healthcare decisions. When encounters between healthcare workers and patients do not enable patients to give such accounts, both patients and healthcare workers suffer. A patient who is, for example, facing a decision about whether they should continue a certain treatment or undergo a certain operation can, by articulating their life as a story, come to understand how they want their story to continue and what choice they should therefore make.² A patient who is instead denied such an opportunity for story-telling may remain confused and uncertain, and their health care providers may struggle to act on their behalf. Thus, the telling of and listening to such stories should, narrative ethics argues, be central to healthcare practice. Healthcare workers should not only be listening for their patients' stories but should also be creating opportunities for patients to tell these stories more fully.

The writings of Richard M. Zaner (1993), a philosopher who worked in hospitals as an ethicist, testifies to the need for narrative ethics' complementary form of ethics. Much of his time was spent talking with patients who were critically ill and with the families of these patients. As he describes it, one of his most critical tasks was facilitating conversations between healthcare workers, patients, and patients' families in which all involved could articulate their most pressing concerns and, in doing so, make sense of their situation. It was not uncommon for him to discover that patients and their families were simply being left out of conversations healthcare workers were having about patient care. This did not usually reflect any unwillingness by the healthcare workers to talk with patients and their families. Rather, occupied by the intricacies of administering tests, procedures, and

² Yet as Frank recognizes, the very experience of being ill can make it more difficult for patients to tell their stories: “[s]eriously ill people are wounded not just in body but in voice. They need to become storytellers in order to recover the voices that illness and its treatment often take away.” (1995, xx)

operations, it often did not occur to healthcare workers that they could—or should—speak with their patients about what the patients perceived as the goal of all the medical care that had been—and still might be—provided.

Yet as Zaner writes, patients want to know “whether the people who *take care of* them also care *for* them” (1993, 144; emphasis in original). When healthcare workers and their patients actually began to speak about what, for example, further medical care could actually accomplish and whether it was, in light of this, worthwhile to pursue further care, healthcare workers often discovered that the patients shared their concerns. A situation that had seemed to be leading to an intractable ethical dilemma led instead to mutual understanding and agreement.

III. CONVERSATIONAL ACCESSIBILITY

Having noticed first that everyday encounters between healthcare workers and patients, insofar as they can amplify or ameliorate a crisis in the patient’s lifeworld, have ethical implications, and second that the absence of certain kinds of conversations between healthcare workers and patients can itself be an ethical issue, I want to spend some time thinking about what enables healthcare workers and patients to have the kinds of conversations that Zaner describes and that narrative ethics strives to make standard practice: conversations in which everyone will, in fact, voice their most pressing concerns and questions. We cannot take for granted that this will always happen. There are, of course, material conditions required for such conversations to take place. Patients and their families need a place, either physical or virtual, where they can gather to talk with healthcare workers. If family members do not have access to transportation or cannot take time off from work, it may not be possible for them to gather at a hospital or skilled nursing facility, and if family members do not have access to the internet, it may not be possible to gather virtually. Also, translators may be needed to facilitate communication, and distractions must be limited to allow for serious conversations.

But even if these material conditions are met, we should not assume that such serious conversation will be possible. Natali Cvetanovska et al. note that while “patient participation in healthcare communication has been shown to improve recall and understanding, satisfaction with care, adherence to treatment and health outcomes in patients,” patients find it challenging to “ask questions and be involved in treatment planning . . . and most participation does not extend beyond answering direct questions posed by clinicians” (2023, 1). The literature on epistemic injustice offers insight into the obstacles speakers may face when they attempt to communicate with others.³ As Dotson, drawing on the work of Jennifer Hornsby, writes: “[e]very speaker needs certain kinds of reciprocity for successful linguistic exchanges . . . [T]o communicate *we all need an audience willing and capable of hearing us*” (2011, 238; emphasis in original). Yet audiences are not always willing and capable of hearing a speaker. Those with whom a person speaks may, for example,

³ See, for example, Miranda Fricker (2009), Kristie Dotson (2011), and Gaile Pohlhaus (2012).

fail to understand her intent or may fail to take her seriously, thereby silencing her. For example, a patient may encounter what Dotson (2011) identifies as “testimonial quieting”: she may speak only to find that healthcare workers fail to recognize her as a valid source of knowledge and simply dismiss what she says as unimportant.

The realities of such practices of silencing reveal that the power of speaking cannot be understood as a kind of private possession, distinct from the contexts within which and the people with whom we speak. Nonetheless, given the individualistic and rationalist understanding of agency that informs much contemporary thinking, including our thinking about health and illness, we may tend to assume that if we can speak in one situation, then, barring any physical restraint, we should be able to speak in any other situation.⁴ Understanding our actions as primarily a matter of personal responsibility, and, relatedly, understanding our bodies as objects that are—or at least should be—controlled by rational minds, is so engrained in us as to go unnoticed and unquestioned. It is, as Laura McMahon writes, “what we might call the ‘natural attitude’ of liberalism” (2020, 3).

As the work of phenomenologists like Merleau-Ponty (2012) demonstrates, this individualistic and rationalist conception of agency fails to recognize the embodied and interpersonal character of our existence. Merleau-Ponty’s discussion of the phantom limb in the *Phenomenology of Perception* makes clear that our bodies are neither merely physical objects whose interactions with other objects are devoid of all intention, nor are they merely objects of thought whose interactions with other objects are governed by conscious choice.⁵ Rather, whatever meanings our environment holds for us, whatever possibilities for action appear to us, reflect our bodies’ engagement with the world in ways that allow these meanings and possibilities to arise: “[c]onsciousness is originally not an ‘I think that,’ but rather an ‘I can’” (139). Furthermore, the specific meanings our environment holds for us also always reflect our relations with other people, including our childhood relations with others that cultivated the specific habits that undergird our adult existence. The social world, Merleau-Ponty writes, is the “permanent field or dimension of existence” (379).

Thus our freedom, Merleau-Ponty argues, is not realized in separation from the world and others but instead through our relations with them. Extending a phenomenological conception of agency to the voice, therefore, means recognizing that our voices are neither possessions nor private but instead interpersonally accomplished ways of being-in-the-world. To better understand what this means, I want to first focus on another bodily power: the power of mobility. For people with mobility devices like wheelchairs, this power may involve arm movements or even—with motorized wheelchairs—mouth movements, and for people without wheelchairs, this power may involve leg movements. Yet the power of mobility is not simply these movements; it is, more significantly, a way of making sense of the world, a way of having the world appear as it does. The power of mobility is, for example, a power of experiencing the world as accessible: of having sidewalks and streets and buildings and subway systems appear as routes rather than obstacles to where one

⁴ For a discussion of how an individualistic conception of agency informs contemporary healthcare practices and policies, see Talia Welsh (2021).

⁵ See, for example, Merleau-Ponty (2012, 78–85).

wants to go and what one wants to do. It is a power of having neighborhoods appear as welcoming rather than unwelcoming of one's projects.

Yet while we speak about a person's power of mobility, this power does not so much belong to the individual person as to the relation between a person and the world. Without surfaces that a body can, to use Merleau-Ponty's (2012) language, "gear into," or, to use psychologist James J. Gibson's (1986) term, surfaces that "afford" mobility, a person's leg movements remain mere movements and the power of mobility remains unrealized. As Gibson points out, while the surface of a lake affords walking to a water bug, it does not do so for people; people, unlike water bugs, cannot walk on water (1986, 38). Furthermore, the things with which a person interacts have largely been created by other people, and even interactions with natural things are mediated by laws and social norms. To engage in phenomenology as a critical practice is to recognize that the relations between a person and the world are always deeply informed by her social and political situation. As Perry Zurn writes, "[c]ritical phenomenology is poised to attend with unusual attention not only to the body schema, intercorporeality, and lifeworld of walkers, but also to the socio-political structures and histories that shape them and which they in turn shape" (2021, 13).⁶

What the world affords any one person is a cultural—rather than a simply natural—phenomenon, and these affordances are often not equally available to everyone. A surface that affords mobility for a person without a wheelchair, for example, is not always also a surface that affords mobility for a person with a wheelchair, and at the present moment, far more surfaces afford mobility for those without wheelchairs than for those with them; many sidewalks still do not have curb cuts, and ramps are still not as common as stairs.⁷ Thinking of the power of mobility as simply a power of an individual person does not, therefore, adequately appreciate the myriad ways in which the world has not only been designed and built by others, but has also been designed and built in ways that, while enabling to some human bodies, are also disabling to other human bodies.⁸ Indeed, insofar as racism, sexism, ableism, colonialism, and other forms of discrimination and violence continue to structure our lives, the availability of affordances for some people will often be premised on the unavailability of affordances for other people.

Thus while we may refer to a person's power of mobility, we should recognize that mobility is actually realized communally rather than individually. Each of us depends on other people designing and constructing this world in ways that enable our bodies to realize

⁶ On phenomenology as a critical practice, see also Lisa Guenther's (2021) account of critical phenomenology and Kim Q. Hall's (2021) account of crip phenomenology.

⁷ For a discussion of the kinds of obstacles that a person who uses a wheelchair may experience on a regular basis, see S. Kay Toombs (1995). Public bathrooms can be particularly disabling to those who use wheelchairs; see, for example, Jackie Velez (2023)

⁸ This idea is central to the social model of disability, which argues that disability is not inherent to individual bodies but instead results from social and political practices that discriminate against people whose bodies deviate from what society deems "normal." For a discussion of this model, see Joel Michael Reynolds (2022, 75–78).

the power of mobility.⁹ As Judith Butler, in conversation with Sunaura Taylor, states, “I’m just thinking that a walk always requires a certain kind of technique, a certain support. Nobody takes a walk without there being a technique of walking” (2009, 187).¹⁰ In other words, every person who walks down the street is receiving an accommodation, even if it is the accommodation of those who use mobility devices that is more often remarked upon than the accommodation of those who do not; the sidewalk is, for example, constructed of a material that supports the weight of human bodies, with a width and a grade that allows the passage of human bodies.

Furthermore, while I have focused on the physical objects that can support or impede mobility, other people’s responses to a person’s mobility can be as, if not more, significant sources of support or impediment. Hall (2021), drawing on the work of Rosemarie Garland-Thomson (2009), notes that those whose way of walking does not conform to ableist and cisheteronormative conceptions of bodily movement, are often stared at—or even glared at—by others. Their own “limping-swaggering” walk, Hall writes, not uncommonly encounters

a stranger’s stare that first goes to my foot or leg and then takes in the rest of me . . . In limping along, I confess that it’s difficult, if not impossible, for me to know whether the stare is directed at my limp or my gender non-conforming, swaggering occupation of space, but from a crip phenomenological perspective, both converge to shape how I am enmeshed in and navigate the world and thus my embodied self. (25)

Toombs (1995), who has multiple sclerosis, describes how others’ perception of her can have a direct impact on her mobility:

I remember the occasion of receiving my doctoral degree. I could still walk a few steps if supported, and I could climb stairs with assistance. The day before the ceremony, a colleague and I went over to the auditorium to practice climbing the few steps onto the stage where I was to be seated. I negotiated the steps without too much difficulty. However, on the following day—in the concrete experience of about sixteen thousand eyes watching me—I was completely unable to lift my right leg. It was not just that I was conscious of the fact that my body moved in a peculiar fashion. Rather, I was temporarily paralyzed. (19)

Toombs draws attention to how critical our being-with-others is to our way of being-in-the-world. Others’ perception of our movement as graceful or awkward, confident or tentative can affect how—or even if—we will continue to move.

⁹ For a discussion of how the world is designed and built in ways that enable certain bodies while also disabling other bodies, see Sara Hendren (2020).

¹⁰ For further discussion of this passage, see Hall (2021, 17–18).

Having recognized that the power of mobility is not a private possession, let us now turn back to the voice. First, it is important to recognize that just as not everyone can walk, not everyone can speak. Nonetheless, just as people who cannot walk can still have powers of mobility, people who cannot speak can still have voices.¹¹ Still, the very situations that afford a voice for speakers may not do so for non-speakers. In their podcast interview with Sharlene Cooney, a non-verbal visual artist, Rachel Gray and Debbie Ratcliffe (2022) note that listeners “will not hear Sharlene talk, but you will hear her voice.” Cooney communicates by pointing to images and words in an album and through gestures, drawings, and writing. “Art,” Cooney states in the interview, “is not just beautiful for me . . . Art is a way for me to give my opinion, put something beautiful into the world, advocate, express feelings, and communicate with people.” For the podcast, Cooney worked with both her long-time support worker, Linda, who read and interpreted the words and images Cooney pointed to, and with a storyteller, Kim Kilpatrick, who spoke Cooney’s words. Thus, while a spontaneous meeting, for example, generally affords a voice to speakers, it may very well not afford a voice to non-speakers. Without significant advance planning, Cooney’s podcast interview would not have been possible. Dave Finch and Barry Prizant (2023), the hosts of the podcast “Uniquely Human,” note that when they interviewed Elizabeth Bonker, a non-speaker who uses an augmentative and assistive communication device, they submitted their questions “ahead of time due to the length of time it takes to formulate and type responses. This is a common procedure when non-speakers are asked to respond to interview questions.” Likewise, situations that leave limited time for conversation may afford a voice to speakers but not to non-speakers who, like Bonker, need time to type out their responses.¹²

Thus, just as we can recognize that movements of legs or wheelchairs do not alone constitute mobility, so too can we recognize that the movements of mouths, tongues, and throats and the resulting sounds, or the movements of fingers on a keyboard and the resulting words, do not alone constitute a voice. The voice, like mobility, should be understood as a way of making sense of the world; it is the appearing of a world through these movements, rather than the appearing of these movements themselves, that is definitive of these powers. In much the same way that walking enables us to experience certain things in the world as accessible—as supporting, rather than hindering, the projects to which we are committed—so, too, does speaking or communicating with an augmentative and assistive communication device. Yet while for mobility these things that appear as accessible include sidewalks and buildings, for the voice, these “things” are conversations. The voice is a power of experiencing conversations as accessible, of experiencing others’ voices as constructively developing, rather than undermining, whatever we are trying to say. Moreover, having a voice, like being mobile, requires traction. While for mobility

¹¹ See also Eva Feder Kittay’s (2019, 7) discussion of speaking for her daughter, who cannot speak for herself.

¹² In a conversation between Bonker and Judy Heumann, Heuman (2023) noted that “when I’m talking with you and other friends who use communication devices, there are these long pauses when I’m listening. And I’m wondering when you are also speaking with others who are also using communication devices, what do you think about when you’re waiting for an answer?” Bonker replied, “I try to clear my mind. Those of us who don’t speak tend to be careful listeners.”

this traction is directly with things and indirectly with the people who design and create these things, with the voice, this traction is directly with other people.¹³ Unless other people recognize the sounds or movements a person makes as a form of communication, then understand what is being communicated, and then also experience what is being communicated as making demands upon them—as calling for conversation—a person’s voice remains unrealized. In other words, a person’s voice is also a power that does not belong so much to an individual person as to relations between people.

In addition, therefore, to offering rich descriptions of people’s experiences of built and natural spaces and noticing how what they experience always reflects their relations with others, we can also offer similarly rich descriptions of people’s experiences of conversation. By considering conversations as part of the existential landscape we are always navigating—as sites, or to use Edward S. Casey’s (2013) term, “places,” that are continuous with or an aspect of the places that are ours or others’ homes, workplaces, commutes, places of worship, seats of power, and so forth—we can begin to notice dimensions of our experiences of conversation that we might not otherwise notice and to make sense of differences between our experiences that we might otherwise have difficulty making sense of. We can notice, for example, that we can feel at home in some conversations more than in others, and that we can navigate some kinds of conversation more adeptly than others.

As trauma-informed care shifts healthcare workers’ response to patients from a question of “what is wrong with you?” to one of “what happened to you?,” so can we shift the response to a person who remains quiet during a conversation from a question of “why didn’t you speak up?” to one of “was this conversation accessible for you?” Moreover, when people do not experience conversations as accessible, this should inspire reflection on the ways in which the others engaged in the conversation may have contributed to its inaccessibility. In other words, the question of whether the conversation was accessible should focus as much, if not more, attention on those who were participating than on those who were not.¹⁴

By thinking about encounters between doctors and patients in terms of conversational accessibility, we can notice if the material conditions for conversations between patients, their families, and healthcare workers are present: the transportation, time off from work, translators, and so forth that enable everyone to, so to speak, get to the borders of conversations about what matters most to them. But we can also notice whether, as they talk with each other, avenues of discussion actually appear for them to speak about what matters most. Do patients, for example, who start down such an avenue get any traction from the healthcare workers with whom they are speaking? Do healthcare workers recognize, in effect, where their patients are trying to go and respond in ways that make this possible?

¹³ John L. Austin (1975) refers to such traction as “uptake.” For a discussion of uptake in relation to issues of trust and trustworthiness, see Nancy Nyquist Potter (2002, 147–79).

¹⁴ I want to thank Martina Ferrari for suggesting this line of thinking to me. In other words, we should take care that asking the question “was this conversation accessible for you” not, in effect, force the person who has been quiet into a conversation that continues to be inaccessible, thereby exacerbating the problem rather than beginning to remedy it.

IV. COMMUNITY

Having focused on conversations between individual healthcare workers and patients, I now want to think about issues of conversational accessibility with respect to a broader topic in healthcare: public health research. Nina Wallerstein and Bonnie Duran argue that in the past few decades, a new “participatory” paradigm of scientific research has been emerging (2008, 26). This new paradigm challenges an older paradigm in which researchers with academic credentials such as university professors and healthcare professionals unilaterally decide what the “problem” is that they will be studying, how they will study it, how the results of the study will be disseminated, and, often, how these results will impact healthcare practice and policy.¹⁵ In this older paradigm, the community members whom the researchers study may be referred to as research participants, but their participation in the research process itself is quite limited. In other words, the subjectivity of these “research subjects”—their own capacity for asking questions and offering answers, their own capacity for knowledge—is recognized in only a very minimal sense. Community members may, for example, sign a consent form and engage in the services or interventions the university researchers make available, but they are not expected or invited to contribute to the design of the study. They are not consulted about what they experience as the primary challenges to their health or what kind of responses they think will best address these challenges. Moreover, they likely never learn what conclusions researchers draw from the study and likely never play a part in shaping healthcare practice and policy in light of these conclusions. This unilateral relationship between researchers and communities is particularly stark in what is now referred to pejoratively as “helicopter” or “parachute” research in which a researcher flies in and takes information from a community “without leaving anything in return” (2008, 31).¹⁶

The field of bioethics emerged in part as a response to the inhumane treatment of research subjects exhibited by Nazi doctors in Germany. The trial of a group of these doctors for war crimes in 1946 and 1947, often referred to as the Nuremberg Doctors’ trial, “drew unprecedented attention from the public, from the medical and scientific professions, and from public authorities. That attention marks a new beginning in the moral traditions of medicine, a beginning that would become bioethics” (Jonsen 1998, 134).¹⁷ Yet one might wonder, in addition to preventing research subjects’ objectification, if it is also possible to

¹⁵ Linda Tuhiwai Smith (2021) notes that with respect to research involving Indigenous communities, “many researchers, even those with the best of intentions, frame their research in ways that assume the locus of a particular research problem lies with the Indigenous individual or community rather than with other social or structural issues.” One result of this is that “[f]or many Indigenous communities research itself is taken to mean ‘problem’; the word research is believed to be, quite literally, the continued construction of Indigenous peoples as the problem” (106).

¹⁶ For a discussion of “parachute” research with respect to research on the Zika virus, see David L. Heymann et al. (2016). See also *The Lancet Global Health* (2018).

¹⁷ The judges’ verdict in this trial articulated principles for permissible research involving humans, now often referred to as the Nuremberg Code, which were influential in the development of practices and policies, including consent forms and institutional review boards, to ensure that research subjects are not treated as mere objects.

promote research subjects' subjectivity and their own capacities for knowing. This question has been central to the development of community-based participatory research (CBPR).

In contrast to the older paradigm, CBPR conceives of public health research as a collaboration between researchers and communities. CBPR “invests community members in the processes and products of research” (Mullany et al. 2012, 505). The theoretical foundations for CBPR include the work of the Brazilian educator and philosopher Paulo Freire (1995). In the *Pedagogy of the Oppressed*, Freire argues that education, beyond teaching particular topics—geometry, grammar, and biology, for example—also teaches us how to be a person. Some forms of education teach us to be passive and obedient, while others teach us to be active and questioning. In other words, some forms promote our agency while others undermine it. Freire refers to the former model of education as the “banking” model and to the latter as the “problem-posing” model. The banking model conceives of teachers as alone possessing knowledge that they then deposit into their students, and thus conceives of the relationship between teacher and student as one of domination and subordination. Educational systems that adopt a banking model, Freire argues, reinforce existing systems of social, political, and economic oppression. The problem-posing model conceives of both students and teachers as knowers, and thus conceives of the relationship between teacher and student as a collaborative process of mutual learning. Problem-posing education, Freire argues, is fundamentally liberating, and educational systems that adopt this model enable all participants to recognize oppressive economic, social, and political structures and to transform them in ways that more fully realize human freedom.

Rather than assuming that university researchers have all the knowledge about the communities they study while the communities themselves have none, CBPR recognizes community members as knowledgeable about both the problems they face and about the resources that can be brought to bear on these problems. Researchers who use a CBPR approach partner with community organizations and community members—often referred to as “stakeholders”—to identify the community’s most pressing problems. Discussions between university researchers and community members can significantly redefine university researchers’ understanding both of a community’s problems and of the possibilities for addressing these problems.¹⁸ Community members then work with university researchers to create and implement a research project that reflects their collaborative definition of a key problem and their collective agreement about a desirable response to this problem. Together, community members and university researchers collect and interpret data, present findings, and perhaps most importantly, put these findings into practice in the community through further transformation of existing programs and services. By engaging with community members as active participants in the research process, in effect engaging with them as fellow researchers, CBPR projects aim to dismantle, rather than reproduce and reinforce, oppressive social and political conditions, including racism and colonialism, that may have previously defined a community’s interactions with educational, healthcare, government, and other institutions.

¹⁸ For discussion of how community members can shape university researchers’ conception of the issues to be addressed by their research and how they will address these issues, see Britta Mullany et al. (2012) and Darren Ranco et al. (2018).

Any kind of research can take a CBPR approach, yet CBPR is increasingly recognized as essential to research projects that involve under-resourced, marginalized, and oppressed communities who, though often the focus of research projects, have rarely had their values and priorities reflected in these projects.¹⁹ Mullany et al. (2012), for example, describe how their team of public health researchers from Johns Hopkins University partnered with several Indigenous communities to design and implement a research project focused on reducing behavioral health disparities for members of Indigenous nations in the southwest United States. The project began with collaborative discussions between the university researchers and community members about the healthcare challenges their community experienced and how these challenges might be best addressed. Community members identified teen mothers and their children as most vulnerable to behavioral health disparities, identified a family-based approach to promoting effective parenting as a preferred strategy to address them, and proposed that services be delivered to community members in their homes to reduce the stigma associated with receiving services in public places. To overcome barriers to accessing services, community members also proposed that services be delivered by local paraprofessionals to overcome language and cultural barriers. These discussions led to the creation of the Family Spirit program in which local paraprofessionals visited teen mothers at their homes forty-three times over the course of about two years to deliver a series of lessons about parenting skills, maternal drug abuse prevention, and maternal life skills. Results from the study of this program suggested that these home visits were effective at reducing behavioral health disparities for both the teen mothers and their children, and similar studies are now being conducted elsewhere.

In inviting community members into university researchers' conversations—or, perhaps more accurately, in making an invitation into community members' conversations a condition of university researchers' projects—CBPR projects like the Family Spirit program give community members access to conversations in which voicing their concerns enables them to have a say about what kind of healthcare services exist within their communities and about the policies and practices of these services. Furthermore, CBPR creates opportunities for conversations whose implicit lesson is one of collaboration rather than one of domination and submission. CBPR thus contributes to community well-being not only by ensuring that the healthcare programs and services provided in that community answer to it but also by increasing community members' capacity for self-advocacy.

Thinking back, then, to the kinds of conversations I discussed earlier between healthcare workers and patients, we can now ask what these conversations may implicitly be teaching all involved. Do the conversations between healthcare workers and patients teach patients to voice their concerns and teach healthcare workers to listen for these concerns? Or do these conversations instead teach patients to keep quiet and healthcare workers to continue depositing knowledge? That is, we can ask whether a conversation, in addition to itself being accessible or inaccessible, also contributes to or undermines patients' capacity for experiencing future conversations with healthcare workers as accessible. In other words, the discussion of CBPR enables us to notice another aspect of conversational accessibility.

¹⁹ On the increased interest in CBPR in public health contexts, see, for example, Meredith Minkler et al. (2003) and Mullany et al. (2012).

Not only is the power of speaking a power of a person in relation to the world, it is a power of a person whose habits are integral to this relation. The habits a person has with respect to speaking, like the habits a person has with respect to other activities such as walking, reflect their past engagements with the world and with others. We can now appreciate, therefore, that what is at stake in patients' interactions with healthcare workers is not only the amelioration or exacerbation of the present crises in their lifeworlds but their very ability to speak with healthcare workers and others about such crises in the future. A person's experience of conversational accessibility within one conversation has implications for their experience of the conversational accessibility of future conversations.

Practices like CBPR ask us to rethink much of what we take for granted about how healthcare research is conducted and how healthcare services are provided. Given the complexity of the systems within which such research is conducted and such services are provided—systems that can include hospitals, skilled nursing centers, county, state, and federal social services programs, non-profit agencies, and many more—imagining alternatives to these systems is not easy. Yet CBPR projects remind us that the systems of policies, practices, programs, and services we find ourselves implicated in are not givens to which we must submit but instead reflections of human choice. We cannot choose that they immediately be replaced by different systems, but we can choose to align ourselves with people, programs, and institutions that recognize the inherent freedom—and the attendant ethical responsibilities—of our human situation and work to realize this freedom more fully for all.

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BEING TOUCHED BY WELLNESS: MERLEAU-PONTY, NANCY AND THE INTENSIVE CARE UNIT

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My thoughts often return to Bronzino's painting of *Noli me tangere* (1560) that hangs in the Louvre (fig. 1). When I first saw it, I was reading Jean-Luc Nancy's book ([2003] 2008) of the same name in which he dwells on various interpretations of this gospel theme where Jesus of Nazareth, having risen from the tomb, meets Mary Magdalene and says to her, "do not touch me." Nancy meditates on what this phrase might mean within the context of the secular world of painting. Of all the *Noli me tangere* paintings, this one particularly attracts me. There is so much love and desire communicated between the two bodies—Jesus's and Mary's—in their gazes, in the way they hold their bodies, particularly their hands; it is a dance of attraction and distancing, of action and passivity. Jesus's body spirals both toward and away from Mary Magdalene's, while her arms are open, ready to embrace him, at once kneeling, and turning around him in the vortex of the dance his words initiate. With the vibrant colours magnified by the sheer size of the painting, their dance evokes sorrow and longing, but also tenderness.

Perhaps it is this dance that draws me back to this painting now when I am



Figure 1. Bronzino, Angelo di Cosimo. *Christ appearing as a Gardener to Mary Magdalene (Noli me Tangere)*, 1560/61. Oil on canvas, 289cm x 194cm. Louvre, Paris, France. Photo © Photo Josse/ Bridgeman Images.

thinking through my experience of being in a hospital's Intensive Care Unit (ICU) with my ill sister, whom it seems fitting to call by her middle name, Mary, when I am thinking about what it means to be well, particularly in a constrained situation. In Bronzino's rendering, Jesus clearly withdraws from Mary's touch, his body flexes backwards as he does. Of course, movement in a painting is not movement from place to place. A painting is objectively still. But paintings like Bronzino's show us movement in stillness: the movement of animating and gathering, and the movement of being moved (Merleau-Ponty 2012, 243).

This painting and Nancy's reflections will help inform my meditation on what it means to be well. What I learned in the three and a half weeks I spent with my sister in the ICU is that we are always already in a "stance before death," and the ICU lays that bare (Nancy [2003] 2008, [33] 18). There is nothing else but this stance. There is not just the living and the dying; there is living that is a stance before death. A stance can be understood as a posture, a way of standing. But it can also be a comportment, a way of holding oneself in relation to other beings.¹ You don't have to stand to take a stance. A stance also implies a kind of movement; it can be a movement of stillness and receptivity, but it can also be one of aggression and obstruction. Wellness is, in fact, a certain stance before death. The stance that welcomes wellness recognizes the interconnectivity of all life, of all beings. It is a relating connectivity that does not subsume or oppress. To come to these insights, I draw on Nancy's meditations on touch and Maurice Merleau-Ponty's phenomenological approach to movement.

What is at stake in this stance of wellness is how we touch and are touched by others. What is required is a touch that is relational and not oppressive. Perhaps those European painters were fascinated by the *noli me tangere* scene at the beginning of the modern era because they were also contemplating another kind of contact with alterity. Perhaps within the structure of colonial expropriation and exploitation some artists, like Bronzino, were able to explore alternative ways of relating within the given structures available to them as painters, ones that preserve difference. Perhaps Bronzino's painting moves me because the touching in his painting is a relation of contact without coincidence, like love.

It was contact without coincidence I experienced in the ICU. "Do not touch me." For the first three weeks my sister spent there she was in isolation as she struggled to overcome a respiratory syncytial virus (RSV) infection contracted in the hospital while being treated for non-Hodgkin lymphoma. Entering the room meant donning mask, gown, and gloves. Bronzino's painting reminds me of this time: Jesus withdrawing from touching might mean "don't touch me, for it is I who touch you' . . . 'and this touch is such that it holds you at a distance [écart]" (Nancy [2003] 2008, [60] 35–36). I wanted to touch my sister but was prevented from doing so. I was touched. I was moved by my sister's suffering; she moved me. But it was not a physical touching I needed—though I thought so at the time. What I did not realize then is that she was already touching me.

¹ "Stance" is translated from "*une tenue*" with its root of *tenir*, to hold. "*Se tenir*" is translated as "to hold oneself" ([2003] 2008, [33] 18). But, as the translators note, it could also be translated as "to hold each other" (2008, 111).

The ICU presents a strange paradox. It is a place of healing in an environment stripped of what constitutes each patient's living existence, of the meaningful context of their lives. It purports to support life but is a healing space closed to some bodies.² It comes out of a colonial system that employs a disembodied and ideological perspective, a stance that is fixed (Wynter 1991, 253). In this view there is only one right way to understand the world. Sylvia Wynter identifies the exemplary hold or stance toward reality as the "idea that Columbus discovered America" (1991, 253). How, she asks, could this idea have ruled with such tenacity and longevity in both academia as well as "folk perception." How could our "hold" on "the reality in which we participate," our stance before the world, be so governed by concepts derived from norms shaped by one fixed perspective on colonial history? Humans are both biological and creative beings, capable of providing diverse ways of understanding the world. Wynter suggests we create new holds, holds that begin with embodied being (1995, 12).

Embodied being allows for creative and new ways of relating to the world; it provides us with multiple and dynamic perspectives. Unlike established concepts and ideas, bodies are always in motion. Even the most "elementary" movement is still an expression of the body (Merleau-Ponty [2011] 2020, [148] 107). Take breathing for example. Just as it takes place within us without us—we cannot control our breathing—we might still be able to modulate it. Our inner diaphragm is the "norm or privileged position" of our breathing that precedes modulation ([2011] 2020, [143] 103). Similarly, before we respond to "stimuli," we must acknowledge "a sort of inner diaphragm," one that shapes how we move into the world through our "reflexes and perceptions," one that governs "the scope of our life" and our possibilities (Merleau-Ponty 2012, 81). Changing how we respond in certain situations requires thoughtful creativity to perceptual situations. Merleau-Ponty, like Wynter, reminds us that humans are cultural and biological; the two are inextricably intertwined (Merleau-Ponty 2012, 174). Movement joins the "sensible world" and the ways we make sense of it ([2011] 2020, [149] 107).

In Bronzino's painting, the intersection of creativity and sensing in the *noli me tangere* scene is reconfigured. Though the painting gives this scene to us visually, it is not vision that is at work here: it is listening and touch. Mary Magdalene is touched by what Jesus says, and not by what she sees. Even though Jesus is withdrawing from his earthly life, this light that shines on his body and face, and on Mary Magdalene's face, arm, leg, and foot, draws the viewer's gaze to their embodied being that nevertheless cannot be reduced to the visible. Mary's body is turned toward Jesus. Her eye, illuminated, gazes at him, whereas her ear is in shadow. But she does not see him for she assumes he is dead; she sees only a gardener. She knows him only by his voice when he says her name (Nancy [2003] 2008, [53] 30). Similarly, in an ICU, individual embodied beings, illuminated by Western medical science, are seen only as patients. Given the norms of the Western medical caregiving system, it is difficult for hospital caregivers to see the individuals lying in beds. The stance before patients provided by the ICU makes it difficult for caregivers to see the norms that precede their perception. Indeed, they need the norms to function in this system.

² See Marshall et al. (2017) for a discussion of the "global discrepancies in critical care capacity."

What is needed is a creative response, an embodied response that allows for perceiving differently. When one looks at patients in the ICU out of the context of their lives, dressed alike in hospital gowns, they appear only as patients. What changes when caregivers diverge from the given normative stance and become more open to perceiving—a perceiving that allows for being touched—a perceiving that does not belong to the coloniality of which the Western medical system is a part? Although the *noli me tangere* paintings also belong to coloniality, a few of them give us some clues as to how we can perceive outside that system. They show us how to perceive passively, to become open to new meanings. Just as caregivers are part of the system, so too are these paintings; they were painted as colonialism was coming into full swing.³ Indeed, the economic prosperity that supported European artistic endeavors was largely due to the colonial expansion that the paintings in turn indirectly supported. But some of the paintings, like Bronzino's, also veer from this stance in the truths they provide. Nancy observes that in some, hands do “come to touch” ([2003] 2008, [57] 33). He assumes the “ambiguity is intentional” and that some kind of contact has taken place, whether spiritual or earthly. But this contact is not about presence, about one body physically touching another. It is rather, “in the emptying out of presence that the light shines;” while the physical bodies are there, the contact happens elsewhere ([58] 34, [45] 26).⁴

It is these alternate ways of making contact that are covered over by coloniality. Wynter suggests that we need to be creative in the ways we come to know about coloniality, that is, the “contemporary global order of reality” (2000, 59). There are different ways of knowing: empirically verifiable knowledge, and knowledge governed by categories, but the two are, nonetheless, intertwined. Similarly, both compliance and resistance are shaped by the same norms (1995, 12). Katherine McKittrick reminds us how Jimi Hendrix was able to creatively improvise only because he was constantly practicing guitar (2015, 157). With his music, Hendrix drew “attention to the governing musical codes” that support what Wynter calls the “overrepresentation of Man,” the limiting of what it is to be human to one “ethnaclass” (2003, 260). Creative improvisation can work from within these codes to expose these generative categories for what they are (McKittrick 2015, 157). It is this

³ As part of its own violent history, Bronzino's painting was seized from a church in Florence, Italy by Napoleon's army in 1812 (*Lowre* 2023).

⁴ Dolleen Tisawii'ashii Manning describes this relation between the finite and the infinite in terms of Anishinaabe “*Mnidoo-Worldling*.” The infinite is never where we perceive it to be. Successful spearfishing (fig. 2) requires not aiming at where the fish appears to be, because it is already somewhere else. The finite is one impoverished articulation of an infinite relationality. Assuming that the finite is all that there is means a failed thrust; it means going hungry. The drawing “assembles the overlapping contour of infinity as expansion seen through the reflection of finitude's recoiling contraction into signification” (2017, 155). As she explains further, “this sketch does not represent spearfishing in itself. Instead, it articulates our thoroughgoing permeation with *mnidoo*, as seen through routine acts—that is, without recognizing it in an obvious way. The arrow depicts the direction of the thrust . . . This diagram pronounces how a *mnidoo* structure of correspondence and discord (or division/difference) is enmeshed without paradox when their variant dimensions are taken together as a fluctuating co-responsiveness” (175). *Mnidoo-worlding* is an “encrusted exchange between ‘animacy, ‘inanimacy,’ and immateriality . . . [that] interpenetrates and fluctuates in cascading patterns akin to the murmuration of starlings” (158). This relation between the infinite and the finite resonates with Nancy's observation it is “in the emptying out of presence that the light shines.”



Figure 2. Dolleen Tisawii'ashii Manning, Spearfishing. Courtesy the artist. Manning, 2017, 154.

combination of “structure and ungoverned musical possibilities [that] draws attention to the simultaneity of physiological, neurological, and creative labor implicit to [Hendrix’s] work” (McKittrick 2015, 159). For Wynter, ideas are assumed as unmoving norms when humans forget they are “*artistically creating*” subjects who can also create new truths from within the given structures (1991, 253; emphasis in original). Although we cannot escape these norms, we can still shift them.

Shifting norms is what Eli Clare addresses in disability studies. He describes the normative stance as the ideology of cure. For Clare (2017), cure is grounded in the belief that “damage” is located in individuals, as though each body-mind has its own ecosystem rather than being part of the larger structures or systems, as we know to be the case. Cure is also based in the belief that an ill or disabled person can be returned to a former state which is deemed superior (2017, 15). But cure is not wellness. I certainly had to wonder about the supposed cure for my sister’s non-Hodgkin’s lymphoma. The extraordinary technology behind this cure did not protect her from contracting an infection through the air she breathed. I felt as though we were living Michel Foucault’s description of modern biopower “to *foster* life or *disallow* it to the point of death,” where some lives are made to live and others, seen as worthless, are allowed to die or worse (1980, 138; emphasis in original). As Robyn Maynard, in her letters to Leanne Betasamosake Simpson, writes, “isn’t this a grave of sorts for all of us, when some must die or live in deprivation in death’s proximity so that others may live in an excess of luxury” (2022, 249)? “There is no *wellness* here . . .

Only more corpses” (Simpson 2022, 249; emphasis in original). I wanted my sister to live but could not help but question the expensive resources that went into trying to keep a middle-class white woman in a Western culture alive when in other parts of the world, as well as in North America, people of color and Indigenous people die from lack of clean drinking water, access to basic health care, low-cost malaria vaccines, etc.⁵

This colonial stance before biopower, that distinguishes between those made to live and those let to die, is also a particular stance before death. Inclusion is offered to some, but inclusion to a world that does not does not uphold wellness for all, where the structures stay firmly in place, is not a solution. But, as Maynard reminds us, we too rarely recognize wellness, let alone choose it. And when she says “we” she means not only those with privilege who work to exclude, but also those “who have little to gain from this status quo” (2022, 244). Still, as Maynard suggests, “there is a knowledge in us that runs deeper” (244–45). It is a knowledge of what it means to be well, and it is not the definition of wellness operative in the ICU. On the one hand there are Indigenous cultures that continue to flourish despite lack of “resources,” and not without suffering inflicted by the deprivation and violence of coloniality. On the other hand, there is the ICU, focused on keeping people from dying, that has enormous resources directed its way. To be clear, I am grateful to all the caregivers who attended my sister in the ICU, and that there is allopathic medicine available for treating symptoms and disease. As Maynard was writing, fires were burning across California sending smoke across the continent. As I write now, forests in Québec and Northern Ontario are burning uncontrollably, sending smoke plumes down through eastern Canada and the U.S. Some days it is hard to breathe. We desperately need firefighters, but firefighters, like ICU healthcare workers, are necessarily not concerned with wellness; they put out fires. Putting out fires does not create worlds.

* * *

The patients in an ICU are, for the most part, unable to move. They cannot engage their embodied being in an oriented and experiential world. Movement is, for the most part, on the side of the caregivers; good caregiving requires being attentive to the slightest gestures, and anticipating the needs of those who receive care. Daily goal forms, care structures etc. are important, but ultimately, they cannot replace or work without the perceptual attention of caregivers who cannot rely on oral communication with the patient. A physician who attended my sister maintained she could not communicate because she could neither speak nor move. But he was wrong. She could move. She communicated with the slightest of facial gestures, or with complete stillness or a steely glare. As with an artwork, meaning was communicated otherwise than by words. We just had to move into the relational dance with her greatly altered body schema, to perceive with and for her; the body schema shifts to accommodate changes according to its own sedimented history of encountering the

⁵ See for example Leyland Cecco (2021) for a discussion of First Nations communities that don’t have access to potable water or adequate medical care in Canada, and Paul J. Kim (2019) for a discussion of how the social determinants of health affect Indigenous peoples in Canada.

world (Merleau-Ponty [2011] 2020, [157] 116). I know I am pushing Merleau-Ponty's understanding of the body schema here, but the essence of my sister persisted. As I wrote at the time, "her body is so tiny, so delicate, so vulnerable . . . but I feel her essence . . . because it still shines through." In this moment, as she is leaving me, that I feel love and joy at their purest, that I understand *noli me tangere*, do not touch me. My sister touches me but not with her hand. In this moment I glimpse what wellness means.

Wellness begins with recognizing the limits that allow for living, limits that come out of our interconnectedness. In the ICU love guides my perception: I hear my "own ear listening." I see my "eye looking, even at that which opens it and that which is eclipsed in this opening" (Nancy [2003] 2008, [19] 10). What I perceive teaches me how to perceive. To see I must run my eyes over the scene; I cock my head to hear more clearly, and my hand explores or caresses surfaces. Merleau-Ponty calls the movement inherent to perception its "light" ([2011] 2020, [125] 85). From the perspective of the caregivers, my sister was unable to move. But she taught me how to perceive her. I perceived her otherwise. In paying attention to how I perceived and the norms that shaped my perception, it was possible to diverge⁶ from them. Perceptual norms such as those that guide caregivers in the ICU, norms that do not take into account the reciprocity and interconnectedness of all existence, are in the background shaping how caregivers perceive, which is why it is so hard to bring these norms to appearance. Bringing these norms to appearance allows for the possibility of perceiving otherwise. If we follow the lines of perceptual reflection they radiate in all directions. They undergird cognition even when it imposes categories and concepts since even categories and concepts are initially derived from lived existence. Multiple perspectives are provided by the particularity of our experiential bodies; we each "bring sensory and cultural fields" with us ([170] 127).

These sensory and cultural fields interconnect with one another both within bodies and without. Maynard begins with the most basic of movements, the respiratory cilia that move the layer of mucus in the lungs. As she describes from the videos she has seen, "where the cilia are magnified and their movements slowed down, they appear almost sentient as they gently pulse backward and forward. Millions of tiny parts working together with what can only be described as graceful movements" (Maynard and Simpson 2022, 250). Cilia inspires her to think of ways of living together collectively without basing the "livingness" of some on the death of others (250). All parts of the body must support the others for there to be wellness. Just as the body is a collective effort towards survival and flourishing, so too must we work together to support the wellness of all humans. But we must do this from the particularity of our own communities.

Wellness then must be rethought in terms of our interconnectedness. The linear passage of time from birth to death is suspended in the ICU. But this suspension opens new possibilities for what can be: possibilities that were previously unimaginable but were nonetheless always already there. We can see this waiting for new possibilities in Robin D.G. Kelley's (2022) "An Afterwor(l)d" to Maynard and Simpson's correspondence where she turns to the story of the "Ghost Dance" to discuss the hope for wellness in the Lakota version of a prophecy, as a stance before death. According to the prophecy:

⁶ Diverge is from "divergence" translated from "*écart*" in the text.

A Northern Paiute spiritual leader named Wovoka . . . predicted the imminent rising of Native ancestors to cleanse the land of whites and restore balance, Wellness, and Indigenous sovereignty. He and his followers performed what became known as the Ghost Dance to help prepare for the coming world. We know what happened next: President Benjamin Harrison dispatched the Seventh Cavalry to Wounded Knee, South Dakota, in 1890 where they killed Lakota spiritual leader Sitting Bull and massacred some three hundred unarmed members of his nation including women and children. (Kelley 2022, 265)

There are different ways of reading this event. For U.S. colonizers, this story marked and still marks the on-going U.S. expansion across the continent after first contact, whereas for Indigenous peoples the Ghost Dance is about the future (266). Maynard recognizes that the Nation State was built to exclude both Black and Indigenous bodies. But such exclusions do not lead to wellness since all existence is interconnected. Simpson addresses this interconnectedness in her description of water: “the cycle of water is global, and it connects us to all of life on planet Earth. She reminds us that Indigenous peoples understand the interconnectedness of bodies, land, and water. Nishnaabeg know the creeks, rivers, streams, and lakes in [their] territory as the lifeblood of the earth,” which is why various Indigenous communities have responsibility for caring for the water on their land (258–59). Indigenous communities rely on one another to take care of their respective responsibilities. Water cycles through all breathing bodies connecting us with one another as we breathe each other’s breath: “What happens outside my body, also happens inside my body” (260). But wellness also extends beyond Simpson’s body to other bodies: “I want to build societies where we take care of the land and the waters and live in a way that promotes more life . . . Where we literally change the air, and it saves the planet” (Maynard and Simpson 2022, 199). Water, *nibi*, in Ojibwe language, connects it all.

Stories like Kelley’s are given in words to be read or heard, but artists give the parables to be seen. Just as the “history or legend of Jesus of Nazareth” is given to us in parables, paintings reveal the possibilities for finding new, even divergent meanings (Nancy [2003] 2008, [7] 3).⁷ They rely on making sense beginning with perception, which is different than beginning with the cognitive linguistic region of existence as stories do.⁸ According to Nancy, the *noli me tangere* scene provided in the Gospel of John is about seeing itself as the “participation of sight in the visible and, in turn, the participation of the visible in the invisible” ([2003] 2008, [15] 7). Looking at a painting requires making sense of what is

⁷ “*Parable* descends from the Greek *parabolē*, ‘a comparison, analogy,’ from *paraballein*, ‘to compare,’ from the prefix *para-*, ‘beside,’ plus *ballein*, ‘to throw.’ The sense of comparing, or throwing an idea beside another, is at the heart of the word. When you hear a parable, you’re meant to use the comparison to learn how to act—the fox’s ‘sour grapes’ are compared to your own downgrading of the thing you cannot have” (<https://www.vocabulary.com/dictionary/parable#:~:text=A%20parable%20is%20a%20short,recorded%20in%20the%20four%20gospels>).

⁸ In his reading of Merleau-Ponty, Samuel B. Mallin (1996) distinguishes four regions of existence: perceptual, motile, affective, and cognitive-linguistic. Of course, they all intertwine with one another, but in different situations one might come more to the fore. In our age it is generally the cognitive-linguistic that reigns (275).

there; it is a relational practice. As well, artworks can also bring to appearance that which is not so obviously visible to sight. *Noli me tangere* is also about hearing and touch. An artwork that attracts or repels us solicits our attention. Passion has the power to bring into appearance. The question for us is how to shift our passions, what solicits our attention, what we want to bring to appearance, and how we make sense of it. The parables reveal our freedom to create our own meanings (Nancy 2008, 86). Paintings capture this freedom, and they do so by arresting our gaze. As “initiator of every kind of sense: sensible, sensory, or sensual,” sensing is both passive and passionate. To see, hear or touch the sense of the parable one must have eyes to see, ears to hear or a body to touch. To be clear, Nancy is not talking literally about functioning bodily organs that can see, hear, or touch, but rather about the chiasm of understanding that is both active and passive. We are responsible for our own perceiving. When he writes that one must know where to look, where to listen, where to touch, he means one must be open to being touched by the infinite. He is clear that “this is not a religious mystery, it is rather the condition of receptivity itself, of sensibility and of sense in general” ([2003] 2008, [13] 6). One must be open to receiving this sense that is one’s passion.

To the extent that we are in touch with what we perceive, “we are not in touch with it” because in perceiving something, the background which supports its appearance recedes.⁹ To the extent we allow what is in the background to recede—we give it no thought—“we are in touch” with what we perceive (Merleau-Ponty [2011] 2020, [51] 15). This openness to perception takes time to cultivate; it requires settling into the specificities of each new patient and their ways of being, communicating, and suffering.¹⁰ Usually, only friends and family who sit with a patient have the time to do this work. Nonetheless, amongst the many caregivers who attended my sister, I did experience a few who took the time to become attuned to her subtle way of being. Achieving effective communication is a challenge in caregiving settings (Shafipour et al. 2014, 235). One study found that implementing a daily goals form in ICUs indicated a shift from “provider-centric” care to a clearer plan for communicating with patients, families, and other caregivers. But it is still a plan provided in advance. They also found that “the structure of the form varies widely among hospitals” and that ongoing modifications to the form were important to meet specific cultures and their needs (Pronovost et al. 2003, 74). A successful form, they found, was one that was flexible and adaptable. The problem with working with a rigid form, structure or idea is that, as Merleau-Ponty reminds us, it is imposed on a situation; it does not work with the network of relations such as can be found in the ICU that includes patients, family members, caregivers, and illness. Even with forms adapted to the cultural specificities of medical units, the form necessarily assumes a kind of situational standard, that ICU patients are unable to communicate—that the problem lies with the patient who is often unable to speak due to intubation (being placed on mechanical ventilation), or being unconscious, sleeping or hallucinating; they are often weak and may have lost

⁹ See Alia Al-Saji (2009) for a discussion of how what shapes racializing vision falls into the background.

¹⁰ Samantha Sii Siaw Zhen, Corrienne McCulloch and David Swann (2015) found that patients’ “key needs” include addressing discomfort related to the ventilator, bed or breathing, emotional needs, trust building with healthcare staff, and the need for more information.

muscle function. My sister certainly experienced all these states in her time in the ICU. Nonetheless, even as she weakened, when conscious, she could communicate, though I had to pay very careful attention: raised eyebrows meant no. I became attuned to those subtle fluctuations of her facial expressions and the slightest movements she made.

My attending to her was also a waiting, a waiting for her resurrection, for her return to life. “Resurrection” is a “raising or uprising” (Nancy [2003] 2008, [33] 18). In French, the word *ressusciter* translates as either to resurrect or to resuscitate. In the ICU my sister is alive but already on her way to death, sustained artificially through life support. She is prevented from dying, which is not the same as living. In the ICU they sometimes work miracles. They bring those who are dead back to life. They resuscitate them. But this is not the same as resurrection. As Nancy points out, “to say ‘I am dead’ one would have to be ‘resurrected,’” both impossible statements ([35] 19). In the biblical sense, having faith in resurrection “is not to believe that a corpse” can be brought back to life; it is rather to hold oneself in a certain stance “before death” ([33] 17–18). In the ICU, where my sister is “neither dead nor living,” I hold myself in a “stance” before death; “there is quite simply only a *present*” ([33–36] 18–19; emphasis in original). I cannot plan for a future. Without planning, all distractions slip away. The present expands and becomes everything: past and future. Existence itself is stripped down to what really counts, and what is left is a fullness that expands. But my present does not coincide with my sister’s. She lives another temporal existence I cannot access. It is instead an arising of her within me. She does not so much resurrect me as resurrect “for me.” She is resurrected within my “dead self” ([33] 19). The “‘emptiness’ of the tomb . . . reveals that this emptiness is really the emptying out of presence.” What I thought was presence, the temporal intertwining of past, present and future, is instead the fullness of the present in its emptiness. The brilliance of the resurrection is the *écarter*, the divergence or pushing away of the “outstretched hand.” It is “the same gap [*écart*] that one dares not touch, since it is the gap that touches us to the quick” ([30] 16). But this does not mean there should be no hope, or no joy; it’s not the resurrection of a life that came before that is sought. It is the passion of existence itself. Death does not coincide with itself any more than does life ([36] 19). Instead, it reveals how we never coincided with life to begin with. What presences in death is the continual disappearance of the loved one ([31] 16). It is the searing *gap* of the touch, then, the drawing apart, not the coincidence that moves us. While the corpse remains, the dead one has already departed, is gone, yet they are resurrected, have a new life within us, those who loved them. It is love that brings me to myself, for ultimately, the gap that is love cannot be collapsed.

The love that belongs to wellness begins with love of the self. Maynard (2022) shows us how, for her, love of self comes out of questioning colonial logic. As we know, she is inspired to support her own life by seeing videos of respiratory cilia that “under normal conditions” allow us to “breathe clearly.” These “tiny, tentacle-like structures, one thousand times smaller than a human hair . . . cover our respiratory tract” (242). The “complexity and fragility” of the cilia remind her that she is embodied, and she too must take care of herself which means for her not smoking: “Because of course I am a product not only of my chosen political community. I am also, to some extent, a product of my society, and I live in a society that has committed itself to evading wellness at any cost” (243). As

Maynard points out, we accept that wellness does not govern our world. Those “whose needs are already met” refuse wellness to those who still need it (Maynard 244). Learning from the insights provided by her own embodied being that seeks wellness, provides her with a place to begin. It is a matter of wellness for everyone that so many communities do not have proper access to safe drinking water. It is about the interconnections among land, water, and bodies, but also among communities. Wellness is about interconnectedness. With wellness, resurrection is not just a stance before death; it is living.

Perhaps recognizing this interconnectedness provides a potential ground for wellness in the ICU. Maynard begins with the gap of perceptual meaning making—the passion that directs perception, the overlappings and mixings that mean there is no coincidence with what is perceived. A night nurse expressed anger to me as I sat with my sister: “You know she will die—hoping won’t make her live.” But one does not need hope or whatever it is that propels one to keep on doing what one is doing to support life. Simpson writes in her letter to Maynard,

we both know hope is a luxury; my ancestors have taught me that. My people got up and worked really hard all day with or without hope. My ancestors didn’t need hope to build resistance, to build Nishnaabeg life and imaginings beyond regulation . . . The absence of hope is a beautiful catalyst. (2022, 257)

As she points out, there are other emotions, such as “stubbornness, rage, resentment, . . . and despair” as well as “joy, love, . . . truth, . . . respect and reciprocity” that motivate (257). Pessimism and optimism are only two of the rich emotions we are able to experience. There is also guilt. Sitting with my sister in the ICU I had many little tasks that contributed to my insertion in that world, fetching another blanket from the warming closet, moistening my sister’s mouth, consulting with the physiotherapist, the respiratory therapist, the physicians, and nurses. I nonetheless felt incapable—inadequate to the task—because the task of living was not mine to accomplish. The being of the patient is not toward the world; it can nonetheless be complete, even or perhaps precisely because this towardness inherent to living is shut down. I wrote at the time:

I sit here at my sister’s bedside in the ICU. She is hooked up to a ventilator, to a tube that enters her stomach, a catheter, and other tubes that go into venal lines on her chest and arms. She can barely move, and she can’t speak. And yet, I have never been so aware of the subtlety of a moving body, a body that moves.

At the center of the reaching out for love is the *écart*, translated in Nancy’s ([2003] 2008) text as “distance,” but elsewhere variously as divergence, spreading, gap, or chiasm. In drawing near, we sense the distance that is at the heart of love, that is the truth of love, or love as truth ([60] 37). It is in that gap that love is sensed. My sister did not need to be able to physically move; our relationship is a movement that bears meaning in the gap between us. I am told my sister must strengthen her muscles to allow her to breathe

again. After more than three weeks on a ventilator, breathing muscles weaken (El-Khatib and Bou-Khalil 2008). I rarely attend to my own breathing. My sister’s body was learning how to breathe again with now damaged and weakened lungs—a creative endeavor—an improvised dance with technology as aid. I became aware of my own breathing in a new way. We start my sister with short intervals off the machine, fifteen minutes at a time. For Merleau-Ponty, the embodied subject expresses itself through movement; but in moving, it simultaneously transforms consciousness ([2011] 2020, [159] 117). Even breathing, the first independent achievement of the newborn, the primary movement of the body, transforms consciousness. Movement already contains consciousness, and consciousness can only direct a body that already knows how to move into a situation and to take it up ([159–160] 117–118). Moving and being conscious are both the same, and not the same. If there is some slippage amongst the Marys—Mary-Magdalene, Jesus’s mother, my sister, and even my mother and grandmothers who also bore that name—that is as it should be because the gap held open by the hyphen is not stable. There are interpenetrations, and mixings, overlappings, and encroachments that ultimately destroy the binary, without collapsing all difference (Nancy 2008, 64–65). But it is precisely because patients in the ICU are so often intubated or unconscious, and unable to talk, that the touching that can never be realized comes to the fore. Nancy concludes that “love and truth touch by pushing away” ([2003] 2008, [60] 37).

Leanne Simpson writes how living as she is with the driving need to analyze how ongoing coloniality destroys wellness—by instigating climate catastrophe, differential access to health care, economic insecurity, and land dispossession—she nonetheless resists her urgent need to lecture her daughter. During their nightly runs her daughter teaches her not “to crush her joy . . . Each night Minowewebeneshiinh pulls me out of myself and insists I remember that running through inky bruises seeking light from the moon and beside someone you love is one of the best parts of this life” (Maynard and Simpson 2022, 53). My sister was never merely bare life attached to a life support machine. Even as I was aware of the perversity of her situation—of her body having lived beyond its own capacity to live, there was still the capacity for extraordinary joy. In our time together in the ICU my sister taught me to find joy where I least expected. She taught me that joy cannot be planned, but it can astonish. I learned that sometimes we are so focused on the tasks, on what needs to be done, on the future, that is, on the cure, that we forget to just be, the immense joy that can be found in that moment of living even when it is, objectively speaking, a prelude to dying.

When life is stripped of all tasks, the things that need doing, the things that can get in the way, that is, the “I can” with its emphasis on ability and accomplishment, all that remains—all that can be communicated—is love. Doing tasks of any kind, praxis that is, is a kind of agency that comes with a sense of control however tenuous. But praxis does not open us up to alterity with all its attendant vulnerabilities in the way that love does. Love, like faith, cannot be accomplished. This is perhaps what Bronzino’s *Noli me tangere* is telling us with this dance. Though hands are usually associated with tasks, these hands do not take hold. They do not take a stance before death because they belong to the resurrected: “These are hands ready to be joined but already disjoined and distant, like the shadow and

the light, hands that exchange greetings mixed with desires . . . We are certain that he will not take hold of her, that he will not even take her hands in his” (Nancy [2003] 2008, [56–57] 32). This is the parable of Jesus’s life, gathered in this one scene of the prohibition to touch. There is nothing for Mary Magdalene to do in that moment but experience Jesus’s love for her, and hers for him. In that moment, she cannot “do” anything but experience that love. Nothing else matters but the joy it brings with it. This joy belongs to wellness.

Sitting with my sister over time was like a dance where shifts in her being transmuted into subtle shifts in my own. It was not all suffering. Wondrously, I could also feel the joy of love, stripped bare of words, tasks, responsibilities, and sibling rivalries; it was just that—love. These feelings are noncausal. They come from body-minds; there’s no disentangling. I am there to support my sister in her bid to be well, but she supports me—she raises me up in myself—she resurrects in me. My sister was never near to me in the sense I thought. Love has this passivity at its heart—it cannot be accomplished—it is a gift that does not coincide with the one loved. The “expression *the raising of the body* [la levée du corps],” which in French means “funeral” or literally the transporting of the body, also means, for Nancy, that the living body is the center of our existence, even as it can never be present to us, even as it intermingles with other bodies, even as, or rather, because it holds a stance before death ([2003] 2008, 2, [36] 19).¹¹ The raising of her body in my body exposes our interconnectedness and noncoincidence; it points toward what it means to be well.

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¹¹ Italics are in the original text. The translation is provided in the original text without italics.

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THE SPIRITED INTERWORLD: CAREGIVING AND THE LIMINAL PHENOMENOLOGY OF DEMENTIA¹

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I. KINDRED SPIRITS

In the later stages of my mother's decline from Parkinson's disease, she would occasionally look at me across the room, smile shyly, and ask me if we were alone. There was vulnerability in her asking. She was aware of her dementia diagnosis and was tracking her own cognitive decline to the extent that she could, which meant that she was contending not only with the cognitive distortions that dementia necessarily brings, but also with fear and embarrassment that made her reluctant to communicate with others about her experience. As a part-time caregiver to my mother during the last years of her life, I knew that it took courage for mom to ask me if we were alone, and I knew why she was asking.

In my view, there was seldom anyone in the room save for my mother, myself, and a sleeping cat. Mom's perceptual reality, however, was different. As her Parkinson's disease progressed, my mother developed dementia with both visual and auditory hallucinations, clinically referred to as Parkinsonian psychosis, which affects about forty percent of those with Parkinson's in the later stages of disease progression.² Protracted visual and acoustic

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² The numbers vary widely, in part because not all symptoms of Parkinsonian psychosis are reported. Parkinson's is a degenerative neurological disease, and Parkinsonian psychosis is best understood as a hybrid neuro-psychiatric condition wherein mental health symptoms are caused by neurological

hallucinations were common during the last year of her life.³ At times, the hallucinations were of people she knew: me, my brother, my late father, her siblings, parents, friends, and acquaintances. At other times, the hallucinations were complete strangers. Not all the hallucinations were human; a menagerie of animals often kept her company.⁴ Whether they were foreign or familiar, mom referred to the hallucinations as “the spirits” and interacted with them freely. Across the arc of her illness, the spirits were for the most part a banal and even benevolent presence. She became attached to them. If I suggested we go out for a walk, reluctant to part with their company, she might become alarmed at the thought of leaving them behind. Once, on the way to the doctor, she started talking to one of the spirits, who (unbeknownst to me) was apparently tagging along in the back seat of the car. Often she would speak or emote in a way that made it clear that she was interacting with spirits who remained imperceptible to me. When I would tuck her into bed at night, she would occasionally look up at me and smile. “Thank you all very much,” she said more than once, even though, in my view, I was the only other person in the room.

Mom’s life began to unfold to a soundtrack that was inaudible to me. She would occasionally ask me to turn off the radio when the radio was not on. I would see her tapping her foot and ask her what music she heard. “We love this tune,” she’d answer with me never quite knowing who this “we” was. Sometimes she was unable to hear me above the din of the spirit-crowd; she was often distracted by perceptions that I could neither discern nor name. From my perspective, it seemed that my mother and the spirits were in cahoots. She might become frustrated when she asked something of them and they wouldn’t oblige. For instance, she complained that the spirits left the lights on all night, or turned the television volume up too high, and watched too late into the evening, refusing her requests for peace and quiet. But for the most part, at least until the very last stage of the disease, mom’s communion with the hallucinations was peaceful. It was only in the very last weeks of her life that the hallucinations progressed into delusions, understood as more thoroughgoing and fixed belief systems or worldviews, often paranoid or persecutory.⁵

pathologies in the brain, specifically declining levels of dopamine. Hallucinations are actually the side-effect of medications prescribed to increase dopamine levels in the brain in order to alleviate the motor symptoms of the disease. This is particularly the case with Carbidopa/Levidopa (L-DOPA), the current standard-of-care pharmaceutical. L-DOPA can dramatically improve the motor symptoms of Parkinson’s disease, but the drug also affects biochemical changes in the brain that can cause hallucinations and delusions. This puts those with Parkinson’s and their caregivers in a bind. An adequate dose of L-DOPA might slow the deterioration of motor capacity at the expense of psychiatric wellbeing. In the context of Parkinson’s, hallucinations and delusions can be the price paid for safeguarding the motor capacity to walk, grasp, and swallow.

³ While Parkinsonian hallucinations are most often visual, those with PD may experience hallucinations across all five senses. The evolution from visual hallucinations to hallucinations in other sensory modalities (auditory, tactile, and olfactory) accompanies the progression of Parkinsonian psychosis.

⁴ Parkinsonian hallucinations can be passage hallucinations (where a person or animal crosses the peripheral visual field), illusions (e.g., seeing a dog instead of a plant), and presence hallucinations (a feeling that a person or animal is proximate). Based on her own testimony, my mother experienced all these phenomena at various times.

⁵ The distinction between hallucinations and delusions is salient in the clinical literature on dementia, and Parkinsonian dementia in particular. Hallucinations are “false” sensory perceptions; delusions are false beliefs.

The question my mother posed that day—“are we alone?”—speaks to the liminal phenomenology of Parkinsonian psychosis. The spirits were real to her; of that there was no question. But the fact that she asked if we were alone indicated that, at some level, she was aware that the spirits were spirits. While she would not have used this language, it was clear that in the early stages of her illness, when she engaged with the hallucinations, she often did so with the latent understanding that they did not lay claim to the same ontological status as the cat, me, or my brother. In the current clinical vernacular, this liminal state is referred to as “retaining insight,”⁶ and while he does not call it by that name, it is the perceptual experience on which Maurice Merleau-Ponty (2012) fixates in his discussion of hallucinations in *Phenomenology of Perception*.⁷ There, Merleau-Ponty claims that the hallucinating subject can distinguish between perceptions and hallucinations, a claim he justifies with reference to the “plenitude” that hallucinations lack in reference to “real” perception, insofar as they do not gear into the intersubjective horizon of others’ perceptions in that way that “true” perceptions do (349). “Hallucinations,” he writes, “play out on a different stage than that of the perceived world; it is as if they are superimposed” (355). Merleau-Ponty’s assurance that hallucinations and “true” perceptions phenomenologically differ from one another is grounded in an understanding of perception as spatially and temporally “thick.” By this, he means that variable dimensions are “implied by my own spectacle, just as the back or bottom of objects is perceived at the same time as their visible side, or the room next door pre-exists the perception that I would actually have of it were I to walk over there” (354). Every perception thus implies, by extension, the “insurmountable plenitude” of the phenomenal world. In this account, hallucinations fall short of perceptions to the degree that they fail to gear into the world in the way that perceptions do; Merleau-Ponty’s claim is that they do not anticipate, echo, or communicate with other things in the phenomenal world in the way that a “real” perception does. But it is not only that hallucinations do not anticipate or imply other aspects of the phenomenal world because they are not of a piece with them; hallucinations also fail to accomplish a level of perceptual traction because they are not endorsed by others. In this sense, the “thickness” of perception is (to a meaningful degree) bestowed by others, as they implicitly and explicitly endorse the horizons of my own phenomenal world. The hallucination, lacking the traction and depth of perceptions that are intersubjectively confirmed, “slides across time, just as it slides across the world” (355). Merleau-Ponty’s claim is that varying degrees of intersubjective traction, depth, and thickness manifest as a salient difference between the phenomenality of hallucinations and “real” perceptions.

This phenomenology of hallucination is germane for many at the onset of Parkinsonian psychosis: in the beginning, those who experience hallucinations typically experience them with insight. This means that they are able to recognize the hallucinations as a symptom of their disease, and to understand that they are not real. Indeed, in the early days of my mother’s dementia, it was impossible for me to occupy the exact same space-time as a hallucination. I laid claim to an ontological density that they lacked, so if I moved into

⁶ “Insight” is the recognition that experiences are hallucinations. Insight is typically lost as Parkinson’s disease progresses. Some clinical literature refers to hallucinations with insight as “pseudohallucination.” See Dominic Ffychte et al. (2017).

⁷ See also Sergio Benvenuto (2015).

the same visual plane that they occupied, my presence would dissipate the hallucinations. If I took a seat on the couch where a hallucination was already sitting, for instance, the hallucination would dissolve. For this reason, advice for caregivers for those with Parkinsonian dementia occasionally includes the tip that one can contest hallucinations simply by moving to where they are. As long as insight is retained, the perfect syncing of “real” and hallucinatory realities is not possible. My own ontological density was sufficient to displace the hallucinations if and when our spatial and temporal locations overlapped.

Merleau-Ponty’s sequestering of hallucination apart from “true” perception, no less his rather categorical conviction that those with hallucinations maintain a capacity to differentiate between them, are assumptions readily troubled through the acknowledgement that not all hallucinations are known as hallucinations by those experiencing them. Indeed, hallucinations can grip the subject in ways that foreclose any possibility of recognizing them as such. Nonetheless, Merleau-Ponty’s recognition that the experience of hallucination might be one in which the subject moves (lucidly) between striated ontological levels remains an accurate account, and a helpful one for understanding the paradoxical perceptual architecture of “retaining insight.” Likewise, Merleau-Ponty’s recognition that even hallucinatory perception participates in “that movement that carries us beyond subjectivity, that places us in the world prior to every science and every verification through a sort of ‘faith’ or ‘primordial opinion,’” nods toward the impact of hallucinations, and to why and how they matter, in registers both ontological and ethical (2012, 359).

II. PLAYING ALONG OR BEING WITH?

For some time, I enjoyed a special kind of ontological density (and priority) in my mother’s phenomenal world. As her Parkinson’s progressed, however, and insight was lost, mom began to afford the hallucinations greater and greater credence. It was common for her to start talking with them and interacting with them. At this stage in the evolution of Parkinsonian dementia, the hallucinations may become more protracted, and can cause agitation, fear, and aggressiveness.

Literature on caring for those with advanced Parkinsonian dementia often urges caregivers to refrain from arguing with, or contesting, the hallucinatory landscape.⁸ On the one hand, the rationale for this prescription is ethical, borne of compassion; arguing with or about hallucinations can be deeply distressing for the one experiencing them, and can even be unsafe. Contesting hallucinations can cause panic, anxiety, and harm. Of course, the clinical recommendation is also pragmatic: typically, there just isn’t much point in arguing. Indeed, Parkinsonian hallucinations count as such because they are phenomenologically salient for the one experiencing them and casting them into doubt is not often efficacious. Hence the clinical advice is often to go with the flow and play along.⁹

⁸ See Gail Weatherill (2020). Also see the Parkinson’s Foundation’s (2018b) *Cognition: A Mind Guide to Parkinson’s Disease*.

⁹ See the Parkinson’s Foundation’s (2018a) *Caring and Coping: A Caregivers Guide to Parkinson’s Disease*.

It is the above prescription that I aim to trouble here, on phenomenological grounds. While I agree that, in certain circumstances,¹⁰ it is helpful to engage with, and endorse, the hallucinations, I contend that the language of “playing along” does not adequately or sincerely capture the overlapping worlds of sense that can occur in such contexts. Indeed, such language rings of infantilization, albeit, well-intended.¹¹ The implication is that there is some pretense or inauthenticity involved: what is happening is rendered in terms akin to a child’s game of make-believe. The trope of “playing along” artificially cleaves the phenomenal world in two, reinforcing the idea that the caregiver remains anchored within the bounds of the “real” and “true” perceptual world, while the cared-for is given over to a distorted phenomenological and ontological landscape that is typically understood as little more than a phantasm, a world of deception and illusion. The caregiver may engage this hallucinatory “pseudo-reality” for the sake of offering reassurance and keeping the peace, but in the reigning clinical perspective, is never called upon to question the veracity of their own perceptions. In my experience, however, this view elides the genuine overlap in phenomenal worlds that can occur in the context of caregiving for those with dementia. What this bifurcated ontology fails to capture are the ways in which my mother’s hallucinations, the spirits, became real to me, too, which is to say they mattered to me, even as they remained invisible, inaudible, and unlocatable within my own perceptual horizons.

The hallucinations were significant in ways that surprised me. They kept mom company during the hardest time in her life, and they eased her loneliness as she navigated a profoundly isolating illness. The spirits were with her, they attended to her, and as her Parkinson’s progressed, the spirits became a familiar presence to me, too, one that impacted my sense of my mother’s wellbeing in unexpected ways. Merleau-Ponty’s notion of the perceptual faith—understood as the credence we afford to the phenomenal world as it appears to us, before and beyond questions of judgment, knowledge, justification, or proof—is helpful here. The perceptual faith is the belief that what we see and sense requires no proof or justification. It is a faith that does not occur at the level of knowledge. Merleau-Ponty writes, in *The Visible and the Invisible*, that “the methods of proof and cognition . . . do not enable us to understand what the perceptual faith is, precisely because it is a faith, that is, an adherence that knows itself to be beyond proofs . . . at each instance menaced by non-faith” (1968, 28). Considering its fragility and vulnerability to doubt, Jack Reynolds (2020) rightly notes that the perceptual faith is consistently understood by Merleau-Ponty as both a paradox and a problem for us. The faith I have in the world that I see, touch, smell, hear and taste is braided through with doubt, but it is a commitment nonetheless, one that tethers me to the world, offering me the assurance that what I see and sense is real. In the face of a loved one’s hallucinatory psychosis, there may be a temptation to reify the phenomenal givens of the perceptual faith, to shore up the veridicality of one’s own

¹⁰ This account is concerned with what it means to care for another who is hallucinating, but who does not pose an immanent risk to themselves or others. The clinical recommendation to “play along” is not meant to apply in cases where endorsing another’s hallucinations may cause harm.

¹¹ See Lisa MacFarquhar’s (2018) “The Comforting Fictions of Dementia Care” in *The New Yorker* for a discussion of the well-intended manipulation and deception of those with dementia, and the moral quandaries that attend these practices.

perceptual horizons. In my experience, however, caring for mom required the opposite: a loosening of the grip,¹² an expansion of my own phenomenal world via my acceptance of her hallucinatory landscape.¹³ My experience of my mother's hallucinations taught me that, as often as not, what was called for was not the contraction or consolidation of the perceptual faith, but its relaxation and expansion—not for the purposes of “playing along” so much as being-with.¹⁴

Merleau-Ponty writes: “Insofar as he has sensory fields and a body, the normal subject himself also bears this *gaping wound* through which illusion can be introduced: the normal subject's representation of the world is vulnerable” (2012, 358; emphasis mine). By defining susceptibility to illusion as a potential site of wounding or injury, Merleau-Ponty betrays something significant about who he takes the “normal” subject to be, i.e., one whose perceptions guarantee their reliable anchorage in the “real” world. However, this passage also implies Merleau-Ponty's recognition that perception's purchase on reality is fragile. If even the “normal” subject bears the “gaping wound” that is vulnerability to hallucination or delusion, the gaping wound itself becomes normative. In this account, the possibility of hallucination and delusion consistently haunt perception; perception and the specter of hallucination are thus braided together. And here is the other side of Merleau-Ponty's story: if he is fascinated by the phenomenal difference between perception and illusion, he is also sure that the two are radically interconnected. As he writes, “my confidence in reflection also comes down to taking up the fact of temporality and the fact of the world as the invariable frame of every illusion and every disillusion: I only know myself in my inherence in the world and in time; I only know myself in ambiguity” (360).

Most relevant here is Merleau-Ponty's identification of the perceptual faith as a site of vulnerability, which allows for a reimagining of the perceptual faith as a site of ethical solicitation and response. Here, the perceptual faith is understood as a site of potential injury and abandonment in the event that one's own perceptual horizons cease to sync up with that of others. So, too, the perceptual faith becomes a potential locus of responsibility, care, and fidelity. Its ethical significance cannot be captured in ontological and epistemological registers alone.¹⁵

¹² In “The Phenomenology of Rheumatology: Disability, Merleau-Ponty, and the Fallacy of Maximal Grip,” Gayle Salamon argues for “the insufficiency of grip as an apposite metaphor for wordly engagement” (2012, 244).

¹³ This is not to deny those instances in which the endorsement of hallucinations would cause harm, either to the one having the hallucinations or others. There are many such instances. In this paper, however, I am concerned with the possibilities for coexisting with hallucinations that are for the most part benign.

¹⁴ The relaxation and expansion of the perceptual faith arguably enables us to share in many experiences where the other's phenomenal world does not neatly map on to my own, and my own perceptual “style” may differ radically from another's. This dynamic does not apply in the case of hallucination alone.

¹⁵ In *Disorientation and Moral Life*, Amy Harbin (2016) looks to experiences of disorientation for the role they play in nudging us to cultivate deeper understandings of vulnerability. In “Being at Home: A Feminist Phenomenology of Disorientation in Illness,” Corinne Lajoie (2019) draws on Harbin's work in order to explore the generative aspects of disability in illness: “The instability of bodily dwellings in experiences of disorientation,” Lajoie writes, “can suggest ways of being in the world that are more attentive to interdependency, unpredictability, and change in human experience” (Lajoie 2019, 546).

Emmanuel de Saint Aubert (2021) captures this ethical dimension of the perceptual faith beautifully in his essay on “The Perceptual Foundation of Care” when he writes that “the perceptual attitude, thus understood, proves to be at the foundation of care” (2021, 189; 192). While Saint Aubert does not cite the passage from *Phenomenology of Perception* on the “gaping wound” that is exposure to hallucination and delusion, the idea is deeply resonant with his own elaboration of the relationship between perception and care: “To perceive is already to take care of the perceived being. If at least we understand that perception opens onto the vulnerability of this being by opening, beneath itself, onto something more fundamental. And that ought to be at the foundation of care” (191).

René Descartes, too, was preoccupied with perception’s vulnerability to deceit, but the Cartesian response was to shore up the perceptual faith with reference to what is most clear, distinct, and indubitable. More tellingly, indubitability itself is linked, in Descartes’ (2006) Second Meditation, to what is most proprietary. In the Cartesian frame, what is clearest, most veridical, is so because it is mine. Indeed, Descartes cheerfully concludes his Second Meditation with the reassurance that “I manifestly know that nothing can be perceived more easily and more evidently than my own mind” (19). This is in clear contradistinction to Merleau-Ponty’s account, which understands the veracity of perception to be wedded to other’s confirmation of my own perceptual horizons. It is through and in intersubjectivity that perception acquires its nuance and depth. Anxious and proprietary, the Cartesian account of perception cannot readily speak to what my mother, myself, and the spirits shared. By renouncing the ethical and pedagogical potential of hallucination and illusion, it refuses the possibility of a spirited interworld of ethically-meaningful exploration and care, an interworld of meaningful dialogue between multiple overlapping phenomenal worlds.

Merleau-Ponty nods toward this interworld when he claims that

[w]hen the person suffering from hallucinations says that he sees and hears, we must not *believe* him, since he also says the opposite; rather we must *understand* him. We must not restrict ourselves to the opinions that the healthy consciousness has of the consciousness suffering from hallucinations, and take ourselves to be the sole judges of the proper sense of hallucination. (2012, 352; emphasis mine)

Merleau-Ponty cautions against the hubris at play in reducing the other’s hallucinatory world to a “pseudo-reality.” Contra-Descartes, for Merleau-Ponty, perception is not an act of possession but instead a dispossession and an opening. “What is given,” he writes,

is not myself over here and others over there, nor my present here and my past over there, nor healthy consciousness and its cogito here and the hallucinating consciousness over there . . . rather what is given is the doctor *with* the patient, me *with* another person, and my past *on the horizon* of my present. (Merleau-Ponty 2012, 352; emphasis in original)

The sense that one should engage with, rather than dismiss, another's hallucinations aligns with a position explored in a May 2022 article for *The New York Times Magazine*, which highlights the work of the Hearing Voices Network, a group that eschews the language of psychosis in favor of the idea of nonconsensus realities, and works toward diminishing the senses of secrecy, deviancy, and horror that so often accompany hallucination in the public eye: "Instead, partly by lifting the pressure of secrecy and diminishing the feeling of deviance, the talk will loosen the hold of hallucinations, and, crucially, the grip of isolation" (Bergner 2022).¹⁶ The goal is to work for greater acceptance of patients' experience of voices and hallucinations and to create spaces where people can describe and discuss their hallucinations, thereby refusing the stigma and isolation that too often surround hallucinatory illness. This is not to claim that nonconsensus realities are always benign; no doubt many are profoundly malignant and injurious. Nonconsensus realities can be scenes of horror and abandonment. Moreover, we live in a time when essentially hallucinatory, collectively-held epistemic structures can have devastating and malignant consequences. Hence the injunction to attend to nonconsensus realities is not intended as a universalizable prescription or a recipe for care in all circumstances.¹⁷ The volatility of nonconsensus realities, and the broad spectrum of possible responses to them, must be acknowledged even in the context of projects whose specific aim is to cultivate a greater understanding of hallucination and delusion, and the possibility of responding to them without fear, aversion, or violence.

Experiencing my mother's dementia taught me that the anodyne examples that phenomenologists tend to nominate as illustrations of intentionality don't come close to celebrating the full array of intentional possibilities. The canonical texts often find us reaching for pens and glasses of water. Our movement toward objects is frequently rendered in instrumental and somewhat sanitized terms, in scenes that are often solitary. ("I am sitting at a desk . . . I reach for the glass of water . . ."). But in caring for those with dementia, the intentional arc is reconfigured and vivified. I cannot see, hear, or touch the hallucinations, but I am intended toward them nonetheless. Indeed, the horizons that are opened by caregiving exhibit an expansiveness and ambiguity that classical examples of intentionality may lack. Caring thus illuminates the world in ways that subvert and depart from more orthodox renderings of perception in the phenomenological tradition. Care may guide the radical transfiguration of relationships in illness, in one instance of what Gail Weiss (2008) has called a refiguring of the ordinary. What comes into relief is a spirited interworld whose phenomenological ground is not the reassurance or confirmation of perceptual overlap, but instead the invitation and the desire to see with another, even and perhaps especially when this "seeing" will reveal nothing that is visible to me at all.

¹⁶ The article especially highlights the efforts of Caroline Mazel-Carlton, the leader of the Hearing Voices Network. In an intersectional vein, Mazel-Carlton affirms her wish for the expansion of different options for healing, viewing her efforts as meaningfully aligned with the successful challenge to society's understanding of autism posed by those in the neurodiversity movement (Bergner 2022).

¹⁷ Much of the contemporary literature on hallucination concerns schizophrenia and contexts wherein hallucinations are far from benign and may cause trauma or injury. See Matthew Ratcliffe's (2017) *Real Hallucinations*.

This mode of intention—caring—is the residuum of a phenomenological reduction whose impetus and evidence is interrelation. Bracketing questions of veridicality and truth, what comes into relief through the caring reduction or *epoché* is human relation in its cognitive and ethical complexity. When performed in the register of caregiving, what the reduction reveals is not only the epistemic and ontological fact of our being for and with others, but also the manifest truth that the other’s world matters to me. *Vis-à-vis* hallucination, the question “is it real?” can, and often does, claim less experiential priority than the question “how shall I respond given that this is real to her?”

III. CARING ACROSS MULTIPLE WORLDS

I stood in line at CVS waiting to purchase an over-the-counter medication that my mother had requested. She was convinced that the spirits had tampered with the nearly-full bottle of that same medication she had at home, and was refusing to take the medication for fear it would harm her. Frustrated, she had asked me to go out to get a new bottle. I was at CVS to purchase a medication that I knew we did not need. Standing in line at the pharmacy that morning, I wondered what I was doing. I pondered the privilege of being in a position to buy medicine that we already had in abundance. To do so was arguably absurd, ridiculous, and wasteful. To be sure, I can narrate the decision to acquire the surplus medicine in reference to a desire to keep the peace, to placate my ill mother, to not have the last few weeks with a beloved parent marred by memories of having deceived her. These are all explanations that could have been given for what I was doing, but none of them were exactly on target.

In fact, there was a genuine felt sense that to trick mom into taking the medicines that she believed to be contaminated—which would have been easy enough to do—was wrong, not because it would mean I had lied to her or somehow deceived her, but because the medication that felt contaminated for her truly felt contaminated to me, too. It is here where the prescription to “play along”—and the bifurcated ontology (one real, one hallucinatory) that informs it—comes up short. What I was doing in line at CVS that morning wasn’t playing along, or if it was, I was pretty deep in the play myself. The standard view would hold that the medicine sitting on the counter in mom’s apartment was safe in my reality, compromised in hers. But there is a phenomenological register in which this bifurcation blurred, and where these two senses ceased to be mutually exclusive. This is the register of care, whose compass is set to the poles of love and fidelity far more so than any conscious concern with veridicality, skepticism, and truth.¹⁸ Here Emmanuel Levinas comes to mind, both for his recognition of the felt sense of the ethical force of the other’s alterity, and for the priority he assigns this ethical sense above and beyond the registers of comprehension and knowledge.

¹⁸ In “Playfulness, ‘World’-Traveling, and Loving Perception,” María Lugones powerfully describes travel between incommensurate phenomenal worlds and notes possible connections between world-travel and love (1987, 3). The sense of love and playfulness that Lugones explores is certainly relevant here. Lugones also describes world-traveling as *willful*, however, whereas part of what I aim to capture in this account is an involuntary, nonvolitional orientation toward others that is care.

At the beginning of the section on “Sensibility and Proximity” in *Otherwise than Being*, Emmanuel Levinas writes of “making oneself a sign” as an expression of “self, sincerity, passivity” (1998, 62).¹⁹ This passage is nested in a broader discussion of the dynamic between the saying and the said, or between the expressive opening to, and welcoming of, the other, and the particular signs that will render this gesture intelligible within particular social and cultural horizons. What might it mean to “make oneself a sign” in the case of caregiving? In the context of dementia, it may mean looking down at the plate to remind someone that they are eating, or it may mean holding eye contact long enough to dissipate a felt sense of solitude. To “make oneself a sign” in this context is to abide in a phenomenal field that you did not craft, whose contours may be alien and even frightening in their imperceptibility, and to refuse to let the sense of strangeness and alterity that abides there give way to only mystification or fear.

IV. IDENTITY AND ANONYMITY

My mother bakes in the kitchen as I sit some distance from her and watch. I read her bodily comportment, the arch of her back and neck, and I can tell that she thinks there is someone standing behind her. She looks at me across the room and asks: “Am I in your way?” In that moment, it is clear to me that, even though our eyes are locking across a distance of twenty or so feet, she also thinks I am standing immediately behind her, supervising her cooking.²⁰ This was the first of many episodes when I had to reckon with the fact that mom’s hallucinations included multiple versions of me moving through the world simultaneously. Once, when we were out on a walk together, she turned to me and asked: “I wonder if Ann would have liked to come?” Another time, she failed to greet me at the door with the happiness to which I’d grown accustomed. This stung a bit until I realized that mom’s lack of affect was due to the fact that a hallucination of me had actually been keeping her company all morning. Over time, I made an uneasy peace with the idea that I was often co-present with hallucinations of me. Sometimes there was more than one of me in the same room or house; other times I would be right next to mom and she would also think I was several states away. I often suspected that my hallucinatory doubles were acting on my behalf when I was away from her, doing or saying things that I would never know. In the event that my mother had a surprising or sharp emotional response to something I did or said, I wondered if this was because a hallucination of me had already been on the scene, behaving differently, speaking on my behalf, making promises I wasn’t keeping. I worried that it might be confusing for mom to have simultaneous perceptions of the same loved one moving through her phenomenal world.

¹⁹ My thanks to Tim Stock for a series of conversations on *Otherwise than Being* in spring 2022 that brought this passage to my attention.

²⁰ This is known in the clinical literature as a “presence hallucination”: it is the feeling that something or someone is nearby.

While my mother never forgot my name and recognized me as her daughter till the end of her life, it was also the case that in her perceptual reality I had become immune to the laws that typically bind us in our movement through space and time. Hers was a phenomenal world in which I had become a time-traveler; in her world, I routinely kept the company of relatives and kin who had died before my birth. I ate dinner with her in Baltimore at the same time that I taught class in Albuquerque. By now, the ontological density to which I had once laid claim in my mother's phenomenal world had dissipated, and with it her ability to recognize me as singular among the hallucinations, which now included so many other versions of myself. This marked a progression in mom's dementia and a notable change in the hallucinatory landscape. The insight that had been retained was now lost, and mom moved through a spirited world that I was less and less able to track, or participate in, with any regularity, predictability, or efficacy. I slipped into an ontological register that felt strange and depersonalized. In my case, this took the form of being dissipated in a loved one's hallucinations, such that there were multiple versions of me gliding through my mom's phenomenal world in ways I could only roughly track.

I am still thinking through the questions of responsibility that arose by virtue of the fact that, in my mother's experience, there were multiple versions of me caring for her. In the end, I could only be obliquely aware of what this felt like for her, and I could only imperfectly trace the contours of where and when I was for her. There are also myriad questions that emerge regarding what responsibility one has for caregiving when one is already there in some meaningful sense (albeit as a hallucination). These are questions I am still trying to parse. For now, I remain interested in how one can be with dementia in ways that resist the tendency to exoticize or pathologize it. I remain hopeful that we can collectively cultivate the means for being-with dementia, and caring for those with dementia, in ways that transcend the grip of fear, crisis, and aversion.

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SHARING TIME WITH MISFITS: WE-EXPERIENCE ACROSS BODILY DIFFERENCE

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Sharing time with others is one way, perhaps a foundational one, that we connect with others. Sharing time can underlie “we-experiences” whereby we feel ourselves to be part of a collective or group. Similarly, sharing time can give us a feeling of belonging—we can feel we have a place among others. It likewise can engender “pro-social” feelings towards others and encourage us to endure hardship for their sake. On the other hand, being “out of sync” with others gives us a sense of disconnection, exclusion, and “otherness.” It can make us feel shame or abjection. We can feel that we are different and incompatible with others if we cannot find a way to share time with them.

Some have been inclined to explain such social asynchrony as a direct consequence of bodily difference. This is especially true in when it comes to disability. Disability has long been “fetishized” in ableist paradigms, which means that the bodily difference of disability is treated as an object independently of the social conditions that created it (Bakan 2019, 244). Those with bodily differences can be denied the possibility of sharing time due to being ostensibly “too different,” despite the real possibility of doing so. When we understand Maurice Merleau-Ponty’s body schematic temporality as a source of shared time, we can appreciate how bodily difference alone is not sufficient to generate allotemporality—the feature of being produced as temporally “other” despite having the capacity for sharing time. In this paper, I illustrate the concept of sharing time across bodily difference using Merleau-Ponty’s (1962) concept of body schematic temporality from the *Phenomenology of Perception* in two contexts: becoming ill and playing music.

I. ALLOTEMPORALITY: BEING PRODUCED AS TEMPORALLY OTHER

For scholars such as Alfred Schütz (2006) and Johannes Fabian (2014), sharing time is not only a key source of collective experience but is also an enabling condition for important

dimensions of intersubjectivity, such as communication.¹ For both, however, sharing time is an *achievement* rather than an abiding condition that can be assumed to obtain: we are not necessarily sharing time simply in virtue of occupying the same room, for example, or attending the same (online) event, or having the same type of body. Schütz introduces the “tuning-in relationship” to articulate how we move from being merely co-located to sharing time, a condition Fabian refers to using the term “coevalness”: “the participants involved are coeval, i.e., share the same Time” (2014, 31). Rather than emphasizing the conditions under which we become coeval, Fabian, unlike Schütz, focuses on situations in which such shared time is refused or denied. For Fabian, the denial of coevalness is the central mechanism by which anthropologists “other” their subjects: “anthropology has been constructing its object—the Other—by employing various devices of temporal distancing, negating the coeval existence of the object and subject of its discourse” (50). Fabian designates the “othering” occasioned by the denial of coevalness “allotemporality” (32).

Allotemporality—the quality of being denied coevalness—finds expression as one of the forces constitutive of disability in the view presented by Susan Wendell (2013) in *The Rejected Body*. For Wendell, the denial of coevalness is not only or primarily enacted discursively (as it seems to be for Fabian [2014]), but is instead an outcome of the *speed* of dominant society:

When the pace of life in a society increases, there is a tendency for more people to become disabled, not only because of physically damaging consequences of efforts to go faster, but also because fewer people can meet expectations of “normal” performance: the physical (and mental) limitations of those who cannot meet the new pace become conspicuous and disabling, even though the same limitations were inconspicuous and irrelevant to full participation in the slower-paced society. (2013, 59)

For Wendell, we find one source of disability itself defined in the very inability to “meet the pace” of dominant society.² Wendell’s view of disability not as a necessary consequence of “impairment”³ or bodily difference but as a state of incapacity relative to specific social conditions (speed) is one that de-fetishizes disability and foregrounds the question of shared time and its denial as a key determinant of intersubjective social life. On Wendell’s account, however, a tuning-in relationship between “normates”⁴ and disabled folk whereby

¹ “We-experience” refers to experience understood as occurring in a group or collective and has been theorized by philosophers such as Michael Bratman (2014) and Margaret Gilbert (1990) as a type of shared agential structure. In Schütz’s view, however, the we-experience that results from sharing time should not be reduced to shared agency but is rather understood to be a wider form of co-experiencing. See Rachel Elliott (2022).

² We find a similar view in Moya Bailey’s “Ethics of Pace” (2021, 285).

³ The physical dimension of disability has often been distinguished from its “social” or enactive dimension using the vocabulary of “impairment” and “disability,” respectively. In Lennard J. Davis’s formulation: “An impairment involves a loss or diminution of sight, hearing, mobility, mental ability, and so on. But an impairment only becomes a disability when the ambient society creates environments with barriers— affective, sensory, cognitive, or architectural” (2002, 41).

⁴ See Rosemarie Garland-Thomson (2011, 592–95).

coevalness would become possible seems foreclosed, considered strictly in terms of the one source of disability addressed here, although the possibility of an intersubjective “crip time” is left open (this possibility is explored below).⁵ While I would want to accept this part of Wendell’s (2013) account of disability insofar as it highlights the disabling effects of denied coevalness, I would want to also affirm the possibility of sharing time between disabled folks and normates such that we-experiences and belonging would be possible across difference.

II. SHARING TIME: MERLEAU-PONTY’S BODY-SCHEMATIC TEMPORALITY VIS-À-VIS “CRIP TIME”

As I (Elliott 2022) have argued elsewhere, sharing time across bodily difference can be achieved by sharing the time of what Merleau-Ponty calls the “body schema.” Body schemas are one of the quasi-transcendental structures of consciousness described by Merleau-Ponty (1962) in the *Phenomenology of Perception*, and they possess an endemic temporality.⁶ The pattern of movements and perspectives that comprise a body schema necessarily imply a temporality insofar as they entail a sequence and a pacing. A further feature of body schemas that Merleau-Ponty emphasizes is their ability to be shared: the body schema can be shared or “transferred” (1971, 117–18). Among other things, this insight can be used to helpfully re-interpret the concept of the tuning-in relationship developed by Schütz as well as Fabian’s (2014) concept of coevalness. In this section, I will lay out what it means to share time through sharing a body schema. Following this explanation, I will lay out how sharing a body schema across bodily difference can help us conceptualize we-experience across bodily difference using the examples of interpersonal relationships during illness, on the one hand, and playing music, on the other.

The body schema is an acquired *a priori* intentional structure described by Shaun Gallagher as a “system of processes that constantly regulate posture and movement—a system of motor-sensory capacities that function below the threshold of awareness” (2005, 24). It is not an image I hold of my body’s position but rather a dynamic template through which my body comes to coordinate itself such that the world becomes perceptible to me. In Merleau-Ponty’s words, it is “neither the mere copy nor even the global awareness of the existing parts of the body” but is rather “active integration of these latter only in proportion to their value to the organism’s projects” (1962, 100). A body schema emerges between my body and the world as my body calibrates itself to resolve instances of perceptual indeterminacy. We adopt a body schema to resolve or explore perceptual demands in an organic way through our being-in-the-world.

Body schemas possess a temporality that Merleau-Ponty describes as a “network of

⁵ “These moments out of time, out of productive, forward leaning, exciting time, can become moments of disability culture politics,” writes Petra Kuppers (2014, 29).

⁶ The phrase “quasi-transcendental” used in this way derives from Lisa Guenther (2019, 12).

intentionalities” (1962, 417). In other words, what I now perceive or enact is continuous with what I will perceive or enact next by the through line that is the body schema’s hold on both (as well as the recent past). Merleau-Ponty explains this notion with reference to Edmund Husserl’s vocabulary for describing time-consciousness:

Husserl uses the terms protentions and retentions for the intentionalities which anchor me to an environment. They do not run from a central I, but from my perceptual field itself, so to speak, which draws along in its wake its own horizon of retentions, and bites into the future with its protentions. (1962, 416)

If the intentionalities that anchor me to an environment are, for Merleau-Ponty, precisely what Husserl called “retentions” and “protentions,” then for Merleau-Ponty, such retentions and protentions are species of the body schema, since it is for him the body schema which anchors us to our environment.⁷ This is to say that there is a way in which a body schema is shot through with a temporality: a sequence of movements according to which a situation formerly indeterminate unfolds perceptually. If this is so, then through sharing a body schema we arrive at a way of sharing time across bodily differences, insofar as different bodies can nevertheless share a single body schema.⁸ In other words, if we appreciate the way we can share time through sharing a body schema, we can see how insisting on bodily sameness as a precondition for sharing time is an instance of coevalness denied.

Merleau-Ponty (1971) best articulates the shareable feature of the body schema in his lectures on “The Child’s Relations with Others.” There, he outlines how the “‘postural,’ or ‘corporeal schema’” of another person speaks “directly to my own motility” as “themes of possible activity for my own body” (117). That is, I can grasp a general pattern in the gestures of another person that inspire me to enact that same pattern—or one compatible with it—relative to a perceptual task. When I do this, we are sharing the same body schema and concomitantly sharing the temporality endemic to it. This is not to say that unshared temporal dimensions, such as habit or affect, do not *also* exist between participants. However, to the extent that a body schema is shared, there is at least one arc of intentionality that is in common.

The notion that sharing a body schema can offer a route to shared time and we-experiences that does not presume bodily sameness would help overcome an acknowledged problem in Schütz’s original conceptualization of the tuning-in relationship. Gail Weiss has highlighted that Schütz’s tuning-in relationship *is* premised on bodily sameness (2011, 172). This assumption is one that we will re-encounter again below in my discussion of illness. Weiss articulates her critique of Schütz in the following way:

Although Schütz doesn’t say this explicitly, his implication is that because human bodies share basic physiological similarities despite their manifest

⁷ For more on the notion of body-schematic anchoring in Merleau-Ponty, see Elliott (2023).

⁸ In Elliott (2022), I argue that it is above all body schemas that possess the features of flexibility, emergence, and bi-directionality that can be shared across bodily difference.

differences of age, sex, skin, hair, eye color, height, weight, and so on, there will be corresponding structural similarities in our temporal experiences. However, recent work by disability theorists has challenged even this rudimentary assumption. (Weiss 2011, 172)

Weiss raises a “question of incommensurable durées” between “normates” and those with disabilities who are not “able to draw upon the same basic motor capacities” (172–73). The notion that folks with disabilities inhabit a temporality that is incongruous with that of normates is one we can recall from Wendell’s (2013) definition of disability as allotemporality (or coevalness denied). A similar idea has gained currency in disability circles through the use of the notion of “crip time.” As Ellen Samuels writes in “Six Ways of Looking at Crip Time”:

When disabled folks talk about crip time, sometimes we just mean that we’re late all the time—maybe because we need more sleep than nondisabled people, maybe because the accessible gate in the train station was locked. 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” like work schedules, deadlines, or even just waking and sleeping. My friend Alison Kafer says that “rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds.” I have embraced this beautiful notion for many years, living within the embrace of a crip time that lets me define my own “normal.” (2017)

I quote this passage at length to give voice to the two senses of crip time it encapsulates. Samuels expresses crip time as, on the one hand, an incommensurability with normate schemas and, on the other, a vision of “stretching” (to anticipate Tucker et al.’s [2016] vocabulary below) or “bending,” which does not imply such an incommensurability.

It is this second version of crip time that I want to explore as a means by which sharing time across bodily difference might be achieved. I want to articulate such a “bending” via a certain view of what is entailed in sharing a body schema. As I (2022) have laid out more fully elsewhere, body schemas can possess different degrees of flexibility and rigidity—some *can* exhibit a “stretching” or “bending” which allow them to be enacted across bodily difference; other schemas, however, are too rigid to permit this. Other features that are relevant to whether schemas can be shared include how they are generated (pre-fabricated/top-down vs. co-created/emergent) and their relationship to those assuming them. I can join your body schema (uni-directional) or we can create one together that is new to both of us (bi-directional). If we engage with others using body schemas that are flexible, emergent, and bi-directionally assumed, then there is no requirement for “bodies-at-this-moment”⁹

⁹ In *Phenomenology of Perception*, Merleau-Ponty writes “our body comprises as it were two distinct layers, that of the habit-body and that of the body at this moment” (1962, 82). The body-at-this-moment could be understood as the limbs, organs, appendages, and prostheses which are organized by a body schema

to be the same for them to share a body schema. It is possible to share this kind of a body schema between folks across bodily difference.¹⁰ In so doing, we might partake in the unfolding of a shared temporality that opens onto we-experiences of enhanced belonging. Understanding we-experiences as shared temporality across bodily difference can help us see how interpersonal relationships can withstand changes in bodily capacity. In the next section, I want to show how changes in embodiment that result from the onset of illness need not lead to the loss of shared meaning posited by Havi Carel (2015) who ties shared meaning to bodily sameness.

III. EMPATHY AND BODILY DIFFERENCE

The breakdown of existing interpersonal relationships in the face of bodily difference has been explored by philosophers of illness like Carel (2015). Carel discusses a refusal of empathy in the face of bodily difference. What I hope to show here is that we-experiences can still be achieved in illness through the tuning-in possibilities afforded by sharing a body schema across bodily difference.

Carel argues that in illness our bodies can become “alien to others” resulting in a “lost bodily empathy” (173). Here we see the presumption of bodily sameness as a pre-condition to social recognition, or empathy. Empathy is a much-studied concept in phenomenology, philosophy of mind, and enactive cognitive science, and it goes beyond the scope of this paper to present a fully fleshed out argument that empathy can be understood as shared time. Here, I hope to make the more modest claim that, even if empathy is compromised across bodily difference (which I do not believe it must be, an intuition I cannot explore here), there is nevertheless a form of we-experience possible through shared time.

“Empathy depends,” Carel writes, “on intercorporeality because fundamentally, I perceive others as bodies that are similar to mine in that they, too, sense, perceive, etc., and I am perceived by others as a body that is similar to theirs” (178). The idea that empathy depends on bodily sameness is not new. However, many of us exist in a state of bodily difference and are nevertheless seeking to connect with others. Our loved ones remain our loved ones even as they pass in and out of illness or disability. Carel appears pessimistic about the possibility of empathy across bodily difference, writing about someone recently fallen ill, “the radical difference between her embodied being and that of others undermines the foundational power of empathy and will require deliberate and forceful effort to overcome” (2015, 180). However, we could look to Merleau-Ponty’s (1962) account of

for a specific perceptual task. I understand the body schema to be a less entrenched or sedimented version of the habit body mentioned as the other term in this quotation.

¹⁰ The bi-directionality of body-schematic assumption refers to whether the schema was generated by the individual using it or by someone else, and in this sense, it cannot be multi-directional even if generated by several people. A body schema generated in a group would be bi-directional because it would be created by the one using it, on the one hand, and by others, on the other: the number of others involved would not alter the bi-directional nature of the body schema on this view.

the body schema as offering a means of achieving we-experience across bodily difference, leaving aside the question whether Carel is correct that empathy requires bodily sameness.

As I outlined above, tuning-in relationships do not depend on bodily sameness but rather on a shared body schema. While not all body schemas can be shared across bodily difference, some can be. Attempting to share a body schema that is rigid rather than flexible, pre-determined rather than emergent, and top-down rather than bi-directionally assumed makes the tuning-in relationship difficult in the absence of bodily sameness. However, if the body schema is flexible, emergent, and bi-directionally assumed, a body schema can be shared across bodily difference and so too its pattern of temporality (Elliott 2022). When we look at Carel's account of why empathy tends to breakdown in the face of bodily difference, it appears to arise from the loss of the shared meanings we once enjoyed with others, and not purely from bodily difference as such: "the shared meanings of terms like 'difficult' and 'fair,' the ability to partake in taken-for-granted social activities like walking to the pub, the spontaneity with which we engage with others, and the ability to reciprocate social gestures are lost or modified in illness" (2015, 179).

It is not just that our bodies are different from their presumed sameness after one of us becomes ill: it is that the shared activities and embodied significances which are thought to depend on that sameness are now in question. However, we can question whether it is bodily sameness upon which those shared meanings depend. Bringing forward the question of shared body schemas at this point allows us to see that it may not be the loss of bodily sameness that threatens the shared activities and meanings, but rather the absence of a shared body schema flexible enough to accommodate bodily difference. Carel argues that this loss can be accounted for by a loss in bodily sameness, however it is not bodily sameness alone that enables such shared activities: shared time through a shared body schema is also required.

As highlighted earlier, Carel regards the empathetic chasm instituted by illness as capable of being overcome, but only with "deliberate and forceful effort" (180). However, if we apply our analysis of the body schema to Carel's example, the shared activities once premised on bodily sameness could still be possible as we-experiences across bodily difference.¹¹ It may be that instead of a "deliberate and forceful effort," what is called for is a shared body schema flexible enough to accommodate bodily difference. It may be the case that following the onset of an illness, an existing shared schema is no longer suitable, and this may merit grief. But the unsuitability of the former schema may be due to its inflexibility, not due to the new fact of bodily difference.

If we look at the examples given by Carel (2015) to illuminate the interpersonal shifts that occur during illness, we can see how re-framing them through the lens of the body schema re-conceptualizes them as potential we-experiences, and not only as moments of lost empathy. Carel notes four vectors of interpersonal modulation that result from

¹¹ Carel may be inadvertently positing a type of body schema that cannot be shared across bodily difference in her account of the shared meanings which are lost in illness. There is not space in the current essay to explore this possibility, however.

illness: the meaning of terms like “difficult” or “far”; “taken-for-granted social activities”; “spontaneity”; and the “reciprocation” of social gestures. If we consider each of these types of change through the lens of the body schema, however, we first ask which form of body schema each example presumes (rigid or flexible). Is it only when we assume a rigid, pre-determined, and uni-directional (top-down) body schema that these examples evoke the chasm of lost empathy that Carel suggests they do? If so, then it is possible that a we-experience would be possible in these cases on the condition that a flexible, emergent, and bi-directional body schema were enlisted instead. For instance, “taken-for-granted” social activities like walking to the pub presume a pre-determined body schema, rather than an emergent one. In virtue of being posited as “taken-for-granted,” this shared activity relies on a “pre-determined” body schema insofar as it is not in question what the event will be or how it is carried out. Likewise, the loss of a shared sense of “difficult” or “far” only refers to the inapplicability of a previous body schema to a new situation, not the loss of the chance to create a new shared sense through a shared (emergent) schema.

I do not mean to deny that changing a body schema long taken for granted can be a circumstance that merits grieving. However, the complete loss of shared meanings may not be what must be grieved—perhaps, it is the loss or change of a particular habit shared for a long time. Carel is correct when she emphasizes the personal grief that may ensue at having to change how one inhabits one’s own environment (independently of shared meanings). It may be overwhelming and disorienting to develop a “new individual norm—a new way of relating to the environment, or a new way of being,” as Carel puts it. And Carel is also correct to highlight the ways in which this new individual norm “interacts with and is affected by social norms and one’s social being more generally” (182). Carel particularly highlights that it is the *flexibility and openness* of this new individual norm (or schema) that “will always be affected by its position vis-à-vis social norms” (183). On my reading, Carel is asserting that the possibilities for the ill person to develop a new individual norm are limited by the possibilities offered by societal norms more generally in terms of what is permissible for an individual body schema. And it is certainly true that the prevailing ableist norms present in society influence the possibilities for schematic re-generation on the part of the ill person. The societal norms that shape our subject position and quasi-transcendental structures of experience (such as the body schema) are described here as existing prior to their application to the person experiencing illness (they are pre-determined rather than emergent), unalterable (or inflexible), and top-down rather than bi-directional (the norms constrain the possibilities for the new individual norm). However, if social norms embraced body schemas that were to be flexible, emergent, and bi-directional, they would be able to accommodate the new individual bodily norms, potentially reducing the sense of alienation and exclusion undergone by the person experiencing illness.

IV. MUSICKING ACROSS DIFFERENCE

It is possible to create new shared experiences with our loved ones after the onset of an illness through the use of body schemas that allow us to share time across bodily difference.

Similar to how shared activities can mistakenly be thought to necessitate bodily sameness, musical practices can often presume a need for bodily sameness as well. For example, the use of traditional scores in community choirs presumes bodily sameness in terms of visual function—traditional scores can pose difficulties for those with dyslexia, for instance. Like in other shared contexts, the norms and conventions that guide the practice of musicking render some folks unable to participate while prioritizing the comfort and inclusion of others. As Blake Howe writes, “conventions of music performance have the power to include and exclude” (2016, 196). As a second demonstration of the usefulness of a Merleau-Pontian account of body-schematic temporality to a theory of shared time and we-experience across difference, I shall turn to experiences of disability within music. Here I highlight how flexible, emergent, and bi-directional body schemas in the context of musicking, to use Howe’s words, “have the power to include,” whereas rigid, pre-existing, and uni-directionally assumed schemas, on the contrary, “have the power to exclude” (2016, 196).

Musicians and scholars working in the disability space have been vocal about calling out the prevalence of what Joseph Straus terms “the blithe assumption that we all inhabit the same kind of body, a normatively abled body” (2006, 123). As we have seen earlier, the move to cite bodily difference as the reason for exclusion from coevalness is to fetishize difference and ignore the rigid, pre-determined, and uni-directional body schemas that make bodily difference a problem for achieving shared experience. While this picture will become more complex as we go, classical music performance might come to mind readily as a genre of music that is particularly exclusionary in this regard because of the strict demands it places on performers in the interest of maintaining norms that precede the playing and derive from a historical tradition. Howe expands on this notion:

concert performance is a venue with especially high expectations for exemplary able-bodiedness, typically showcasing a performer’s prodigious skills—like those that govern aspects of technique (speed, agility, range, precision) and musical sensitivity (nuance, finesse, emotionality). (2016, 191)

Howe names the body that is called to perform these prodigious musical acts the *normal performance body* (196). The normal performance body, however, is only “normal” relative to the high-level of skill demanded in these high-pressure performance contexts: they are in many ways exceptional. Therefore, even bodies that may seem “normal” in other contexts may find themselves with what Howe calls *performance impairments* when it comes to high-level stage performance.

However, others may find that, in the context of high-level music performance, their “disabilities” become exceptional abilities. Canadian pianist Glenn Gould is often referenced as a performer whose neurodiversity contributed to his musical virtuosity, for example (Straus 2017, 137). Scholar and pianist Stefan S. Honisch, similarly, has explained how studying and performing at a high level in the genre of Western art music has engendered specific feelings of exceptional bodily capacity, which “(momentarily) disrupt the perceptions certain publics may have of my physical difference” (2009, 2). Honisch

challenges the presumption of bodily sameness in classical music training while affirming “existing (and highly necessary!) standards of excellence” in the field (Honisch 2009, 4). He writes: “the standard literature on piano technique does not, for the most part, substantially address bodily variation as a factor in the development of technical and mechanical fluency at the keyboard” (2). Adopting what he calls the “affirmative model” of disability whereby bodily difference is embraced as a valid and enriching aspect of human variation, Honisch rejects approaches to music that embrace “the simplistic equation of normative standards of able-bodiedness with artistic and technical excellence in piano playing.” Honisch argues instead that physical difference can contribute to “testing boundaries and challenging entrenched conventions,” enriching both the musical tradition and individual experience (4). Honisch therefore demonstrates that it is not the genre itself that excludes or includes so much as it is the ability for such genres to abandon their assumption of bodily sameness and affirm variation as a resource for enriching experiences for performers and audience alike.

Discussing a series of concerts featuring artists of different abilities called *Stretched Boundaries* (curated by Pauline Oliveros), Sherrie Tucker et al. asks:

What if experimental musical communities committed to explorations of difference in realms such as harmonics, time, timbre, and form, were equally avid about the differential variables in musicians’ and audience members’ modes of sensory and perceptual relationships to sound waves, as well as differences in mobility, range of motion, ratios of voluntary/involuntary mobility, multiple modes of cognitive processing and language? (2016, 183)

If we embraced bodily and perceptual difference as a source of musical experimentation rather than assuming bodily sameness and demanding compliance with pre-existing rigid norms, we might observe a sort of real-time interpersonal rehearsal space fostering what is often referred to in the academic improvisation community as *social virtuosity*—a workshop for developing the sensitivity and responsiveness it takes to co-generate emergent, flexible, bi-directional body schemas.¹² For genres seeking to experiment with aesthetic norms, there is arguably more capacity for emergent, bi-directional, and flexible body schemas to take priority. But as we have seen with those working in the tradition of classical or Western art music who are insisting on a space for disability within that tradition, bodily sameness is also not required for traditional styles such as Western art music, so long as a flexible approach vis-à-vis the creation of new body schemas is adopted.

¹² The notion of social virtuosity is attributed to Maggie Nicols in the preface to a published interview with her by Chris Tonelli (2015, 1).

V. CONCLUSION

One way that we connect with others in we-experience comes through sharing time. However, questions have been raised as to whether time can be shared between normates and misfits, or in other words, it has not been obvious that sharing time across bodily difference is possible. This difficulty sharing time across abilities has sometimes been articulated as an incommensurability on the level of speed. Crip temporality has been put forward as a concept to describe a slower time outside of the accelerating pace of capitalism, an intersubjective disabled temporality that operates in an inclusive way. The difficulty of sharing time between normates and misfits has also been articulated as a problem of bodily difference: it can be assumed that bodily sameness is required for tuning-in relationships and shared experience.

However, when we re-articulate the problem using Merleau-Ponty's concept of the body schema and its endemic temporality, a solution presents itself. This paper maintains that sharing a body schema is a way we can share time—or in Fabian's (2014) terminology, enter coevalness. So long as body schemas are emergent, bi-directional, and flexible rather than pre-determined, imposed, and rigid, sharing time through sharing a body schema offers a viable framework through which to conceptualize we-experiences across difference, achieved through shared time.

On the view developed here, the inability to share time due to incommensurability on the level of speed could be re-cast as a lack of care in the very process of assuming a body schema. When speed is exclusionary, insufficient allowance for the “onboarding” required to assume a body schema may be at issue. In other words, speed offers little provision for the time it takes to interactively “agree” on a schema and to assume it while shaping it. When we are forced to keep up with an imposed pace, we have no room to figure out our own way of enacting a pre-determined schema and this leads to exclusion. If we want to share time with misfits and normates as so many of us do, we must make room for the phase of sharing time that precedes the sharing of it, so to speak—we must allow for there to be room to co-create a schema inhabitable by all present.

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AN-ARCHIC TIME: MELTING THE CLOCK AS HYPERNORM OF THE I CAN—AND PHILOSOPHY

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On the level of being, we will never understand that the subject is simultaneously creating and created, and simultaneously infinite and finite. But if we uncover time beneath the subject, and if we reconnect the paradox of time to the paradoxes of the body, the world, the thing, and others, then we will understand that there is nothing more to understand.

—Merleau-Ponty, *Phenomenology of Perception*

There are changes/transformations [mutations] that do not happen at the same pace [rythme], [that happen] at different levels of knowledge. . . . The plurality of times = the impossibility of a single measurement standard, but this does not prevent the unicity of time as a melting time [temps fondant], which is not measured; this [melting time] would be like . . . [a] stuff/fabric [éttoffe] of time that is not made up of serial events, but is presupposed by them.

—Merleau-Ponty, Unpublished Note from January 1959

Nature does not interest us in itself . . . but as the index of that within things that resists the operations of free subjectivity and as concrete access to the ontological problem.

—Merleau-Ponty, “Nature or the World of Silence” (author’s trans.)

I. MELT THE CLOCK!?

Sara Hendren’s (2020) superb book, *What Can a Body Do? How We Meet the Built World*, offers great insights into ways that ability and disability are not matters of our bodies alone, but the ways our built world empowers or disempowers bodies. Hendren is an artist turned teacher of design for disability at the Olin College of Engineering. Her training, together with resources from thinkers such as Rosemarie Garland-Thomson and Eva Feder Kittay, let her reveal, in concrete detail, how affordances of the built world (such as lecterns and lecture rooms, chairs, and streets) or affordances incorporated into our bodies (such as

prosthetic limbs), variously fit and misfit our moving bodies. This fitting and misfitting, enabling and disabling, are due to the presuppositions and standards built into these affordances and their design.

Hendren’s book finishes with a chapter titled “Clock.” But wait a minute! How are clocks part of the *built* world? Don’t clocks just measure time, which flows of itself the same, as Newton would say? Hendren’s point is that the clocks by which our modern world runs impose expectations about how fast we move, when we are to move, and so on. For example, city planners calculate the duration of “walk” signals on traffic lights based on expectations of how many meters per second a body can move. The built world thus times us, sets our beat in both temporal and spatial senses,¹ according to a clock that not all of us are able or wanting to follow.² Think of the worker scrambling to keep up with the assembly line, think of a worker punching the clock or waiting for their shift to end. Think of students or colleagues who haven’t been able to meet “on time” because their needed transport was delayed or their access to buildings was blocked by construction undertaken with no thought for accessibility. (If you live in Montréal, you almost certainly have such stories.) The beat of the clock can be debilitating. In this juncture of moving bodies and time, Hendren’s “Clock” chapter contributes to studies of *crip time* as challenging prejudices of normate clocks by revealing how spatial fittings and misfittings of bodies and built worlds crosslink with the clock as an even deeper presupposition of the design of our built world.³

My purpose is not a direct discussion of crip time or the clock as building ableist expectations into the world. Rather, I aim to contribute to critical thinking about the role of time in ability and disability by studying what clocks and time are in the first place and challenging typical views of what time is. In some ways, the result is, perhaps, a “cripping of *time itself*.” We tend to think there is a “time itself,” with its own fixed beat, that time is already set to go. And indeed this concept of time does hold within our cosmic epoch and locale and on the usual scales of our experience. However, I argue, under the hood of visible, experienceable time, being itself, the invisible of the visible, cannot yet be said to have a fixed beat or even forward creep. Being is not “in time”: being creates time by operating as what I call “deep change.” Deep change does turn out to manifest clocks and time—but we cannot claim that clocks and time are a foreordained necessity of being.

To link this challenging point back to Hendren (2020), clocks are indeed part of our built world. The way clocks are built into our human-built world appears to draw on time as necessarily built-in, in advance, well before us. I call such a fixed and built-in time *timeframe*. Such a timeframe would “naturally” need to be tracked and thus appears to enjoin and justify clocks. And the clocks that track time thus enjoin and justify “being on

¹ Someone following a regular path through their neighborhood is “on their beat.” So too sailors follow a beat, and hikers beat paths through the landscape. The timing of traffic lights sets the beat of pedestrians and neighborhoods.

² Consider the “fifteen-minute city” wherein all the places one needs to go are reachable within fifteen minutes. We would need to ask: Whose fifteen minutes are we talking about? Whose reach?

³ For some work on time and crip time in connection with phenomenology, see Corrine Lajoie (2022), and Lajoie’s work in general; Emily Douglas (2022) takes up issues of “sick time” in ways important for this topic.

time.” And then bodies that cannot do so need to argue for a crisp time that follows not the clock but life and experience. Still, the presiding figure here is a clock that beats out time itself. I argue that on cosmic and quantum scales, there is no such time, there is only deep change. While deep change does indeed happen to manifest clockable time, this is not because of a fixed timeframe underlying or prior to deep change. Time is itself a verb, a contingent and ongoing temporizing. Anaximander thought that an ordered, delimited world arose out of a boundless, undelimited *apeiron*, according to the ordering of time.⁴ For Anaximander, time is thus a presiding principle, *arché*, governing being. In contrast, temporizing is an-archic: it does not begin from an ordering *arché* but instead turns out to create one.

Regarding Hendren (2020), we could say that time is the first design that allows for and informs any subsequent design—so it is no wonder that all design inscribes clocks. My Maurice Merleau-Ponty inspired ontological effort “melts” clocks by describing them in ways that reveal that time, as first design, cannot be presumed to happen “by design” (as if time is baked into the “design” of the universe necessarily and in advance). The norms of design and the design of norms thus goes back to an-archic change that challenges our usual presumptions about norms in the first place.⁵

⁴ Simplicius reports that Anaximander said that the *apeiron* was the *arché* of things. *Apeiron* is not readily translated, but it names a principle that does not itself have limit, delimitation, or definition, that which can change into anything. On Anaximander’s view, then: “The things that are perish into the things from which they come to be, according to necessity, for they pay penalty and retribution to each other for their injustice in accordance with the ordering of time.” Here we see a complex linkage of issues of temporal ordering and norms, which is the focus of discussion below. Anaximander’s *arché* may not be delimited, but it proceeds according to the time order. See Patricia Curd and Patrick McKierahan (1996, 16; 12A9+12B1 in the standard pagination).

⁵ While inspired by Merleau-Ponty, the concept of time and being advocated here is not expounded directly in the pages of his books, articles, or even the working and lecture notes published to date. It is extrapolated from my efforts to understand the underlying argument and directions of his works in print, together with as yet unpublished working notes, especially from the period of his writing of *The Visible and the Invisible (VI)*. Claude Lefort does not include all the notes that Merleau-Ponty wrote in this period and tends to avoid those engaging with science—yet time is a recurrent theme in those notes, linked to remarks on nature, biology, and physics (the second epigraph above is a central example). My scholarly efforts (see note 10) also incline me to think that Merleau-Ponty’s work on phenomenology, ontology, and history are an integral whole, connected by the theme of openness, which is a running theme in the notes Lefort selects for *VI* (often discussed through the German *Offenheit*). Openness links to themes of expression, institution, creativity, and generative passivity coursing through Merleau-Ponty’s work. See Don Beith (2018). Regarding history, Merleau-Ponty’s (1969) analysis in *Humanism and Terror* leads him to remark, on the final page, that “[t]he human world is an open or unfinished system and the same radical contingency which threatens it with discord also rescues it from the inevitability of disorder” (188; emphasis in original).

His conclusion would harbour lessons about the ways we design our human world—including the role of clocks therein. But I am pressing further with this theme of unfinished openness into matters of time. In effect, my contention is that Merleau-Ponty’s effort to grasp nature as a place of meaning and expression, in his phenomenology and his analysis of history, conjoins with an ontology in which nature—and the time of nature—are an unfinished system as well. This point is reflected in a remark he makes in his lectures on *institution*, his conceptual name for processes wherein new dimensions—norms—of meaning are established. There, he writes that “[t]ime is the very model of institution: passivity-activity, it continues, because it has been instituted, it fuses, it cannot stop being, it is total because

II. A CRITICAL ONTOLOGY OF TIME AS HYPERNORM OF ABILITY AND DISABILITY

So far, I have articulated these points by focusing on the clock as a built-in norm of our built world. For this contribution to critical thinking on ability, disability, and the normate, it is crucial to link clocks and time to norms in the first place. I am arguing that ordered clock-time is contingent but its perseverance as ongoing result misleads us into taking it as a fixed framework presupposed by philosophy and various sciences. Time as presupposed, fixed framework is what I call a *hypernorm*.

Why *norm*? Time is a presupposition of all norms, since the basis of any normative claim is assessing some entity as complying with or deviating from a norm, which “takes time.” All norms originate from the norm of time as enabling prediction, deviation, and compliance in the first place. Try, for a moment, to think of a norm that would apply as norm *apart* from time. To say there is a norm of X is to say that for X to be X, it must abide by such and such a norm—over different times. To say that X is normal is to say that X is not now deviating from what X is to be—but this is to say that X could change over time. If each and every X were eternally given as the X that it is, there would be no sense whatsoever to the concept of a norm.⁶

Why *hyper*? Time, as the presupposition of all norms, appears to be perseverant above norms, in the way that the earth, sky, or moon, are, in the perception of children, “ultra-things,” or what we could call hyper-objects.⁷ The moon is exemplary of objecthood precisely in overshooting regularly objectivity, because the moon, unlike other objects, never changes where it is, it chases you everywhere you go. Time, likewise, chases you *whenever* you go, it never changes when it is, it perseverates as the order against which all justice is meted out, as Anaximander says; it can even order the boundless *apeiron*.

As Hendren (2020) and others show, down here on Earth, clock-time is deployed to measure out ability and disability. Phenomenologically, we can notice that the “I can” is an inherently temporal structure: it is an “I *now* can do this in the future.” But which future, whose future, whose time? What is the “proper time” of the “I can”? You can

it is partial, it is a field” (Merleau-Ponty 2010, 7). The time wherein norms arise is a time that, contingently, *has been* instituted and remains so by way of being a totality only through openness, being partial, incomplete.

⁶ You might try to think of norms of ideal objects, say Euclidean triangles, as timelessly having a sum of internal angles adding up to 180 degrees. But the way you think of this as a norm of Euclidean triangles is by coming back to the thought of such a triangle, again and again, through examples leading up to an in-principle claim of what it would take to think of such an object, on any iteration, any time. Here I am adopting a Brouwerian, intuitionist approach to mathematical objects (see Posy 2020), alongside Husserl’s ultimate approach to the “Origin of Geometry” and mathematical sense. See Husserl’s text and Merleau-Ponty’s (2002) reflections on this. Note that the point at hand here is transcendental, not psychological: it is about the role of time, memory, noting down, and so on as an unsurpassable condition of experientially encountering something with the sense of a specifically mathematical object.

⁷ See Merleau-Ponty (2011, 192–94). Merleau-Ponty is here discussing Wallon’s results regarding child psychology, but he notes that adults too encounter ultra-things—he gives the example of death. Here I am noting how time operates as an “ultra-thing,” but I think “hyper-object” is a better name for the concept.

see that norms of ability, disability, and time entwine here. Merleau-Ponty is hinting at this crucial confluence of time and norms in his remark at the end of part two of the *Phenomenology of Perception* that “[o]n the level of being we will never understand the subject as simultaneously creating and created, and simultaneously infinite and finite”—as engendering norms over and above yet within nature—until “we uncover time” and its “paradoxes” (Merleau-Ponty 2012, 424).⁸

There is no normalcy without deviation, there is no deviation without time—but there is no time apart from a deep change as an-archic “principle” that can operate as a deviation from time. To echo Henri Bergson, *time is deviation or it is nothing at all*.⁹ Beneath the subject and normativity the ultimate paradox of time is that far from being a fixed hypernorm, time operates out of ultimate deviation. I argue for this ontological point through metrological and phenomenological studies of how we actually encounter time, which reveal how time wells up in and through deep change as a “melting time” that would be what Merleau-Ponty calls “an index, within being, of what resists operations of subjectivity” (2008a, 53; my translation).

I can now situate my effort in relation to recent critical phenomenology, which reveals various presumptions in approaches to phenomena such as ability and disability. In terms of Lisa Guenther’s recent “Six Senses of Critique for Critical Phenomenology,” I deploy “5) the problematization of basic concepts and methods” regarding time, to critically reveal “3) a quasi-transcendental, historically grounded” structure of the life-world, what I call timeframe, through “1) the art of asking questions, moved by a crisis” (2021, 5). Guenther, however, admits that within critical phenomenology, time (for example, in the classic Husserlian sense), would remain as a transcendental. It appears obvious that time is requisite as an ordering principle of any possible experience. While I am not denying that the visible operates according to this principle, I am denying that the being of the visible, the invisible of the visible, operates according to time as transcendental principle.¹⁰ *In fact, my contention is that time itself is a quasi-transcendental, not a transcendental, not a hypernorm.*

III. CLOCKS DO NOT MEASURE INVISIBLE TIME: THEY MANIFEST TIME AS VISIBLE, ACROSS VISIBLES

We are always in tricky waters when it comes to time. Here I plunge in and proceed as quickly as possible. Gottfried Leibniz helpfully demolished the idea of a Newtonian absolute

⁸ This book is cited using the French pagination given in the margins of the 2012 edition.

⁹ See Bergson’s famous claim that: “*Time is either invention or it is nothing at all*” (2023, 341; emphasis in original; in the standard pagination given in the margins of this edition).

¹⁰ Indeed, I think that Merleau-Ponty’s ontology of an invisible of the visible is, in large part, driven by ongoing considerations of time as central to his work—and that this ontology can be understood “temporally,” i.e., the being of the invisible can be understood in terms of time, history, open dialectic, *Offenheit*, and so on. That is a larger story I have taken up, e.g., in David Morris (2018; 2020). See also Luca Vanzago (2017), Glen Mazis (2010; 2016), Ted Toadvine (2009), and Renaud Barbaras’s emphasis on time as central to Merleau-Ponty (2004, 217–21).

time that would flow from itself, self-same, above all changes, an absolute-time within which all changes can be tracked and numbered.¹¹ God might be able to perceive such time, but no one else can. The only way time can be encountered is *relationally*, in changes, specifically in clocklike processes. I broadly construe clocklike processes—“clocks”—to include processes we construct, whether atomic, windup, pendulum, or candle clocks; or evolved, living, or experiential processes, such as the sunflower’s movement clocking solar cycles, or the feeling of hunger growing over the day, or pulses felt or counted. In all these cases “clocks” are *not* measuring some other, invisible “thing,” an absolute time that “flows” above all changes.¹² Clocks are observable change-processes evolved or constructed to pace, periodically synchronize with, or count changes of other observable processes.

I first elaborate this point through recent results in the philosophy and science of metrology and the thermodynamics of clocks. Later I combine these with David Ciavatta’s (2017) superb study of the relation between natural cycles and phenomenological time in Merleau-Ponty. This strategy lets me build my threefold claim, that (1) we encounter time in and as an experienced or constructed form of change. But (2) we do so only *within* change. This entails that (3) time as a visible, observable form is inherently open to the resistance of its relative matter, namely an-archic or deep change. Time’s ontological openness to an-archic change¹³ challenges the view of time as a fixed hypernorm.

Metrology, the account of how we measure things, shows that the effort to clock time as a fixed order internally challenges claims that we are encountering such an order. Galileo discovered the pendulum was an especially reliable oscillator for clocks. How? He learned to count out a regular number of his pulses, happening at a regular resting rate, against repetitions of singing a hymn at a regular pace—and noticed that the swinging of a chandelier in the cathedral was reliably and precisely regular when counted against his regular pulse. At no point in this process could he claim that the chandelier swings regularly against some flow of absolute time. Notice the circularity here: changes are manifest as having regular periods all and only by reference to the regularity of *other* periodic changes. You can check your watch against the atomic clock that broadcasts its signal on the radio, but that clock isn’t checked against some absolutely regular flow of time beyond clocks—it’s checked against *other* atomic clocks.

This sort of circularity is characteristic of all measurement, as Hasok Chang (2007) shows in his brilliant book about the history of thermometry. Here’s a way to put it. A thermometer or chrono-meter is accurate if it shows reading R_B all and only when measuring an instance of something with value V_B (or close to it). For example, a thermometer is

¹¹ See Leibniz’s third letter to Samuel Clarke. Absolute time is requisite for Newton because he understands force in terms of accelerating mass and needs to understand individual bodies as accelerating or not, *independent* of other bodies. See Robert DiSalle (2006) and James Owen Weatherall (2016). Note that Newton himself did not think we could directly encounter or perceive absolute time; we can, however, construct clock mechanisms that we take to track and thus reveal absolute time.

¹² On this point, see R.G Collingwood (1925) or Paul Davies (2019).

¹³ This formulation is too mild: the point is that the being of visible time is the being of invisible, an-archic change. The being of visible time is not some fixed flow, it is deep change operating to generate an ordering that is in disparity with its own an-archism.

accurate to the extent that it gives a reading of 100 Celsius, R_B , all and only when it is measuring an instance of something with a temperature, V_B , of 100 Celsius. Historically, the problem is that this sort of test is pursued using samples of water at its boiling point—but that phrase “water at its boiling point” needs very hefty scare quotes *because water and its ebullitions (boilings) are far more variable than one would have thought, depending on all manner of circumstances, ranging well beyond air pressure and chemical composition of the water to the composition and finish of the vessel.*¹⁴ While this variability would make Merleau-Ponty and other phenomenologists happy (it forces scientists back to the things themselves!) it entails no end of sorrows and *tsures* for thermometicians.

Why? Let me spell this out through the logic of the general case of building and testing meters. Again: a meter is accurate to the extent that it shows reading R_B all and only when measuring an instance of something with a value very close to V_B . So, checking our meter for accuracy entails multiple tests of the meter measuring a thing with value V_B . But first we need to ensure that we are testing our meter against a thing whose value in fact is V_B . And to do that, we need a meter that accurately determines that the value of the thing we’re testing is V_B . *We need the very device we are trying to test!*¹⁵

Given that we are limited to observables, as Chang (2007) shows, addressing this problem requires constructing different meters and comparing their results in tests against various samples drawn from experience. We end up in a circle of cross-checked tests that gradually let us figure out better and worse ways of measuring. In this way we can show, for example, that one sort of clock-mechanism is more regular in *comparison* to others or use tests of this sort to construct clock-mechanisms that increase this comparative regularity.

The key point is that we are stuck within the circle of *phenomena*. In the case of thermometers, scientists eventually figured out that measured temperature can be understood in terms of observable phenomena *other* than temperature itself, namely, useful work accomplished by a system. With clocks, though, we can never directly access some *other* phenomenon, beyond changes of clockable-processes, that clocks measure. Clocks just measure the relative pace of changing systems against one another: clocks manifest changes as having a pace, a count, a form, over and above, yet *within*, what changes.

The mistake, which Merleau-Ponty (2012) cautions against in the *Phenomenology of Perception*, is taking this “time-form,” manifest within change by mechanical or felt and living clocks, to be something there independent of situated subjectivity and perception—as if time is something that flows by us, or that pulls us along in its flow, as if time issues from a fixed origin, source, principle, *arché*. This mistakenly projects an inborn subjective

¹⁴ See Chang (2007) for copious details.

¹⁵ This result probably would also make Jacques Derrida happy: it is akin to the logic of the supplement. In a way, the problem is that the meter has no access to anything *dehors* the text, until (and this is the difference from human texts) thermometry becomes accurate enough to allow for a theory of how thermometers work that can reconstruct their operation in terms of something beyond readings, i.e., temperature understood in thermodynamic terms. But that takes a long time to figure out and is still no easy matter. Temperature is complicated, don’t let quick and easy formulations about average heat and so on fool you.

form as an underlying structure of reality itself, independent of subjectivity.¹⁶ In terms of cosmological and quantum mechanical sciences, the mistake corresponds to taking time as a fixed background within which phenomena unfold, a background that as fixed cannot be explained since it is presumed as a basic principle or as part of a boundary condition that is so to speak fixed at or beyond the limits of the cosmos.¹⁷

The concept of time as hypernorm takes time as an obviously fixed framework and designs the built world on this mistaken presumption, which is pragmatically obvious—obvious in such a way that it obviates and obscures thinking about what underlies pragmatically ordered time and its measures. Where proponents of crisp time reveal the mistakes of these presumptions through insistence on life and experience, I am seeking to complement this through a critique of the clock itself.

We can begin undoing the mistaken presumption of an eternally fixed timeframe by noticing how clocks manifest ordering time-forms only within change. But this means that clocks are *nothing other than complex change-forms*. Clocks do not escape visible change, they do not measure invisible time above change, they internally mutate the resistance of change to birth *new* sensible forms of change.

¹⁶ This is one of the key points of the temporality chapter in *Phenomenology of Perception* (2012), where he criticizes the view that time is either like a river that carries us along past the banks or like a stream flowing down the mountain from the headwaters of the future to the outflows of the past. On the contrary, he argues that there is time only from a perspective (Merleau-Ponty 2012, 472–74.) Nonetheless, he also argues that this does not mean that time is therefore *actively constituted* all and only by subject. Time arises through a transition synthesis that involves a passivity that would also require that what we take up as time is not fully self-constituting and active either (484–85.) My argument in this paper deepens and radicalizes this point to an ontological level that also receives support from and echoes some of his later work in and around *The Visible and the Invisible* and his lectures on nature. But the full argument requires a much longer work.

¹⁷ On this topic, see Lee Smolin (2013; 2018), Smolin and Roberto Mangabeira Unger (2015), Fay Dowker (2020), Carlo Rovelli (2018), and Richard Muller (2016), as well as Thomas Hertog (2023). All of these are physicists who are, to varying degrees, seeking to give an account of the origin or genesis of time, versus presupposing time as a fixed background (to use Smolin’s conceptual vocabulary). For example, Rovelli (2018) argues that we need to understand time as arising out of change and that this is contingent on thermodynamics and the universe starting with a low entropy. Dowker (2020), whose work draws on “causal set theory” offers a “classical sequential growth” model of the origin of time, which conceptualizes “atoms of time” arising through a process of “random birth,” which grows a topological network of time atoms; the topological connectedness of the network is what establishes what we encounter as the order of time. Her guiding remark that the “birth of a baby is not a baby” helps emphasize that the “birth process” of time is not itself a process of/in time (138). This process can be read as echoing the conceptual point behind Merleau-Ponty’s remark about time as the model of institution (see note 5 above): time has been born, and it is total because it is partial. It must be noted, however, that these scientists are (to various degrees) at odds with and in a minority working against a more prevalent and dominant view of time as a more or less fixed order of a “block-universe.” Michael Silberstein et al. (2018) gives an extensive discussion of the block-universe view and its implications for ontology, mind, and perception.

IV. CHANGING CHANGE INTO CLOCKS: OSCILLATION, REGISTRATION, AND COUPLING

I approach this point by sketching what I call a *metrological schema* for clocks. Later I link this back to phenomenology.

In their barest form, clocks require three operations. First, *oscillation*, which constructs or accesses¹⁸ a changing process as cycling back on itself as the *same*. An example is the tick of a mechanical clock: the mechanism is constructed so that an ongoing change keeps resetting itself to make a tick, a tick, a tick—where each tick is exactly the same qua tick. Another example is a pendulum reaching the limit of its swing and changing direction to cycle back.¹⁹

Second, *registration*. This constructs or accesses a changing process as cycling back on itself as *different*. Imagine pressing a button on a mechanical counter. Each press runs through a cycle that each time works the same in resetting the mechanism to be ready for another press. While each cycle is the same qua resetting, each results in something *different*: now the counter reads 2, now 3, now 4, and so on.²⁰ Crucially, the registration operation requires *determinately forgetting* the past result, erasing the record of the previous, determinate, count and replacing it with the new one. The oscillation operation is a change that produces a tick now, that is the same as any other tick, and doesn't need to be recorded.²¹ Registration, however, is a change that registers a different difference in each now.²²

The third operation is *coupling*, for example, coupling registrations and oscillations. On its own, registration, as a cycling that is ever different, would just count its *own* changes,

¹⁸ For example, a sundial accesses a natural process, the sun's daily traversal of the sky, as a daily oscillation through the gnomon projecting the sun's shadow along the dial that registers the progress of the oscillation.

¹⁹ In the case of a candle clock, each candle's burn-down is one oscillation. We need multiple candles for multiple oscillations of such a clock. Note that considering a single candle as a regular oscillator requires comparisons across multiple candle burn-downs and comparisons with other processes—the coupling operation.

²⁰ Registration can also count fractions of an oscillation.

²¹ Oscillation doesn't even have to bother remembering the past: each oscillation cycle just happens, replacing past cycles. Registration events, though, must remember the previous registration and replace it: now it is count 1; now it is not count 1, but count 2, etc. Consider timing an event by making a mark on paper at the end of each pendulum swing. In terms of oscillation operations, it would suffice to make each mark in the same place each time. But these marks do not allow you to count them up. The registration operation requires counting up repeated marks and that means not counting a mark once it is added to the count. On paper, that is nicely accomplished by striking out or erasing marks that have already been counted. Note that this requires determinate forgetting: erasing this mark, specifically. (The oscillation marks that keep on accumulating in the same place could be considered to be erasing the previous marks, but not determinately, and this is not really forgetting the past marks, it's just replacing them.) Note that while oscillators do not remember the past, mechanisms that regulate oscillators adjust them for regularity, do need to remember and forget; this requires the coupling operation. Also note that this clock schema in effect engages with the logic of Husserl's time-synthesis diagram (1991, §10).

²² In "Signature, Event, Context," Derrida (1982) is getting at something like this point about registration, forgetting, and repetition.

as when we repeatedly press a button on a mechanical counter. But when registration is coupled to an oscillation, registration can count changes of something different, namely, cycles of the same. This manifests a form of sameness repeating in change: an image of time.

In fact, given that clocks just are ever changing things,²³ *coupling oscillating changes to registration is fundamental* to clocks appearing to tell time, versus just being flows of change that manifest something ever new. Furthermore, it is only in coupling clocks to one another that we can give meaning to the claim that a change is a *regular* oscillation, or manifests a regular form, within change in a more open-ended sense.²⁴ The mistake, of course, is thinking that the regular form manifest in coupled clocks is some sort of absolute flow that occurs over and above changes.

Notice that this point about coupling means that *clocks as ordered change-forms must in principle be open, exposed to other unordered forms of change*. More precisely, this means clocks that appear to manifest regular, time-ordered forms of change are in fact *necessarily* open to forms of change that are not necessarily ordered in ways that would inherently show time-forms.²⁵

²³ All clocks wind down and wear down, their changes surpass mere counting of change. This is just more obvious with the candle clock burning down or the tree rings counting up years until the tree stops growing.

²⁴ The candle-clock nicely illustrates this: unless you are cross-comparing one candle-burn to another, to calibrate candle-burns as oscillators, all you have is something changing, burning down.

²⁵ In terms of the scientific background, the significance of coupling has to do with thermodynamics. This is quite important. Sometimes physicists distinguish between different sorts of time, e.g., cosmological time (where the origin of time becomes an issue); thermodynamic time (where the one-way irreversible “arrow” of time becomes an issue, as does the running down of the cosmos as a whole); chronological clock time (where time becomes an issue as observable). The point here is that oscillators are drawn out of the thermodynamics of their operation, and that registration too hinges on thermodynamics, because registration requires forgetting, erasure. (The science of information teaches us that erasure of information requires an unsurpassable minimum of energy dissipation.) Coupling links the thermodynamic flows of oscillation and registration to one another. This means that clocks as manifesting time cannot stand apart from thermodynamics. Indeed, recent beautiful results in the thermodynamics of clocks show that: (1) any clock must dissipate a certain amount of available energy into waste heat, and (2) the more accurate the clock, the more heat it must generate. See, e.g., G.J Milburn (2020).

But thermodynamic flows of any sort, and of the sort required by clocks, entail limits on the distributions of energy in the cosmos. Heat needs to flow from here to there in relatively ordered ways for there to be clocks and for time to be manifest in change. See note 27 on David Z. Albert (2000) for some technical points around the arrow of time in relation to thermodynamics. In a word, clocks operate only by not melting down, by leveraging melt-downs of their energy sources into registrable oscillations; this requires escapement or other mechanisms that dissipate heat so as to produce regularity within change. What is marvellous is that nature engenders this spontaneously at all scales: nature operates as exchanges of energies that ratchet out regularities. What is mistaken is thinking that is because regularity is baked in as basic background.

V. LIVING CHANGE AS TIME: COUPLING EXPERIENCE AND NATURE

Given that the effort here is a contribution to critical phenomenology, I now articulate these points about clocks in phenomenologically counterpart terms through Ciavatta's (2017) detailed analysis of "Merleau-Ponty and the Phenomenology of Natural Time," which shows that even though experienced time is a subjective construction, it is neither impervious to nor separable from cycles of natural time. We could say that experienced time translates or expresses natural time cycles as meaningful for us. Ciavatta condenses his results using the illustration of a jazz musician transforming cycles of breathing into musical phrasings on an instrument. He arrives at this through a detailed phenomenological analysis of the ways that natural cycles, such as breathing, heartbeats, or daily cycles of hunger, or seasonal cycles, inform our experience of time. Translated into my metrological schema, Ciavatta's point is that while our bodies feel differences in phases of various natural *oscillation* cycles, that does not yet give an experience of *time*. Oscillations themselves tend to vanish in cycling back as the same. Temporal experience requires coupling oscillation cycles to registration cycles. Our inner, temporal experience *in fact couples* with and takes up *natural* oscillation cycles—but it never rises above or entirely abstracts itself away from its roots in changing nature. Hendren (2020) shows that designers who design places and time movements by abstract clocks precisely obliterate these natural roots: clocked designs expect us to run on their time, not our inbiding natural time.

This is the phenomenological counterpart of my metrological point that all clocks hinge on a logic of coupling that inherently *opens* clocks to the changes out of which they rise. As I put it, clocks are "time-forming" processes: in time-forming . . . change changes into . . . change-forms that manifest visible time within changes. My contention is that time-forming, as manifest in clocks, can never become autonomous from changes that "precede" time-forming—and this point runs counterpart to Ciavatta's (2017) Merleau-Pontian phenomenology of time. This also echoes efforts to crip time: to have time issue not from the clock but from the time it takes to live and move.

VI. DEEP CHANGE

Clocks and experience are open to and open out of change that is not necessarily ordered to the time of clocks or experience. This result with regard to clocks leads to the question: What is the nature of this change that time-forming forms up as time? The question would of course be begged if we claimed that this change is such that it is ordered to or by an already determinate absolute time, or that the change in question is already "in" time. Such a claim would imply time *directly* appears in the changes that it orders, time all and only *is* change. The claim would mistake something experiential, formal, manifest, visible—*time*—for something "material"—the *change* within which timeforms are manifest. A conjoint complication arises here: when we encounter change, we of course encounter it as visible (sequenced "in" time). But the analyses above enjoin us to think of manifest, visible time as

open to a change that is not necessarily, or not in principle, observable and visible in any direct way. In Merleau-Pontian terms, deep change would be the invisible *of* visible time.

At this point it will help to recall something else that Merleau-Ponty says, that “[n]ature is *not* in itself geometrical, it only appears so to a careful observer who limits himself to the macroscopic givens” (2012, 83; emphasis in original). My point here is that nature is *not* in itself chronometrical: it only appears so to a careful observer who limits themselves to the macroscopic givens of clocks, without asking how clocks in fact work; or an observer who limits themselves to the macroscopic givens of experience, without asking how experience ever comes to construct itself out of *nature*.

Nature is far from chronometrical. This is the challenging point: if we go all the way with the results above, we must stop making any direct claims about a “time itself.” The phenomena (indirectly) enjoin us to withhold from making any positive claim that the natural changes from which clocks and temporal experience are drawn is itself necessarily ordered by any invisible chronometric principle that orders and governs change. True, on the macroscopic scale, in the regions of the cosmos that we inhabit and on the timescales in which we observe these regions, clock-like processes that manifest time-forms within change can evolve or be constructed. But that time-forming is a *result* of the way natural change itself proceeds. It is a conceptual mistake to confuse a result of a process with the origin of that process.²⁶ This, I think, is in the background of Merleau-Ponty’s point in the unpublished working note on standards of time arising from a prior “melting time” that is cited as an epigraph to this article.

Nearly any cosmologist would agree that the time and space we encounter are a result of a process of cosmogenesis. The full scientific details do not matter here. What matters is that once we realize that time forms *within* change, then in principle we are conceptualizing time as rooted in a change that *cannot be subjected to a time-ordering principle*.

In principle, *time is subject to change*. That is, time can change, be changed. In principle this sort of change is such that it need *not* be ordered by time as principle. I think this is part of what Merleau-Ponty is getting at when he speaks in the *Phenomenology of Perception* of “time as subject” and deeply links time to passivity: time does not have a principle set up in advance, and in that respect operates as subject, passive to itself (2012, 483–85). In *Humanism and Terror*, he makes a related point in his argument that historical change is not like a “straight line that is always easy to trace,” since its elaboration continually alters its bearing “like a traveller who moves into a changing countryside continuously altered by his own advance” (1969, 94). Here we would have to think of change altering its own advance, not by traveling through place, but by enduring its own changings.²⁷

I call such change, which is not lined up in advance, but radically open to and affected by passivity, “deep change”: deep because, like the rippling, distorting, syrupy water through which alone the pool’s bottom shows up in depth,²⁸ deep change’s *resistance* to

²⁶ See Merleau-Ponty on the experience of error (2012, 27).

²⁷ Gilbert Simondon (2020), Merleau-Ponty’s student, might speak here of changes dephasing themselves.

²⁸ In Merleau-Ponty’s essay, “Eye and Mind” (1993, 142).

being ordered by time is what lets time-forms show up; deep because deep change is its own dynamic dimension, versus being ordered in advance.²⁹

VII. TIME AS QUASI-TRANSCENDENTAL: IMPLICATIONS FOR ABILITY, DISABILITY, AND NORMATIVITY

We do encounter time as an order that is in principle necessary for experience and the visible. We do encounter time operating as a classic transcendental. I am not denying that. But when we study *how* we encounter this ordering principle, we encounter it as manifest in and through change as eventuating, happening, in its own terms. Change does *appear* to be operating according to a transcendental ordering principle of time. But I am arguing that, on the scale of cosmos and of nature, change is not so ordered, and time eventuates as quasi-transcendental.

Indeed, time is an original quasi-transcendental. There is a truth to normativity being inseparable from time. And so far as transcendentals are transcendentals of something determinate, transcendentals are inseparable from normativity. So: no time, no transcendentals.

Here, though, I want to emphasize that it is not as if time orderings begin to operate apart from what they are orderings of—or apart from *where* those orderings proceed. Time as original quasi-transcendental eventuates with and through the cosmos as place where orderings can appear and proceed, where distributions and flows of energy allow clocks and life to appear. This eventuation of time and place together is a process I call *templancement*. Templancement as original quasi-transcendental corresponds to an *arché*, a principle or source of being. But the whole point is that templancement as *arché* of the visible arises out of deep change. So templancement is an-archic: templancement might not have led

²⁹ Martina Ferrari approaches a similar point in her analysis of the temporality of deep silence through the theme of precession (2021, 197–202). Ferrari is drawing on Mauro Carbone’s discussion of Merleau-Ponty’s remark on precession in a note meant to summarize *The Visible and the Invisible* (Carbone 2015, 58–61). Ferrari is linking this to the theme of the virtual in Bergson via Alia Al-Saji.

Precession is a term from physics that Merleau-Ponty employs to capture processes that do not circle back on themselves in regular cycles ordered by a past, present, and future that would always be aligned, in line. Instead, in precession, various processes disturb one another over their time of operation. We see this in the precession of a gyroscope or top, when its axis of rotation begins to rotate in a cone or wobble; in effect, the rotational momentum of the gyroscope’s wheel that was keeping it pointing in a steady direction begins bleeding out over time, diverging from its own futural direction, so it circles round itself in space and then wobbles as it cycles down. In a bicycle, you can feel precession when you wobble away from riding straight and the momentum of your spinning wheel precessing out of line pulls you back in line: you are feeling rotational momenta overhanging themselves in time and pulling themselves together. My point here would be that precession needn’t be pulling things in line: in deep change, being can wildly wobble. Precession in this sense corresponds to Simondon’s (2020) concept of phasing and dephasing of processes.

to a cosmos or nature that manifests clocks, life, time.³⁰ Templacement *might not have led to a being that supports manifestation at all. The being of the phenomenon is not itself a phenomenon.*³¹

What are the implications for ability, disability, debility, and the world? Hendren (2020) and others who think critically about crip time show how clocks impose norms that contribute to disabling bodies. As with other normative and normate practices, clocking practices appeal to or presume what seems obvious and natural. The framework of time seems obvious and natural, to the point of operating as a hypernorm. But normate practices also tell us other things are obvious and natural, for example, that heterosexuality is natural “because reproduction.” But in fact, biologists find that long term pair-bonding between animals of the same sex is very common; what is not natural is the sort of homophobic conduct we find in humans. Anyway, sex, even on the biological level is far more plastic, complicated, and wondrous than what human societies often say.³²

Here the point is that time is far more plastic, complicated, and wondrous if we look into what makes it “go.” Of course, to be a body, to live, to experience, does entail a patterning of change as time, change changing into cycles upon cycles. But these patterns are ongoingly precarious accomplishments that do not run down rigid rails but rather surf on roiling change. Recent results on the thermodynamics of clocks show that the beat of clocks must dissipate heat—clocks run up time by melting down order. And we forge our patterned times of living in and through our own precarious bodies, in relation to one another and to various fabrics of our built- and timed-world. We should not expect that these patterns will remain the same over one’s lifetime or be the same in all lifetimes. Lifetimes are not lived as happening within a fixed time, they are the happening of changes lived and felt through their own changing ebbs and flows. If time itself is born of change and is subject to change, then norms *and the very possibility of their being norms* is, as emphasized above, born and subject to change as well.

I am suggesting that norms are born out of ontologically precarious deep change. That is another way of saying that norms are born out of life as generative of its livingness. Life does not follow norms, norms follow life. And that means that norms aren’t “normal.” Normalized norms, fixed norms, are abstractions. Norms born of life are inherently ambiguous, open ended, plastic, relational, distributed, labile. There is a sequence of ontological lessons that verges here into a moral lesson: the being of the phenomenon is not

³⁰ This claim finds support in David Z. Albert’s (2000) work in the philosophy of physics that indicates that the arrow of time, the way clocked changes manifest an irreversible direction, cannot be guaranteed to emerge if we analyze change through a purely abstract statistical framework—we need to add a hypothesis about a contingent past, that is, an historical fact. See also Rovelli (2018) on this point.

³¹ That, I think, is part of what Merleau-Ponty (1968) is getting at with his thought of the invisible of the visible. Once there is a visible, its invisible is indeed an invisible of the visible (an invisible indirectly indicated in every visible). But an ontology that takes seriously invisibility as a mode of being precisely precludes saying the being of the invisible is a phenomenon, a visible. We therefore cannot rule out an invisible that would never have manifest a visible. Again, Merleau-Ponty’s point is that the invisible of being is not manifest directly, as visible.

³² See Monk et al. (2019), which notes that same-sex sexual behavior is found in over 1,500 animal species; also see Joan Roughgarden (2004) for earlier work on this topic.

a phenomenon; the being of time is not time; the being of norms is not a norm. Everywhere in being we find expression, *écart*, disparity, creativity.

We thus need to invert the relation between time and change, norms and life—bring these abstractions “down to earth” as Merleau-Ponty would say—if each one of us and every one of us are to flourish as following our own living with others. But this following and flourishing require a rethinking of time: time is not a framework wherein all of this happens, rather time is what follows along in the wake of the happening that allows living in the first place. More profoundly, philosophy would no longer be able to pretend to rely on even time as transcendental. This is a case where the ventures of critical phenomenology, into the thought of crip time, advene into phenomenology itself, by exposing phenomenology to a time that phenomenology presupposes yet cannot constitute, an-archic time of nature within which alone philosophers and philosophy come to live and move and have their being.

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MERLEAU-PONTY'S CÉZANNE AS MISFIT ARTIST

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Maurice Merleau-Ponty's phenomenological writings celebrate the artist Paul Cézanne's ability to capture the nuances of lived experience and find expression for the vitality and meaning of sensory perception, as many scholars have noted.¹ Yet the history of Cézanne's reception in the artworld would seem to complicate this praise. Cézanne has the honor of having works appear in both the 1863 *Salon des Refusés* (Salon of the Rejected) and the 1937 Nazi exhibition of *Entartete Kunst* (Degenerate Art). The term "degenerate"—which had been applied to Cézanne's art even before the Nazis began using it to fuel their eugenic propaganda—explicitly casts modern art as the product of illness, deformity, and disease. It is an ableist term meant to convey the dangers of artistic deviations from traditional methods and subject matters by marking them as products of mental or physical illness, rather than artistic genius and its ability to create new forms of expression. Additionally, as Merleau-Ponty notes in "Cézanne's Doubt" (1964), the painter had his own concerns about his artistic abilities. Merleau-Ponty states that later in life Cézanne "wondered whether the novelty of his painting might not come from trouble with his eyes, whether his whole life had not been based on an accident of his body" (9). The "accident of his body" includes many possible indications of health issues, including anxiety, "fits of temper and depression," antisocial behavior, "a morbid constitution," as well as symptoms of schizophrenia (10).

Yet, unlike the critics who thought that Cézanne's paintings lacked artistry because of assumed physical or mental disabilities, Merleau-Ponty asserts that it "is quite possible that, on the basis of his nervous weaknesses Cézanne conceived of a form of art which is valid for everyone" (11). It is important to note that Merleau-Ponty does not reduce

¹ The scholarship on Merleau-Ponty's Cézanne in relation to his phenomenology of painting and visual perception is very rich. Since my discussion of "Cézanne's Doubt" will focus more on its significance for disability aesthetics, I will not engage with these conversations at length, although some familiarity with them is helpful for understanding my argument. For scholarship that focuses more on Merleau-Ponty's aesthetics, I recommend Jorella Andrews (2019), Paul Crowther (2012), Véronique Fóti (2013), Galen A. Johnson (2010), and Rajiv Kaushik (2011).

Cézanne's art to a mere side effect as critics who failed to see the value of his work have. He avoids reductive, causal accounts of the relationship between the particularities of Cézanne's embodiment and his artistic work to preserve his creative liberty. At the same time, he sees their bond and declares that "*this work to be done called for this life*" (Merleau-Ponty 1964, 20; emphasis in original). This statement is not a claim about causality, nor do we know enough about Cézanne's actual physical or mental conditions to make such a claim. At multiple points in the essay, Merleau-Ponty challenges the distinction between freedom and determination, hereditary and spontaneous, and external causes and deliberate choices. While these distinctions attempt to provide clear and distinct ways of understanding life, they set up false binaries that obscure the complexities of life.² Instead, he states, "[t]here is no difference between saying that our life is completely constructed and that it is completely given" (21). For this reason, trying to ascribe a simple causal connection between Cézanne's embodied particularities and his works of art is reductive and deflates the meaning we might find in them. Yet these embodied particularities are still significant for understanding the meaning of Cézanne's art. It is not an either/or problem. Merleau-Ponty ends his essay with the paradoxical claim that "the life of an author can teach us nothing and that—if we know how to interpret it—we can find everything in it, since it opens onto his work" (25). Merleau-Ponty's essay thus raises the question of how we are to interpret not simply Cézanne's art, but also his life.

Recently, Joel Michael Reynolds (2022) has argued for a more disability-centric reading of "Cézanne's Doubt." Reynolds describes how "the question of Cézanne's embodiment, of what one should or should not make of his ability/disability state, continually appears and reappears" in Merleau-Ponty's essay on the artist (200). Treating the essay as a hermeneutic task that asks us to "enact Cézanne's own doubt (and others' doubt about him)," Reynolds shifts Merleau-Ponty's emphasis toward the very meaning of ability (201). With this interpretation, "Cézanne's Doubt" should be read as in light of the "doubt of what it is to have an ability in the first place" (210). Building from Reynolds's *crip* reading of "Cézanne's Doubt," I will situate these concerns with reading Cézanne as a disabled artist within other discussions of vision and art in Merleau-Ponty's phenomenology and, more broadly, within art history and aesthetic theory.

This paper explores what we find in Cézanne's art when we read the particularities of his embodiment as (dis)abled or, to be more precise, as abled through the lens of *disability gain*.³ The concept of disability gain defies the ability-disability binary, which defines disability as a *lack* of ability, by emphasizing what is *gained* through different disabilities. Ableism restricts the concept of disability to a mere lack or deprivation. Yet the lived experiences and testimonies of disabled people defy this harmful misconception.⁴ When read through

² See Don Beith (2018) for an explanation of this dynamic in Merleau-Ponty's philosophy of nature and consciousness.

³ See Georgina Kleege (2018) and H-Dirksen L. Bauman and Joseph J. Murray (2014) for more thorough explanations of how disability can be understood as a way of opening up perception in beneficial ways. Bauman and Murray's collected volume discusses how Deaf people's experiences demonstrate a wide variety of gains philosophically, linguistically, socially, and creatively.

⁴ See Elizabeth Barnes (2016).

the conceptual framework of contemporary disability studies, Merleau-Ponty's Cézanne can be understood as an example of what the artist gained through his disabilities.

Central to my discussion of Cézanne as a disabled artist are (1) Tobin Siebers's description of modern art as vitally and thematically disabled and (2) Rosemarie Garland-Thomson's concept of disability as *misfitting*. Siebers's book *Disability Aesthetics* helps me to contextualize Cézanne within art history and art theory in ways that bring his disabilities to the fore without pathologizing them and without denying his artistic genius. Garland-Thomson's concept of *misfitting* describes disability not as an inherent trait of one's body, not as a lack of ability, and not as a purely socially determined condition. Instead, disability describes a contingent, contextual dynamic between the flesh and world that creates friction. Misfitting allows for a fluid, dynamic, and phenomenological account of disability. Additionally, misfitting involves phenomenological descriptions of disabled lived experiences that emphasize the depth of awareness and creative world-making possibilities that are gained through disability.

By bringing Siebers's approach to disability aesthetics and Garland-Thomson's concept of misfitting into conversation with Merleau-Ponty's "Cézanne's Doubt" and "Eye and Mind," I will explain how Cézanne's unique way of perceiving the world and capturing it in paint helps Merleau-Ponty to dismantle abstract, disembodied concepts of visual perception and trace the nuanced contours of lived perspective. In other words, what is gained through Cézanne's disabilities is a revolutionary optics that overcomes the limitations of Cartesian optics.

To describe Merleau-Ponty's Cézanne as a disabled, or—more precisely—as a *misfit* artist, I will begin with Reynolds's crip reading of "Cézanne's Doubt" before situating Cézanne's art within disability aesthetics. Disability aesthetics will then provide the lens for interpreting "Cézanne's Doubt" and "Eye and Mind." The first section explains why "Cézanne's Doubt" is about the meaning of ability and needs to be read through philosophy of disability. The second section situates Cézanne within the history of modern art and its meaning for disability aesthetics to provide more context for the tension that Merleau-Ponty raises between the artist's great talent and his doubts over his abilities. The third section employs Garland-Thomson's concept of misfitting to characterize Cézanne's unique and dynamic approach to painting as a type of disability gain. Using disability aesthetics and the concept of misfitting, the fourth section turns to Merleau-Ponty's critique of Cartesian optics to challenge the idea that linear perspective captures lived experience more realistically, which leads us to the need for a misfit optics. The fifth section uses Merleau-Ponty's writings on Cézanne to describe his method of painting as a misfit optics and explains how it captures the lived perspective. I conclude with brief reflections on why deviant ways of perceiving and inhabiting the world are essential to phenomenology and to art.

I. THE NORMATE AND THE QUESTION OF ABILITY IN “CÉZANNE’S DOUBT”

Reynolds’s path-breaking interpretation of “Cézanne’s Doubt” focuses on the question of Cézanne’s artistic ability and whether it bears a causal (*because of*) or contradictory (*in spite of*) relationship to his disabilities and impairments. Understanding Cézanne’s art in relation to his disabilities shifts dramatically depending on how one defines disability. Scholars in disability studies frequently draw a distinction between the medical model and social model of disability. For the medical model, disability is a flaw or deficiency in an individual’s body. The medical model would assert that Cézanne is a great artist *despite* his disabilities and impairments (Reynolds 2022, 205). By contrast, the social model describes disability in terms of socially created obstacles and disadvantages that are the result of “the constant disturbances of ableism” (205). With the social model, for example, a paraplegic’s inability to walk is not in and of itself a disability. It is the created environment—a lack of accessible designs for wheelchair users—and social attitudes and prejudices that make paraplegia a limitation. The idea is that a difference in embodiment only has meaning in terms of its social context. As Reynolds notes, for the social model, Cézanne’s greatness as an artist is *shaped* by his disabilities and impairments:

Shaped not merely in the sense that they shape his bodymind but shaped also in the sense that he invariably learned to navigate and live in a world not made for, and often actively hostile to, those with “abnormal” bodyminds such as his. (205)

While the distinction between the medical model and social model is now common in disability studies, it was not available to Merleau-Ponty. At the same time, it can be helpful for considering the meaning of Cézanne’s possible disabilities in “Cézanne’s Doubt.” This distinction, as Reynolds describes, “is a dance between reading Cézanne’s work as a symptom *or* as symbol” (209; emphasis in original).

For Reynolds, this question goes to the very nature of ability and whose experiences and ways of thinking count as being meaningful for others. Engaging with Cézanne’s art as a symptom makes it a curiosity—an outward marker of something that may not be significant to those who do not share his embodied experiences. It dismisses what his art has to offer. This dismissive attitude points toward a problematic concern with what is deemed normal, not simply in a descriptive way but also in a normative way—that is, a concern with how people *ought* to be. Here the concept of the normate as “a persistent and compulsory mythic norm” becomes helpful (205).

At the center of Reynolds’ interpretation is the distinction between *normality* and *the normate*.⁵ The concept of normality is at work in phenomenological method insofar as its *epoche* attempts to identify “regularities of experience either in general or relative to some domain X with respect to some specified set of conditions” (202). Both art and

⁵ Garland-Thomson (2017) coined the normate in *Extraordinary Bodies*. For more information about the history and stakes of this concept, see Reynolds’s (2019) contribution to *50 Concepts for a Critical Phenomenology*.

phenomenology attempt to capture what lived experience is like and in doing so often rely on some aspect of normality. Reynolds further distinguishes between *lived normality* and *represented normality*. They describe *lived normality* as

an act, process, or state of being that is experienced either as concordant, “going-with-the-flow,” and at-home-like or as instead optimal, as going beyond concordance to an ideal or near-ideal fit relative to some set of specific actions or intentions of the individual. (2022, 202–03)

By contrast, *represented normality* judges certain aspects of experience as “normal” according to a social standard for actions or intentions. The *normate* is distinct from both lived and represented normality insofar as it is “a product of and functions through *mythic* norms” and “educes an overriding *ought*” (203; emphasis in original). The forceful *ought* of the normate asserts not only that bodies ought to be and act a certain way but also that they are defective and without value if they diverge from what is “normal.” Moreover, the concept of “normal” at work in valuing some bodies and devaluing others is based on a myth of “how things are and must be” and not any realities of embodiment (203).

In *Extraordinary Bodies*, Garland-Thomson (2017) coins the normate to describe an imagined bodily and cultural configuration, a “veiled subject position” that seems to serve as a general and neutral concept for the human person, until one tries to specify its characteristics in detail and notices that it describes “only a minority of actual people” (8). The normate serves as a “social figure through which people can represent themselves as definitive human beings” (8). Yet this social figure is merely the outlines of what is left when any form of difference or otherness has been excluded. The normate creates a narrow concept of what a human is and should be, which then dehumanizes any form of otherness outside it. As the constructed identity of the normate serves as a reference point for people to assert their humanity, Garland-Thomson points out how often people “try to fit its description in the same way that Cinderella’s stepsisters attempted to squeeze their feet into her glass slipper” (8). The normate is not simply a myth because it is based on the fantasy of what is normal. It is also a myth in the sense that it shapes values, judgments, and feelings at a deep level that is often unquestioned.

Reynolds brings the distinction between normality and the normate to bear on Merleau-Ponty’s reading of Cézanne to highlight how differently his art is evaluated when it is seen as the result of a disability, rather than the expression of artistic ability. As Reynolds explains, “[i]f you do X and are considered able-bodied, there is one evaluative scale. If you do X (the very same X) and are considered disabled, there is another scale” (2022, 207). Yet that scale of evaluation for those considered disabled is highly inconsistent and can express pity or praise. There is no one script for interpreting how an artist’s disabilities contribute to or detract from their work, but such interpretations frequently fall into ableist tropes. Ableism does not always express itself as an outwardly negative response to the disabled. It can also wear the mask of approval, praise, or celebration—such as inspiration porn or superhero narratives.⁶ The artworld is replete with examples of how differently artistic

⁶ See Eli Clare (2015) and Barnes (2016).

ability is read alongside disability. Frida Kahlo's childhood polio and chronic pain caused by injuries from a bus accident are treated as fuel for her artistic creativity, especially since some of her paintings deal directly with her disabilities and hospitalizations. In other cases, disability prevents people from being given the status of "artist." For example, art critics have questioned whether the fiber sculptures of Judith Scott, the Deaf, nonverbal fiber artist with Down syndrome, can be said to be art.⁷ When the normate is at work, whether an artist's work is considered a symptom of an illness or an expression of their life, a pathological behavior or a transformative activity, is determined by how well their bodymind adheres to the fantasy of "normal." These problematic dichotomies, moreover, are part and parcel with the normate and the assumption that any deviations from the norm strip a person and their actions of value or meaning. Reading Merleau-Ponty's Cézanne as a misfit artist attempts to overturn this problematic dichotomy.

A disability-centric approach to "Cézanne's Doubt" thus requires challenging the normate. The normate assumes that ability—including artistic abilities—absolutely must be the result of a "normal" body or mind. It assumes that no great art can come from disabled bodyminds. To assert otherwise would be to acknowledge that deviations from this mythic norm may have value. The mere thought that differences in embodiment can have value would destroy the myth of the normate since it so firmly relies on denying this possibility.

The following section will delve more deeply into how the normate functions in the artworld, both in terms of its history and in terms of aesthetic theory. Here I will rely heavily on Siebers's disability aesthetics as a lens for interpreting modern art. I will argue that disability aesthetics allows Cézanne to be both a great artist and a disabled artist without contradiction and that his greatness as an artist should be considered in terms of disability.

II. "DEGENERATE" ART AND DISABILITY AESTHETICS

The normate helps us to understand the history of Cézanne's reception in the artworld, the ableism that casts doubt on his artistic abilities, and the value of embracing, rather than denying, the idea that his art might be a product of his disability—where disability is not a

⁷ See Siebers's (2017) discussion of Scott in *Disability Aesthetics*. Scott spent much of her life neglected and isolated in an asylum and did not start to create fiber sculptures until she was enrolled in an art therapy program. When she began making these objects, it was not clear if they were intentionally art objects. Her works of art involve weaving pilfered materials, like paper towels, around an acquired object. There is no clear intention to express a feeling or idea, communicate to an audience, or even display her work. Despite the originality, complexity, and skill of her fiber sculptures, critics question whether she should be considered an artist and her creations works of art. For some art critics, Scott's mental impairments and lack of education or knowledge of the world preclude her from inclusion in the artworld. Yet, as Siebers explains, this exclusion has more to do with ableist constructions of what an artist should be, rather than any of the qualities of her art. Siebers explains how Scott's fiber sculptures embody many of the ideals of modern art, including found art. He states that Scott's method of creation "demonstrates the freedom both to make art from what she wants and to change the meaning of objects by inserting them into different contexts" (17). Additionally, he outlines a number of aesthetic principles at work in her technique, which he describes as "a process of concealment and discovery that destroys one object and gives birth to another mysterious thing" (17).

lack of ability but instead a difference that matters. Here it is important to understand the ableist rhetoric around not simply Cézanne as an artist but also the artworld that provides the context for his work and its reception.

More than once, Cézanne's art was excluded from exhibitions for not adhering to norms: the 1863 *Salon des Refusés* (Salon of the Rejected) and the 1937 Nazi exhibition of *Entartete Kunst* (Degenerate Art). The *Salon des Refusés* rescued works of art that were rejected by the Paris Salon for not conforming to the standards of the Academy and put them on display for public opinion. Emperor Napoleon III wrote that he wished to let the public judge the legitimacy of the art, which was a revolutionary democratization of the artworld that we now recognize as the beginning of modernism in painting. By contrast, the Nazi Degenerate Art exhibition was eugenic propaganda that was meant to expose the dangers of modern art for a healthy society by illustrating its relationship to mental and physical disabilities.

Both the *Salon des Refusés* and the Degenerate Art exhibition displayed art that was considered deviant in style and/or content. Yet both exhibits included many famous artists who went on to shape modern art, such as Édouard Manet, Camille Pissarro, Ernst Ludwig Kirchner, Paul Klee, Pablo Picasso, Joan Miro, Piet Mondrian, Marc Chagall, and Wassily Kandinsky. It is significant that, in the end, what was rejected for not fitting came to define modern art. From a contemporary perspective, inclusion in these exhibits demonstrates the role Cézanne played in *redefining* art. While the concept of “normal” often excludes artists and their works from public spaces, especially places where prestige and status matter, art continually transforms into new styles, forms, and modes of expression. In this sense, I want to assert that art, especially modern and contemporary art, tends to push back against the normate and challenge its fear of differences. If we turn to twentieth century art history, Nazi Germany vividly illustrates how the normate suppresses the vitality and meaning of art through its rigid and narrow concept of how bodies and minds ought to be. Here I will focus on the concept of “degenerate” art, its relation to eugenics, and its significance in art history and disability aesthetics.

The normate operates in the artworld by determining what is “true art” or “great art” and what is “degenerate art,” and its justifications always rest on the distinction between what is normal and abnormal. The Nazis were not the first to call Cézanne's art degenerate. A 1916 review by Petronius Arbiter described one of Cézanne's paintings of bathers as a “childish drawing” with “utter extravagance of form” and an “impossible construction” of figures (1916, 205). Arbiter uses highly ableist language to describe Cézanne's art:

Now when these semi-insane happen to be bitten with a desire to shine in Art they are sure to quit the normal ways of seeing, feeling and doing things and to go to the abnormal; finally, under the stimulus of a love for suffering and of parading they creep farther and farther toward the abnormal until they are completely insane. (205)

Due to Cézanne's “abnormal” way of presenting the visible world, Arbiter declared his painting of bathers to be “an absolutely degenerate work of a man who is partially insane”

(Arbiter 1916, 205). According to this bombastic review, Cézanne’s art is not simply poorly executed or lacking in beauty—it deviates from norms in a way that is labeled degenerate and assumed to indicate mental illness.

The Degenerate Art exhibition made a similar judgment about modern artists in general—for example, declaring the artist Klee to be mad based on similarities between one of his portraits and a picture drawn by a schizophrenic patient. The content of the exhibit was based on Paul Schultze-Naumburg’s (1928) *Kunst und Rasse* (Art and Race), which argued that modern art movements like Fauvism and Cubism were corruptions of the artworld resulting from growing mental and physical deformities in Northern European races. These juxtapositions demonstrate the simplistic, pseudo-scientific rhetoric of the normate and the force of its desire to draw a hard line between ability and disability. The works of art were displayed not for admiration, but as a warning of the dangers of “the abnormal.” Viewers were to look at the similarities between the degenerate paintings and photographs of disabled people with disgust and fear (fig. 1).

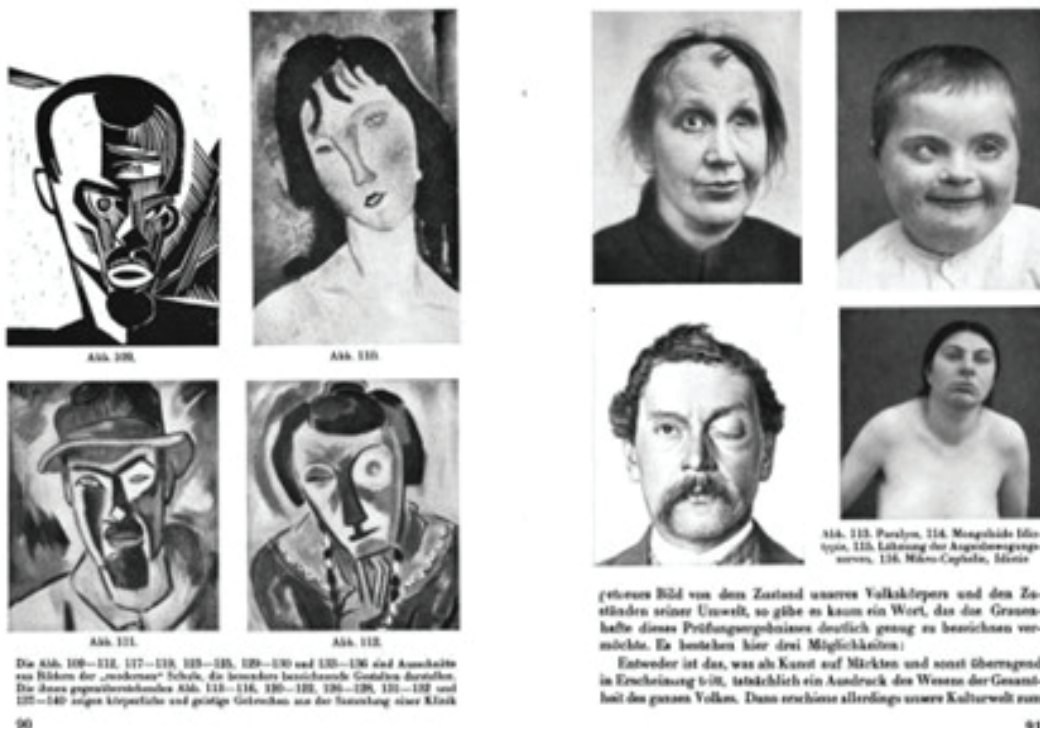


Figure 1. Images from Schultze-Naumburg’s (1928) *Kunst und Rasse* (Art and Race). Commons.wikimedia.org (fair use). Image description: Four portraits painted in expressive styles that characterize modern art movements like Fauvism and Cubism are compared with four photographs of people with visible disabilities.

The normate takes these works of art and strips them of any meaning outside of their perceived failings. When “normal” is the only aesthetic value at work, it becomes impossible to understand or appreciate modern art. More importantly, the Degenerate Art exhibition demonstrates the dangers of the normate. The underlying message of the exhibit is to deny that these works of art or people have any value or humanity and should be eradicated. The exhibit operates according to the same mindset as Hitler’s T4 program, which ordered the mass killings of disabled people in psychiatric and medical institutions.

The Degenerate Art exhibition promotes eugenics through its extreme application of the normate. The significance of the exhibition’s juxtaposition of art and disability reverses, however, if we question the normate. In *Disability Aesthetics*, Siebers (2010) makes this move through the provocative argument that the Nazis correctly interpreted modern art through the lens of disability but incorrectly understood the meaning of this connection. He states:

The Nazis waged war against modern art because they interpreted the modern in art as disability, and they were essentially right in their interpretation, for modern art might indeed be named as the movement that finds its greatest aesthetic resource in bodies previously considered to be broken, diseased, wounded, or disabled. (35)

Instead of contradicting the comparisons the Nazis made between modern art and disability, Siebers explains why this interpretative framework makes sense and how disability creates compelling art. As Siebers describes, “[p]eople quivering with anxiety, howling in fear, or cringing in silent terror populate modernist canvases, openly embracing situations and conditions thought abnormal and feared by the Nazis” (35). For example, art movements like Dada or expressionism used broken lines, unnatural coloring, and distorted figures in ways that made bodies seem disabled. Additionally, he notes how common themes in modern art—“alienation, violence, panic, terror, sensory overload, and distraction”—are often related to a wide variety of disabilities (35). That does not mean, however, that we should react to this art or to disabilities with disgust or fear. It is not the analogies between modern art and disability that are an issue—it is the assumptions that follow those analogies.

The normate denies the possibility of understanding disability in modern art as meaningful and worthy of aesthetic appreciation. Here it is important to emphasize that resisting the normate does not mean denying the influence and presence of disability in art, but instead seeing disability as valuable and meaningful. Nazis failed to see the value of modern art because of their eugenic ideology and extremely narrow concept of what is normal. As Siebers writes,

they attacked modern art for the very features that give it such imaginative and transformative power to represent the human condition—be it the capacity to claim through formal experiments and new content a vast array of human emotions, thoughts, and physical appearances or be it the confidence to leave behind the imitation of nature and to represent what nature might reject or fail to conceive. (35)

Modern art takes up the varieties, complexities, ambiguities, and contradictions of human life. It finds expression for emotions and ideas that are difficult to express. It courageously plays with artistic mediums and styles to explore what is possible. All of these qualities can be understood in relation to disability, and Siebers argues that we ought to make disability more central to our discussions of modern art.

For Siebers, the comparison between modern art and disability is important for understanding its value in redefining art and aesthetics. He argues that we ought to theorize “disability as a unique resource discovered by modern art and then embraced by it as one of its defining concepts” (2010, 2–3). He asserts that disability provided modern art with “a critical resource for thinking about what a human being is” in a broader sense and thus allowed it to portray a wide variety of human forms and experiences (3). In this sense, disability was central to the success of modern art. Disability is consistent with artistic ability and its transformative powers.

Modern art contradicts the normate and can only be understood in contradiction to the normate. The normate’s lack of artistic sensitivity and narrow concept of humanity become even more pronounced when we turn to what Nazi Germany categorized as “great art.” The art Hitler used to illustrate his vision for Germany included many examples of idealized bodies. Part of Nazi iconography includes giant figural sculptures that depicted exaggerated muscular men and women posed as if they were demonstrating their health and vigor. Siebers compares the vibrant, diverse, and expressive modern art that Nazis condemned with the 1937 Great German Art exhibition to demonstrate “how truly unreal and imaginary are nondisabled conceptions of the body” (2010, 31). He examines how extreme fear of bodily variation led to “overcharged regularity” and “emphasis on banal, unvarying, and exaggerated perfection” (32, 33). Nazi art expresses their eugenic ideology and yields cold, dominating presences that lack the humanity of the art they rejected. The Great German Art exhibition presents the “eerie world, sought by the Nazis, in which the desire for perfection quashes individuality and variety” (32). It illustrates how the demand for normality obfuscates our embodied experience and dynamic relationship with the world by replacing generative nuance, variation, and ambiguity with an artificial, unimaginative sameness. Modern art and disability aesthetics reject such limitations to embrace a broader, more varied concept of humanity.

It is important to note that art theorists consider Nazi art to be kitsch or “bad art,” and “degenerate” art to be avant-garde, or aesthetically and culturally significant art. “Kitsch” means “trash” in German and has come to describe bad art and bad taste in general. Art theorist Clement Greenberg (1961) describes kitsch as the “rear-guard,” as opposed to the avant-garde, or “vanguard” of art that is cutting-edge, innovative art. While avant-garde is original and experiments with medium, technique, subject matters, and meaning, kitsch tends to copy and remix ideas in ways that are easy to consume without reflection. Greenberg describes kitsch as art that is “mechanical and operates by formulas” (10). It is thoughtless insofar as “identifications are self-evident immediately and without any effort on the part of the spectator” (14). The avant-garde can address complex, nuanced ideas and values, while kitsch lacks complexity and tends to express simpler emotions like sentimentality. Moreover, Greenberg notes how well kitsch serves as propaganda for

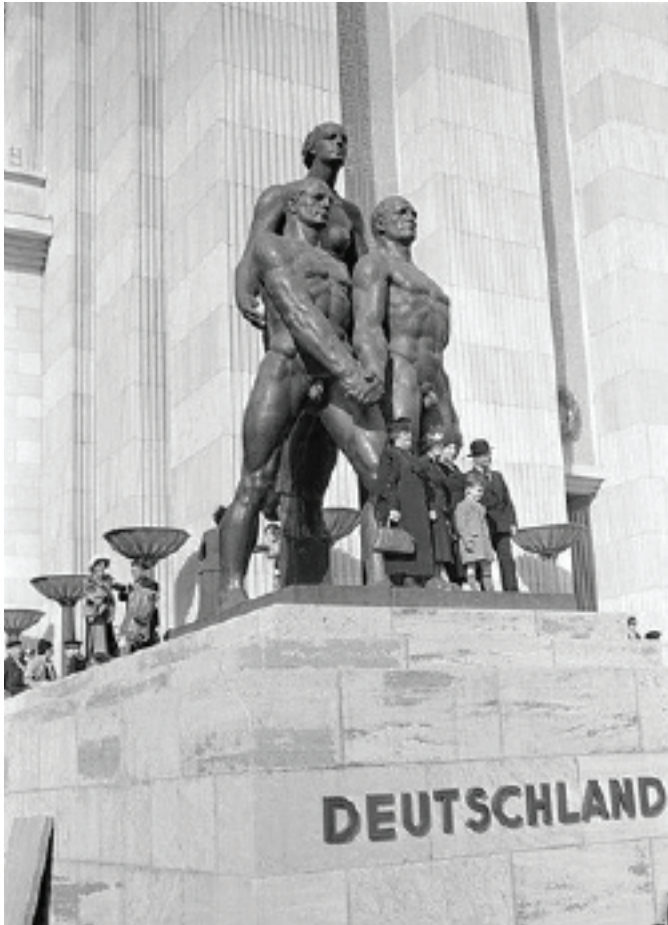


Figure 2. 1937 photograph of Josef Thorak's sculpture, *The Family*. Commons.wikimedia.org (public domain). Image description: Three nude figures, two male and one female, with exaggerated muscles and identical facial expressions stand rigidly on a pedestal that reads "Deutschland."

the rhetorical question, "would Nazi art be considered kitsch if it had not pursued so relentlessly a bombastic perfection of the body?" (5). The answer seems evident the more you examine the differences between the Degenerate Art exhibition and the Great German Art exhibition. Kitsch does not allow disability—or perhaps it makes sense to say that kitsch cannot portray disability because of a superficial and simplistic adherence to perfection. Kitsch art demonstrates the limitations of the normate.

For these reasons, addressing Cézanne's art in terms of his disabilities can enlarge and enrich our sense of its artistry. The following section will examine Cézanne's art through a specific approach to disability, *misfitting*, which is distinct from the medical model and social model of disability and allows a more phenomenological approach that focuses on the dynamics between the body and world.

totalitarian leaders like Hitler (19). The Degenerate Art exhibition and Great German Art exhibition illustrate the stark contrast between kitsch and avant-garde art. The so-called "degenerate" art is multicultural, requires reflection, asks questions, experiments with how we see the world and ourselves, and plunges into the depths of human experience, including experiences that are challenging or difficult to understand. The Nazi conception of "great" art displays one cultural identity, is simplistic in its messages, lacks reflection or any critical edge, hides and eliminates what it cannot understand, and expresses a dangerous nostalgia that is opposed to anything new or different (fig. 2).

As Siebers notes, comparing these two art exhibits demonstrates that "the acceptance of disability enriches and complicates notions of the aesthetic, while the rejection of disability limits definitions of artistic ideas and objects" (2010, 3). Kitsch often expresses an admiration for a superficial sense of perfection. Siebers poses

III. MISFITTING AND CREATIVE WORLD-MAKING

While the normate exemplifies the refusal to understand disability as anything other than a lack of ability, there are many other ways to conceptualize disability. I find Garland-Thomson's concept of misfitting particularly helpful in understanding Cézanne's artistic abilities through his disabilities.

Garland-Thomson describes disability as *misfitting* to address the gap between the medical model that understands the body as the source of disability and the social model that focuses on discursive social practices that create barriers for people with impairments. Rather than focusing on an individual's body as the medical model or on their milieu as the social model, misfitting addresses the tension between the body and world. In general, fitting is when two things correspond and can be joined without friction, whereas misfitting describes an inharmonious relationship between two incongruent things, like "a square peg in a round hole" (2011, 593). The misfit concept of disability thus addresses both the body and the world, which in turn allows for a more phenomenological account of what it is like to experience embodied, material friction with a world that was built to accommodate a very narrow concept of the body. At the same time, misfitting describes disability as contextual and fluid. It investigates a "dynamic encounter between flesh and world" that is neither static nor stable (592). Since fitting and misfitting involve specific dynamics within a concrete context, when "the spatial and temporal context shifts, so does the fit, and with it meanings and consequences" (503). Misfitting is fluid and shifts with changing circumstances and cannot be understood in isolation—it "emphasizes context over essence, relation over isolation, mediation over origination" (593). Misfitting provides a phenomenological approach to disability by "framing the materialization of identity and subjectivity as perpetual, complex encounters between embodied variation and environments" (602). Like Merleau-Ponty, Garland-Thomson emphasizes relationality, contingency, and flesh. Additionally, like Merleau-Ponty, she avoids disembodied abstractions and false binaries that separate the body from the world.

The concept of misfitting also helps us to understand disability gain because it highlights the creative world-making of people who do not fit into the world as it was constructed. While fitting has many privileges, it also supports obliviousness to material realities such as contingency, vulnerability, and dependence. Garland-Thomson describes fitting as "when a generic body enters a generic world" and can move through it without friction (2011, 595). Fitting allows an unproblematic encounter with the world—there are supports rather than obstacles and actions are sustained rather than interrupted. To fit, one must occupy a "dominant subject position" that allows one the privilege of moving through the world anonymously, one's identity unmarked and one's place unquestioned (597). Yet this lack of friction can cause the dynamic between the self and world to recede from attention. Misfitting thus draws out the meaning of disability as a form of subjugated knowledge. While fitting has many social and material privileges, it also supports obliviousness to material realities, contingency, vulnerability, and dependence. As Garland-Thomas explains,

When we fit harmoniously and properly into the world, we forget the truth of contingency because the world sustains us. When we experience misfitting and recognize that disjuncture for its political potential, we expose the relational component and the fragility of fitting. Any of us can fit here today and misfit there tomorrow. (Garland-Thomson 2011, 597)

By contrast, the misfit is more aware of the way the world is constructed because of their dynamic with it. Rather than being generic and anonymous, the misfit is more particular and brings into focus specific material dynamics. There is greater awareness of one's body, the world, and the contingent relationship between them. Fitting can make it easy to forget that we are dependent and vulnerable. It can support the myth of the fully independent, autonomous subject—a *thinking thing* (*res cogitans*) defined by intelligence, rather than materiality. The experience of misfitting shatters these illusions and “ignites a vivid recognition of our fleshiness and the contingencies of human embodiment” (597–98). Misfitting thus makes the body, material environment, and conditions for the possibility of an action come to the fore.

Posing Cézanne as a misfit artist does not pathologize his art but instead highlights his *vivid recognition of fleshiness* and the *contingencies of human embodiment*, to use Garland-Thomson's language. It is because Cézanne does not fit into the narrow definitions of what is normal that he was able to paint the world as he did, which Merleau-Ponty describes as “abandoning himself to the chaos of sensations” (1964, 13). As a misfit artist, Cézanne invites us to reconsider narrow conceptualizations of human embodiment and to reinvestigate what we know about perception. In the following two sections I will argue that it is this quality that makes his painting so useful for Merleau-Ponty's phenomenology of visual perception. I will first begin with the obstacle to understanding visual perception—Cartesian optics and linear perspective—before explaining how Cézanne develops a misfit optics in his paintings.

IV. THE PROBLEM OF CARTESIAN OPTICS AND LINEAR PERSPECTIVE

Cézanne's art is significant for Merleau-Ponty's phenomenology of vision, as well as his phenomenology of art and painting. Merleau-Ponty explains that Cézanne discovered that “the lived perspective, that which we actually perceive, is not a geometric or photographic one” even before psychologists made this realization (1964, 14). While Cézanne's artistic style does not appear to be realistic in the sense of the academic paintings that preceded his work it captures something very real about embodied visual perception. Specifically, Cézanne discovers the lived perspective through his opposition to abstract mathematical models of optics that treat the visual field like a grid. Here I will read “Cézanne's Doubt” through Merleau-Ponty's (1993) “Eye and Mind” to explain why linear perspective does not actually capture visual perception and why a misfit approach to optics is needed.

Merleau-Ponty begins “Eye and Mind” with an account of how the scientific attempt at objectification fails to capture phenomena. He writes,

Science manipulates things and gives up living in them. Operating within its own realm, it makes its constructs of things; operating upon these indices or variables to effect whatever transformations are permitted by their definition, it comes face to face with the real world only at rare intervals. (Merleau-Ponty 1993, 121).

The world is treated as a collection of opaque objects that can be reduced to a set of data “to test out, to operate, to transform” and as a result such experiments admit “only the most ‘worked-up’ phenomena, more likely produced by the apparatus than recorded by it” (121–22). This approach constructs its object in terms of its instruments and their operations and reduces phenomena to the organization of data.

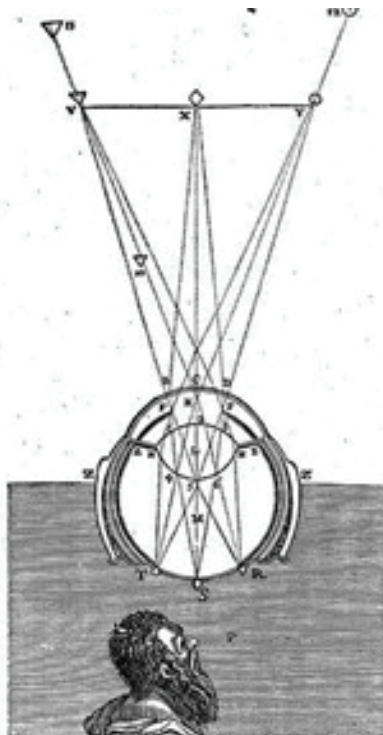


Figure 3. Descartes, *Diagram of Cular Refraction*. Commons. [wikimedia.org](https://commons.wikimedia.org) (public domain). Image description: This image shows the profile of a person looking in the distance. Above the person is a large diagram of an eye, a cross-section with multiple triangles to convey the field of vision. It demonstrates Descartes' geometrical account of vision.

For Merleau-Ponty, Descartes' *Dioptrics* presents a perfect example of the abstract construction of perceptual experience based on “objectivity” and “correctness.” Descartes' optics gives a mathematical model of vision, which is completely distinct from presenting vision as it is experienced: “Here there is no concern to cling to vision. The problem is to know ‘how it happens,’ but only enough to invent, whenever the need arises, certain ‘artificial organs’ which correct it” (Merleau-Ponty 1993, 130). Instead of giving an account of visual perception as it is experienced, Descartes idealizes our vision by giving it geometrical form—i.e., linear perspective and plane projection. Descartes follows the ambitions of the theoreticians who “wanted to forget what they disdainfully called *perspectiva naturalis*, or *communis*, in favor of a *perspectiva artificialis* capable in principle of founding an exact construction” (135). In perfecting the geometry of how objects are seen, early modern thinkers hoped to establish the ideal vantage point, the absolute perspective, from which objects could be seen in perfect clarity with absolute determination. It is an attempt “to rediscover the true form of things” (135). Yet the process of idealizing vision erases our experience of it. Cartesian optics is not personal or subjective visual experience, but rather “a network of relations between objects such as would be seen by a third party, witnessing my vision, or by a geometer looking over it and reconstructing it from outside” (138). In this sense, optics is necessarily artificial and fails to capture the experience of vision. Merleau-Ponty states that Cartesian optics is constructed from

the isolated reason of the thinker, and relies upon the mind, not the world. He explains, “[a] Cartesian can believe that the existing world is not visible, that the only light is of the mind, and that all vision takes place in God” (Merleau-Ponty 1993, 146). The idea that the world can be deduced mathematically from an absolute vantage-point (God) is present within Descartes’ *Meditations* as well as the *Optics*. Cartesian optics, like Cartesian epistemology, declares that things must be clear and distinct to be true. To achieve this clarity often requires a divine vantage point above our flawed human one. Yet Descartes’ idealization of visual experience leads to an artificial perspective that separates rather than joins us to the world. The objective model of vision abstracts from the subject, the object, and more importantly their relation, and replaces everything with mathematical points that are meant to clarify and correct the errors of the lived perspective (fig. 3).

Like Descartes’ optics, linear perspective attempts to replace our field of vision with a geometrical grid. Linear perspective is more than a set of geometrical rules for creating the illusion of three dimensions on a two-dimensional surface; it expresses a way of knowing and being in the world. The history of visual art teaches us that linear perspective had to be invented and with it came many ontological and epistemological assumptions. Many art historians and theorists have asserted that perspective in visual art acts as a theory of space, of bodies, of subjectivity, and of our relation to the world and to each other.⁸ In *The Poetics of Perspective*, James Elkins (1994) explains how much the concept of perspective has changed across time. He contrasts the use of linear perspective with Renaissance art, which used multiple perspectives. For Elkins, linear perspective replaces a set of pluralistic practices with a more monolithic, abstract, geometrical, and unified concept of vision, space, and subjectivity (xi–xii). It substitutes a variety of viewpoints with one that is, as Elkins describes, monolithic. We can see how linear perspective forecloses and limits our ways of seeing. Moreover, linear perspective describes a mastery over the world, the ability to make sense of it and articulate its hidden logic. As Hanneke Grootenboer states in *The Rhetoric of Perspective*, “[p]erspective makes a particular claim to truth” (2005, 3). For Grootenboer, perspective is best described as a *rhetoric*—that is, “a model of thought” and a “system of persuasion” (10). Perspective is not something visible, but a way of making things visible, which means it can often function in invisible ways. Gootenboer notes that the Dutch call it *deurzigkunde* (the art of transparency) and that “because we see through it, we are unaware of its operating system, so we look at objects that appear within this system as if they are truth itself” (92).

Cartesian optics and linear perspective thus might be read as forceful attempts to *fit* the ambiguity of human perspective into the clarity and regularity of a geometric one. Like the normate, it substitutes the imperfections and variations of our concrete, material existence for idealizations. It invents in order to “correct” at the same time that it claims to capture reality through artifice. As Garland-Thomson has noted, “[o]ne of hallmarks of modernity is the effort to control and standardize human bodies and to bestow status and value accordingly” (2011, 598). Cartesian optics, like the normate, asserts an idea of how bodies ought to be based on a myth that oversimplifies the complexity and varieties of embodiment. Garland-Thomson writes,

⁸ See Erwin Panofsky (1997) and Hubert Damisch (1994).

Although modernity presses us relentlessly toward corporal and other forms of standardization, the human body in fact varies greatly in its forms and functions. Our experience of living eventually contradicts our collective fantasy that the body is stable, predictable, or controllable, creating misfits of all of us. (Garland-Thomson 2011, 603)

In contrast to these artificial constructions of visual perception, Merleau-Ponty asserts that “art, especially painting, draws upon this fabric of brute meaning which operationalism would prefer to ignore” (1993, 123). Cézanne’s approach to visual perception differs from the artificiality of Cartesian science because he does not reduce experience to the clarity and order of geometry. He preserves the complexity and ambiguity of lived experience and allows us to experience perception in all its richness. The following section will consider how Cézanne breaks down these false constructions to convey visual perception in all of its dynamic, embodied complexity.

V. CÉZANNE’S MISFIT OPTICS

Cézanne’s artistic style does not fit the sense of clarity and order that traditional perspective painting offers, however, in breaking from such assumptions about vision, he offers a new optics—which I will describe as a *misfit* optics. For Merleau-Ponty, Cézanne’s attempt to develop a new optics through painting captures our perception of the world more faithfully than reductive, absolutizing, Cartesian optics.

Cézanne’s experimentation with perspective captures how we experience the world through visual techniques that we might consider examples of misfitting. In Cézanne’s paintings the outlines between shapes are broken and imperfect, objects are stretched at the bottom, and images collect at different angles. For example, in Cézanne’s (1890–94) *Still Life with Basket of Apples*, the back edge of the table looks dramatically higher to the right of the basket, and the front edges are also broken and irregular (fig. 4). These alterations would seem distorted in comparison to academic painting, which utilizes linear perspective; however, as Merleau-Ponty indicates, such “distortions” are truer to our lived perspective. When lines of one object are broken by another object, the line no longer seems straight and continuous to our lived perspective. Nor do we see things as perfectly ordered on a grid. Instead, “when our eye runs over a large surface, the images it successively receives are taken from different points of view, and the whole surface is warped” (Merleau-Ponty 1964, 14). These distortions are not arbitrary or simply for artistic effect but demonstrate Cézanne’s remarkable sensitivity to the complexity of perception. Breaking the traditional rules of linear perspective allows Cézanne to paint our lived perspective. As Merleau-Ponty describes,

it is Cézanne's genius that when the over-all composition of the picture is seen globally, perspectival distortions are no longer visible in their own right but rather contribute, as they do in natural vision, to the impression of an emerging order, of an object in the act of appearing, organizing itself before our eyes. (Merleau-Ponty 1964, 14)

For Merleau-Ponty, Cézanne's painting evokes our pre-reflective experience in a way that Cartesian optics cannot.

Cézanne's paintings draw us to recognize the unified and dynamic embodiment of experience.⁹ Merleau-Ponty explains that the senses are not distinct from each other, especially touch and sight, unless we abstract from lived experience by introducing the concept of pure impressions or sensations (2012, 4). For Merleau-Ponty, the "perceptual



Figure 4. Image: Cézanne, *Still Life with Basket of Apples* (1890–94). Wikiart.org (public domain). Image description: In Cézanne's painting of apples above, the outlines between shapes are broken and imperfect, objects are stretched at the bottom, and the image collects at different angles instead of along a geometrical grid.

⁹ See also Helen A. Fielding (2021).

‘something’ is always in the middle of some other thing, it always belongs to a field” (Merleau-Ponty 2012, 4). He uses a red rug as an example. If I were to try to isolate my visual perception of the color red as a separate impression from how it appears in the context of the carpet, I would have an abstract concept of red that is far removed from my actual sensory perception. Instead, as Merleau-Ponty notes,

[t]he red patch I see on the rug is only red if the shadow that lies across it is taken into account; its quality only appears in relation to the play of light, and thus only as an element in a spatial configuration. Moreover, the color is only determinate if it spreads across a certain surface; a surface too small would be unqualifiable. Finally, this red would literally not be the same if it were not the “wooly red” of a carpet. (5)

For this reason, dividing objects of experience into clear and distinct qualities that are separate from each other does not account for how we actually experience it. For Merleau-Ponty, a pure impression is “not merely undiscoverable, but imperceptive, and therefore is inconceivable as a moment of perception. If it is introduced, this is because, rather than being attentive to perceptual experience, this experience is neglected in favor of the perceived object” (4). This abstract simplification is an attempt to offer a pure object without ambiguity, rather than an account of perceptual experience. Sensory perception cannot be divided into discrete units without artificial divisions. Merleau-Ponty provides the following example to illustrate this unity of the senses:

If a phenomenon—such as a reflection or a light breeze—only presents itself to one of my senses, then it is a phantom, and it will only approach real existence if, by luck, it becomes capable of speaking to my other senses, as when the wind, for example, is violent and makes itself visible in the disturbances of the landscape. (332).

Cézanne was aware of this original unity. According to Merleau-Ponty, “Cézanne said that a painting contained, in itself, even the odor of the landscape” (332).

Cézanne’s method of painting strikes us because he does not treat sight as a separate sense divorced from our experience of the whole. Merleau-Ponty explains that in Cézanne’s paintings the lived object is not constructed from different senses but instead “presents itself to us from the start as the center from which these contributions radiate. We *see* the depth, the smoothness, the softness, the hardness of objects; Cézanne even claimed that we see their odor” (1964,15). Cézanne’s painting relies upon the interweaving of all elements, which is evident within his use of color (fig. 5). The colors, movement, shape, lines, and textures cannot be separated because it is their relations to each other that allow them to articulate an object. For example, Cézanne traces several outlines of “modulated colors” that allow the shape to body-forth with the appearance of depth “as an inexhaustible reality full of reserves” (15). The effect of these colorful, modulating lines on our eye is the same as when we look at an object ordinarily: our eye must take in different aspects continuously without ever capturing all elements completely. As Merleau-Ponty describes,



Figure 5. Paul Cézanne, *Forest* (1890). Wikiart.org (public domain). Image description: This painting of trees illustrates Cézanne’s technique of layering colorful lines in ways that convey their movement and evoke feeling.

“[r]ebounding among these, one’s glance captures a shape that emerges from among them all, just as it does in perception” (Merleau-Ponty 1964, 15). Cézanne use of color suggests the object as it emerges in experience, rather than a discrete object of pure presence. For this reason, Merleau-Ponty describes Cézanne as capturing “the vibration of appearances which is the cradle of things” (1964, 18). These techniques explain why Cézanne’s paintings of trees are so full of life.

Cézanne’s paintings, moreover, are charged with emotion in a way that speaks to the connection between mind and body. Merleau-Ponty writes that “the distinctions of soul and body, thought and vision is of no use here, for Cézanne returns to just that primordial experience from which these notions are derived and in which they are inseparable” (1964, 14). As painter, Cézanne brings together all aspects of who we are. Yet he does not do so in a way that limits human experience to narrow concepts of what is normal or how we *should* experience the world. As Reynolds describes, “Cézanne’s ‘greatness’, then, turns neither on humanistic universality, nor medical pathology, but on the extent to which his singularity and the singularity of his work both *particularizes* and *collectivizes* each to whom it speaks” (2022, 210; emphasis in original).

Often Merleau-Ponty's descriptions of Cézanne liken him to a phenomenologist, especially in terms of his doubt. When Merleau-Ponty explicates Edmund Husserl's phenomenological method in *Phenomenology of Perception*, he underlines the fact that "the return to phenomena" is not a recovery of what already was, but rather the act of bringing phenomena to sight for our investigation. It is a "return" in the sense that it invokes our pre-conceptual experience. As Merleau-Ponty explains, the "eidetic reduction is the commitment to make the world appear such as it is prior to every return to ourselves; it is the attempt to match reflection to the unreflective life of consciousness" (2012, xxx). This paradoxical demand—that reflection present what is unreflective or prior to reflection—means that phenomenology has a fundamentally different task than simply unearthing the source of experience or providing an explanation of its causes. Recovering experience of the world is not a task that can complete itself by capturing phenomena through concepts, as "there is no thought that encompasses all our thought" (xxviii). Instead of a complete method that totalizes and reifies the world as its object, phenomenology must perpetually renew its vision of the world. Accordingly, the "philosopher is a perpetual beginner" (xxviii). Cézanne's paintings renew our vision. They make the world appear as if for the first time. Merleau-Ponty writes, "[o]nly one emotion is possible for this painter—the feeling of strangeness—and only one lyricism—that of the continual rebirth of existence" (1964, 18).

CONCLUSION

I have attempted to make the connection between Cézanne's art and embodied experiences stronger by reading his painting technique as a misfit optics. Misfitting reveals the qualities of lived experience that fitting hides and, in doing so, allows greater awareness of our relation to the world. Cézanne created a new optics that helps us to understand the irreducibility of sight to geometrical grids and ideal vantage-points *not* in spite of his disabilities but *because of* them. Cézanne's misfit optics moreover demonstrates the limitations of aesthetic theories that exclude, and/or pathologize different ways of inhabiting the world. I have also attempted to show how the normate restricts and undermines the creative, expansive, and transformative impulse of art. For this reason, addressing ableism in aesthetic theory helps us to engage with art in meaningful ways that embrace the diversity of human life. As Siebers states the issue, "how difficult it is to think beyond the ideological horizon of ability and how crucial it is to make the attempt. For thinking of disability as ability, we will see, changes the meaning and usage of ability" (Siebers 2008, 11). Aesthetics requires a new concept of artistic ability that does not exclude disability but instead acknowledges the depth, complexity, and richness that come with different ways of embodying the world.

The task of recovering lived experience requires acknowledging the variety, ambiguity, and strangeness of life—all of which a misfit aesthetics illuminates.

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THE POLITICS OF VULNERABILITY AND THE SCHOOL FOR PEACE: INSIGHTS FROM BUTLER, MERLEAU-PONTY, AND FAMILY SYSTEMS THEORY

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In a November 12, 2023 article, journalist Timothée Boutry interviewed residents of the town of Neve Shalom-Wahat al-Salem about their experiences and perspectives following the October 7, 2023 attack on Israel by Islamist group Hamas, and subsequent beginning of the Israeli “total siege” on the Gaza strip—a siege that, at the time of this writing, is well into its fourth month. With a name that translates as “Oasis of Peace,” Neve Shalom-Wahat al-Salem is a village founded in 1970 halfway between Jerusalem and Tel Aviv/Jaffa, as a democratic experiment in which Jews and Palestinians would live, educate, and govern themselves together. Comprised as of 2023 of 70 families, half Palestinian and half Jewish, Palestinian and Jewish children are educated together in both Arabic and Hebrew, and the town government is led in rotation by a Palestinian and a Jewish mayor.¹ With Israeli Defense Force (IDF) fighter planes *en route* to Gaza audible overhead, Roi Silberberg, Jewish resident and current director of the town’s School for Peace, spoke to the intense trauma suffered by both Jews and Palestinians in the wake of October 7:

Everybody has been traumatized, but the two societies have been traumatized in different ways. The Palestinians are victims in Gaza, and victims of increased racism in society and of campaigns for their expulsion in the West Bank. While on the Jewish side, [Hamas’s] actions and the loss of confidence in the State [of Israel] to protect them have provoked an existential crisis. (Boutry 2023; my translation)

Acknowledging these deep collective traumas, Palestinian resident Noor Abu-Ras expressed despair at the actions of Hamas: “I’m obviously not tied to Hamas’s actions, but I think that the Palestinians need to collectively ask themselves the question: Is this how I want to obtain the liberation of my people?” (Boutry 2023, my translation). Silberberg followed with his criticisms of the Israeli response: “The solution [to the conflict between Israel and

¹ See Wahat Al-Salem-Neve Shalom (2023); Rabah Halabi (2004); Zenger Nathan (2007).

Palestine] will never be military. It will only be by promoting peace, equality, justice, and solidarity that we will obtain security” (Boutry 2023; my translation).

This scene dramatically brings into view much of what is at stake in Judith Butler’s sustained exploration of vulnerability as a potent concept for a liberatory and just global politics. While fighter planes fly overhead, on their way to rain months of enormous death and destruction on a captive population in response to a half-day vicious campaign of murder, rape, and kidnapping, neighbors and colleagues from two ethnic groups talk to one another about the traumas of their collective histories, the violent betrayals of their political representatives, and their fears and hopes for the future.

On the one hand, we have enacted (by Hamas and the IDF) violent reactions to a situation of extreme mutual—though unequally distributed—vulnerability. Palestinians in Gaza and the West Bank live in situations of ongoing physical restriction, material dispossession, political oppression, and existential insecurity on account of a long history of the denial of their existence and aspiration as a national group on the part of the state of Israel, beginning with the *Naqba* of 1948. Jews in Israel live in a state that receives enormous financial, military, and ideological support from the United States and other major Western powers, but that is haunted by a long history of anti-Semitic violence most horrifyingly enacted in the Nazi Holocaust in the years preceding the official founding of the state of Israel by Britain, and invoked again and again in the words and deeds of prominent representatives of Israel’s Arab “enemies,” who, in the case of the Palestinian people, are themselves the victims of seventy-five years of European-and American-backed Israeli colonialism. As Judith Butler (2010) argues in *Frames of War*, with both Hamas and the IDF we have violent attempts to devastate the vulnerability of the Other while enacting a stance of invulnerable sovereignty for oneself. Such a psychological response is always possible, Butler argues, when we come face to face with our own and others’ vulnerability.

On the other hand, with Silberberg and Abu-Ras and other residents of Neve Shalom-Wahat al-Salem, we see enacted a shared human grappling with a situation of mutual—though distinctly differentiated—trauma, as well as a shared situation of mutual hope for democratic and peaceful new ways of living together. This grappling and this hope are not without their intense vulnerabilities and difficulties; residents of the town reported that since October 7, in Boutry’s words, “fear set in; we sensed that something was broken,” but that nevertheless, they recognized that “it’s up to us to find the means to maintain faith in our project, but we know it will take time” (2023; my translation). We see here, in the contexts of multigenerational relationships developed over many years and a radical democratic commitment to equality and peace, a very different response to shared vulnerability than that enacted by militant and state violence.

This paper explores what it might look like concretely to acknowledge shared human vulnerability as “the basis for global political community,” as Butler calls for in *Precarious Life* (2004, xiii). Part one offers a phenomenological account of the lived experience of vulnerability as a relational and, in Maurice Merleau-Ponty’s words, “intercorporeal” affair. I argue here, with Butler and Merleau-Ponty, that our relations with both intimate and distant others precede and never cease to inform our identities as individual selves, such that who “I” am is inextricably bound up with the embodied experiences and

perspectives of others. I argue further that we can (vulnerably) embrace or (violently) reject this inherent vulnerability at the level of perception itself, with distinct ethical and political implications. Part two—the theoretical core of this paper—takes up Butler’s argument that vulnerability should be understood not as an attribute of a particular subject or group, but rather as a feature of social relations themselves.² My specific intervention here is to argue that Butler’s understanding of vulnerability as both a universal condition and as differentially distributed across intertwined social relations can be fruitfully understood through the framework of family systems theory, which empirically studies the specific manners in which our behaviors as individuals (and groups) *are what they are* only in virtue of their participation in larger interpersonal (and political) systems. Part Three explores the political significance of the insights of family systems theory through a study of the “encounters” between Jews and Palestinians staged by the School for Peace (SFP), founded in 1979 in Neve Shalom-Wahat al-Salem. We shall see that difficult and vulnerable dialogue with those with whom our experiences and identities are systematically intertwined can enable us to become perceptually alive to our own and others’ existential indeterminacy—to our open-ended identities as vulnerable and dialogically in-the-making—rather than to violently eschew this relational vulnerability. Such dialogical perceptual development, in the words of SFP facilitator Rabah Halabi, has the power “to unravel and then reconstruct participants’ identities” so as to “permit the option of building a more just and humane society”—one rooted in shared human vulnerability rather than vain and jealous attempts at group sovereignty (2004, 70, 8).

I. INTERCORPOREAL VULNERABILITY AND THE NORMATIVE NATURE OF PERCEPTION

In his lecture course, “The Child’s Relations with Others,” Merleau-Ponty (1964) discusses a study conducted by psychologist Else Frenkel-Brunswick (1949) in the wake of World War II on the phenomenon of “psychological rigidity.” Psychological rigidity—a phenomenon that admits of degrees and to which we are all likely prone to some extent—is defined as

the attitude of the subject who replies to any question with black-and-white answers; who gives replies that are curt and lacking in any shading; who also is generally ill disposed, when examining an object or a person, to recognize in them any clashing traits; and who continually tries, in his remarks, to arrive at a simple, categorical, and summary view. (101)

Frenkel-Brunswick’s study found that psychologically rigid individuals commonly also displayed perceptual rigidity. When shown an image of a dog that gradually transitioned into an image of a cat, they would be unable to “see” the change, holding on to the elusive stability of the initial image (105). Frenkel-Brunswick’s study also found correlations between an individual’s psychological rigidity and their political views. While psychological

² Compare to Rosemarie Garland-Thomson’s argument that we should understand vulnerability to reside not “in” the body of the individual, but in its “fit” or “misfit” with the world (2011, 600).

rigidity was most commonly accompanied by aggressively traditional, authoritarian, and racist political views—views that, in Merleau-Ponty’s words, “rest on a myth and can thus be explained only by a psychological mechanism” (1964, 107)—it could also manifest itself in a rigidly liberal political attitude, “which consists in thinking that all men are *identical*” (106; emphasis in original). What both an authoritarian and a rigidly liberal attitude have in common is less a content than a style intolerant of the ambiguity and indeterminacy—of the contextual, dynamic, and often contradictory nature—of things and people in the perceptual field. As we shall see in a moment, such “intolerance for ambiguity” can also manifest itself in a certain style of militant leftism, too.

Exemplary of the phenomenon of psychological rigidity are political clichés and stereotypes that serve to obfuscate, rather than to phenomenologically disclose, the complexity and dynamism of human existence. Consider the term *terrorism*. According to historian of religion Karen Armstrong (2015), the phenomenon is often defined as “the deliberate use of violence, or threat of its use, against innocent people, with the aim of intimidating them specifically or others into a course of action they would not otherwise take.” However, as Armstrong argues, this definition of terrorism “could also be said of some forms of conventional warfare,” and, indeed, “there is general scholarly agreement that some of the largest-scale acts of terrorizing violence against civilians have been carried out by states rather than by independent groups or individuals.” Despite this definitional indeterminacy, Armstrong argues that the term “terrorism” is deployed as “one of the most powerful terms of abuse in the English language, and the most censorious way of characterizing any violent act” (343). In the history of the Israeli-Palestinian conflict, the term *terrorism* has generally been reserved in the mainstream media in Israel and the “West” for the actions of Palestinians—not only militants but also individuals engaged in explicitly non-violent uprisings—rather than for the actions of the Israeli state, despite the fact that the latter is responsible for far greater numbers of deaths, kidnappings and indefinite detentions, and general levels of daily insecurity for Palestinians in Gaza and the West Bank than any Palestinian militants could ever hope to effect in return. Indeed, for many in Israel and “the West” the word “terrorism” is evocative of stereotypical images associated with Islam and the Arab world—long beards, headscarves—despite the majority of terrorist attacks being carried out by secularists and non-Muslims, and for overtly political rather than religious reasons (Welch 2016, 120–21).³ Thus rather than helping us to grapple with the actual terms of a multifaceted and unjust political reality, the term *terrorism* always already “frames,” in Butler’s words, the world in the psychologically-rigid manner of “us” *versus* “them,” “good guys” *versus* “bad guys,” “security” *versus* “terror” (2010, 5–12).⁴

³ A study of every suicide attack since 1980, for example, shows that suicide bombing has *in every case* been a political response of a people with few military means to the military occupation of a dominant world power. See Armstrong (2015, 363).

⁴ See also Jacqueline Rose (2004). This psychologically-rigid attitude is exemplified in George W. Bush’s (2021) address to Congress and the American people, in which he declared: “Either you are with us, or you are with the terrorists.” In Israel since the October 7 Hamas attacks, this same logic has been deployed with regards to those criticizing the Israeli siege on Gaza, or even to those who are perceived to not condemn the October 7 attacks forcefully enough. See Jackie Northam (2024).

From the other side, in the context of the Israeli-Palestinian conflict the term *freedom fighter* similarly advances a psychologically-rigid stereotype. This term has been widely deployed in the wake of the October 7 attacks by many who subscribe to, in Ben Lorber's words, "a particularly strident kind of decolonial politics, born of rage at decades of entrenched oppression of Palestinians, which has so far proven stubbornly unresponsive to nonviolent resistance or moral appeals to equality" (2023). Assigning such one-dimensionally positive stereotypes to a militant Islamist group like Hamas, with its extreme conservative social positions and the "crude anti-Semitism" (in Rashid Khalidi's words) of its charter, is to reduce a morally and politically complex situation into a standoff between (in Lorber's words again) always justified and liberatory resistance, on the one hand, and a uniform category of oppressors, on the other (Khalidi 2020, 210, 220; Lorber 2023). In this context, terms like *invader*, *occupier* or *oppressor* can be deployed in a similarly dehumanizing way as the term *terrorist*: they can work not just to name condemnable political and military practices, but rather to frame the entire Jewish Israeli population into a homogeneous, black-and-white identity.

Psychologically-rigid perception is politically problematic in two, interrelated senses. First, it denies the vulnerable, open-ended, and dynamic nature of human existence in favor of static, stereotypical images, which in turn helps to "frame" some individuals and groups as subjectable to violence in ways that others are not. Second, it denies the perceiver's own implication in, and hence responsibility for, how others are enabled to appear in the world of perception—and, in turn, how the perceiver is able to apperceive their own vulnerable and dynamic existence. Let us explore each of these points in turn.

First, psychologically-rigid perception denies human vulnerability. Human identity, on both the personal and political levels, does not enjoy clear-cut borders that "serve to delimit and define," to "close in and close off," in Edward S. Casey's words (2017, 15). Butler's understanding of vulnerability in *Prekarious Life* stresses the manner in which we are each "laid bare from the start," radically exposed to and shaped by others from before we could say "I" to begin with (2004, 31). Merleau-Ponty's concept of intercorporeality gives phenomenological evidence for this point.⁵ From our earliest days as infants, there is an important sense in which our own experience is lived in relative indistinction from the experience of others. While growing up is the process of coming to gradually establish the boundaries between self and other, this process is never ultimately complete.⁶ Unlike the borders we often rigidly imagine to separate self from other, the boundaries of the self "act to ground, to receive, and to open"; they connect us to others as much as they hold a dynamic line between us (Casey 2017, 15). A scene in Hala Alyan's (2017) novel *Salt Houses* dramatizes the porous, intercorporeal relationship between self and other. Alia Yousef, an elderly Palestinian woman suffering from dementia, observes her granddaughter soothing her crying child on the balcony of the old woman's Beirut apartment:

⁵ See Merleau-Ponty (1968, 143); Merleau-Ponty (2012, 368). Though Merleau-Ponty does not use the term "intercorporeality" in *Phenomenology of Perception*, his discussion of the manners in which the other's body can be given to me as "the completion of the system" already articulates the main idea of the term.

⁶ See Merleau-Ponty (1964, 119, 135).

There is a mewling sound and then silence, and Alia knows the baby has latched onto the breast, feels the phantom sensation in her own nipples, remembers strikingly that relief.

The woman begins to sing, her voice husky.

“*Yalla tnam, yalla tnam.*”

The words are familiar as water, as Alia’s own hands, which lift now to her face, against her cheeks.

“*Yalla tnam, yalla tnam.*”

The song alights within Alia, a remembering akin to joy. Her mother’s garden, a courtyard somewhere in Kuwait, as she sang to a baby at her own breast. She sits in the dark, listening to the ancient, salvaged music. (Alyan 2017, 310)

We see in this scene how the bodily experience of others can be felt within one’s own body, confusing the clear-cut boundaries between self and other. This kinship is experienced as the “anonymous” level of bodies in general, as we see in the manners in which the nipples of women who have breastfed might tingle in response to the sound of an infant’s cry, even decades later.⁷ It is also experienced in the highly personal, embodied memories of songs and places, as Alia’s own experiences as a child and a mother, and of homes from Palestine to Kuwait to Jordan to Lebanon, are poignantly called forth upon hearing a family lullaby on her granddaughter’s lips.

Much of what we live as our “own” embodied movements, emotions, desires, and actions are deeply and mimetically connected to those of others. Walking down the street in a small group toward a lunch restaurant in an unfamiliar city, I find myself “carried along” by the group, unaware of who is leading and who is following. In the absence of reflective notice or thought—I am quite engaged in conversation and not paying particular attention to where I am going—I stop when the others stop, go when they go, turn when they turn, our bodies forming a kind of intercorporeal form moving along the street.⁸ Something similar occurs in experiences of “emotional contagion”; as Butler writes, affects “are never merely our own . . . but communicated from elsewhere” (2010, 50).⁹ In *Salt Houses*, Alyan (2017) gives voice to an experience of affective contagion on the part of Alia’s brother Mustafa, a young Palestinian man in the midst of a political awakening in the year leading up to the 1967 Arab-Israeli War. An admired *imam* has just told Mustafa the story of his family’s expulsion from the fishing city of Haifa, and his sister’s rape at the hands of a group of Israeli soldiers while her family was forced to watch, in the *Naqba* of 1948:

A peculiar sensation skittered through Mustafa. His limbs tingled. That thing he’d read about in books: the moment when the world seems to sharpen, when colors and objects become vibrant, in focus. He could smell the torched streets, could see the young woman naked and bleeding. The glint of fish scales in the early light . . . “I want to help,” he said. (Alyan 2017, 44)

⁷ See Merleau-Ponty (2012, 86, 369).

⁸ For an illuminating study of intercorporeality and imitation, see Kym Maclaren (2008).

⁹ For a study of affective imitation in Merleau-Ponty, see Shiloh Whitney (2012).

Our own embodied experiences are passionately entangled with those of others, such that in powerful moments we can almost “smell” the scene recounted in the words of the other. Crossing the boundaries that simultaneously open me to and distinguish me from others, others’ embodied experiences can be taken up as my own, as my own embodied experiences can take up a life outside of me in the world of others.

Such sympathetic attunement to the embodied experience of others has its counterpart in another form of intercorporeal experience. Consider the experience of partnered dancing. When my partner steps toward me, I must simultaneously step back; when he raises our clasped hands over our heads, I must simultaneously step under our raised arms for the twirl. Rather than my partner’s movements calling forth symmetrical movements in me, as in the example of walking in a group, they call forth complementary movements. Something similar can be at play in more conflictual and alienating experiences of other people in what Jean-Paul Sartre calls “the look.”¹⁰ In *Salt Houses*, Alia’s daughter and Mustafa’s niece Souad, who emigrated to the United States after growing up in Kuwait in the wake of her family’s exile from the West Bank city of Nablus following the 1967 war, is frozen in her tracks by the objectifying and demeaning eyes of white Americans following the September 11, 2001 attacks on the World Trade Center.

During a trip to Texas once to visit a friend, she and Budur stopped at a gas station for cigarettes. Souad felt the clerks’ gaze—two young Midwestern men, eyes like icepicks—on them the entire time. One of the men flung the change at her, several coins falling to the ground. Souad’s fear was like a bell, waking her. As they were leaving, she caught the words *terrorist* and *bitch* and a burst of laughter. (Alyan 2017, 210)

Here, the normal embodied experience of being outside of herself, engaged in projects like buying cigarettes, is for Souad violently interrupted; in Frantz Fanon’s words, “the body schema, attacked in several places, collapsed, giving way to an epidermal racial schema” (2008, 92). The look of the clerks is felt, so to speak, under the skin; it is an exercise of domination that calls forth, like a confrontational “dance,” a complementary response of paralyzing self-consciousness and fear.

We see through these different examples of intercorporeality three deep ambiguities of vulnerability as a human condition identified by Butler. First, our intrinsic vulnerability opens us to what is best in human (co-)existence: to desire, love, connection, embodied continuity with past and future others, and (as we shall see further below) life-expanding and life-enriching transformation. At the same time, our intrinsic vulnerability exposes us to what is worst in human (co-)existence: to violence, degradation, and oppression.¹¹ The second ambiguity is the complement to the first. On the one hand, the vulnerability of the other is a necessary condition for our intimate connection to them, and the vulnerability of more distant others—others whom we will never meet—can inspire in us responses of care.

¹⁰ See Jean-Paul Sartre (1984, 301–03, 340–62). For an account of Merleau-Ponty’s intercorporeality in terms of both “syncretic sociability” and “the look,” see Scott Marratto (2020).

¹¹ See Butler (2004, 27).

On the other hand, the vulnerability of the other can just as well inspire in us rejection and violence.¹² This is especially the case when it comes to the vulnerability of persons and populations deemed less valuable—in Butler’s terms, less “grievable”—than one’s own person or group.¹³ This point is intimately connected to a third ambiguity of vulnerability. While vulnerability on the one hand names a “universal” human condition shared by us all, it is on the other hand unequally distributed across populations and around the globe (Butler 2010, xxv, 14, 25). As we see in talk of “vulnerable populations,” some groups are subject to death, injury, dislocation, starvation, and more in ways that others—for the most part, privileged groups in the “First World”—are not. The plight of so-called vulnerable populations may inspire in such “First World” individuals and groups responses of care—responses which more often than not take paternalistic forms of charity rather than responses committed to genuinely changing the dynamics of power that exploited and exacerbated the population’s vulnerability to begin with—but they might just as well inspire responses of indifference, exploitation, and violence.¹⁴

Psychological rigidity is a key ingredient in the “framing” of some groups as more vulnerable and less grievable than others. Consider the gas station clerks’ perceptual framing of Souad—and those seen to be Middle Eastern or Muslim more generally—as a “terrorist” and a “bitch” (2004, 32–38). As Butler argues in *Frames of War*,

[f]orms of racism instituted and active at the level of perception tend to produce iconic versions of populations who are eminently grievable, and others whose loss is no loss, and who remain ungrievable. . . . The differential distribution of precarity is at once a material and a perceptual issue, since those whose lives are not “regarded” as potentially grievable, and hence valuable, are made to bear the burden of starvation, underemployment, legal disenfranchisement, and differential exposure to violence and death. . . . [S]uch perceptual categories are essential to the crafting of material reality. (2010, 24–25)

Psychologically-rigid perception “frames” others in static, stereotypical images that enables them to “not count,” in a stroke denying the other’s vulnerability (in its rich sense as a dynamic condition of intercorporeal openness), rendering the other “more” vulnerable to violence and exploitation, and denying one’s own vulnerability as a perceiver.

Psychologically-rigid perception is thus politically problematic in a second sense: as well as objectifying the other in a way that enables the violent exploitation of their vulnerability, it works to deny the perceiver’s own implication in the world of perception, and hence their own vulnerability at its hands. A principal insight of Merleau-Ponty’s phenomenology of perception is that perception always takes the form of a figure or *Gestalt* within a meaningful context.¹⁵ This figure never appears all at once, but always exceeds

¹² See Butler (2020, 27–66).

¹³ See Butler (2004, 32–38).

¹⁴ See Butler (2020, 68–102).

¹⁵ See Merleau-Ponty (2012, 4, 17–18, 69–73, 354–57).

our perception *of* it, and always offers more to explore. Perception is always at work rendering temporarily determinate an inherently indeterminate and excessive perceptual field, allowing certain meanings to “take form” against a background of other possible meanings. The lullaby that Alia’s granddaughter sings to her child does not exist statically, like a stone, but in its sonic unfolding opens a world, spanning geography and generations; the glint of fish scales speak to Mustafa of death, loss of home, and humiliation. Far from being a neutral recording of the world, any perceptual act thus creatively reveals something about the world *and* something about the one perceiving the world. Perception is always an “intentionality”: it reveals (or “frames”) something about a state of affairs in the shared world, while simultaneously revealing something about the affective experience, historical conditioning, and contemporary projects of the one perceiving (Butler 2012, 137–39).

In seeing Souad as the known quantity of “terrorist” and “bitch” rather than as a dynamic and excessive human existence, the gas station attendants draw upon the rich perceptual field in order to reduce it to shallow, stereotypical images. In so doing, they tacitly deny that this is what they are doing: their perception takes the meanings of the world as fixed and given, rather than grappling with their own perceptual involvement in how they appear. As the complement to rendering Souad and her ilk “injurable” because not “grievable,” psychologically-rigid perception attempts to render the gas attendants impervious to the incursion of the other.

The gas station attendants tacitly deny that their perceptual experience is open to, impinged upon, and shaped by the perceptual experience of others: in their attempt to impose strict borders—rather than open boundaries—around the other, they build up walls around their own group identity. In part two, let us explore the manner in which vulnerability is not only an existential condition of all of our individual experiences, but a feature of human existence that is systematically articulated within and across groups, through an engagement with the work of family systems theory.

II. FAMILY SYSTEMS THEORY AND THE SYSTEMATIC NATURE OF VULNERABILITY

The specifically political power of the concept of vulnerability lies, I think, precisely in its ambiguous nature: our own vulnerability opens us to relations of intimacy as well as harm; the vulnerability of others can inspire care as well as violence; and vulnerability is at once a shared existential condition and distributed unevenly between groups and populations that “count” and those that do not according to unequal structures of global power. Precisely because of these ambiguities, the concept of vulnerability both gives us some of the terms in which we can diagnose situations of political violence and injustice that exploit the vulnerability of some while safeguarding (and in crucial respects denying) the vulnerability of others, and gives us some of the terms in which we can begin to imagine political alternatives that dwell with, rather than exploit and deny, our shared vulnerability. However, as Ann Murphy (2012) argues and Butler (2010) themselves grapples with in *The Force of Non-Violence*, the concept of vulnerability on its own

proves somewhat lacking in helping us to imagine a political future that recognizes and protects, rather than denies and exploits, human vulnerability.¹⁶ Family systems theory (FST) can help us to further flesh out what is at stake in recognizing vulnerability not as a property of (some) individuals, but as “a feature of social relations”; it can help us, in Butler’s words, “theorize our interdependency” (2010, 201; 2004, xiii). With its concepts of multigenerational transmission, family narratives, symmetrical and complementary relationships, and feedback loops, FST gives us vocabulary by which to describe the ways in which our identities as individuals and groups are empirically and systematically bound together, in ways we often do not recognize. This allows us also to address Erinn Gilson’s charge that Butler’s work on vulnerability remains problematically abstract (2014, 61). Grappling with the way vulnerability plays out in concrete interpersonal and political situations allows us both to better understand the serious problems we face as individuals and as groups, and to begin to imagine how these problems might be addressed in and through mutually transformative dialogue with others.

FST views individuals as first-and-foremost elements within larger, dynamic systems of relations.¹⁷ FST therapist Murray Bowen defines a system as a cluster of relations in which “a change in one part of the system is followed by compensatory change in another part of the system” (1978, 155). In W. H. Watson’s words, “a system is more than the sum of its parts, and so the properties of a system cannot be predicted from an analysis of its constituent members” (2012, 185); on the contrary, the behavior of the constitutive members of a system can only be understood in the manner in which it “fits” into the dynamics of the larger system. Bowen (1978) describes his own recognition of this reality in terms of a perceptual *Gestalt* shift. In contrast to individual psychotherapy, which is to an important extent limited to the patient’s own individual perspective, Bowen writes that “[a]fter having spent thousands of hours sitting with families, it became increasingly impossible to see a single person without ‘seeing’ his total family sitting like phantoms alongside him” (152). We are, so to speak, “haunted” by our relations with others, such that our own perceptions, behaviors, and understandings of things express, and in turn have an impact upon, the familial—and, I shall argue, the historical and political—dynamics of which we are a part.

A key concept of FST is the multigenerational transition process, which we can observe at play in a case study from the research of psychologist Dan Bar-On (1995), who with his students conducted open-ended interviews with Jewish Israeli survivors of the Second World War and their children and grandchildren. In the case in question, Bar-On (1995) and Noga Gil’ad interviewed Olga Anisevitch, who, after the death of her Jewish grandmother, mother, and younger sister in the Warsaw Ghetto and the anti-Semitic rejection and abuse on the part of her gentile father and his new family, set out alone on an arduous three-year journey to Israel at the age of fifteen. There, she married a survivor of Auschwitz, settled on a *moshav* (a cooperative agricultural community), and had three children. Bar-On and Gil’ad also interviewed Olga’s adult daughter Dina, adult son Benny

¹⁶ See Murphy (2012, 65–84); Butler (2020, 27–66).

¹⁷ On this, see Watson (2012, 185–87).

and sixteen-year-old granddaughter Orit. A particularly striking feature of these interviews is the systemic resonance between the biographies of mother Olga and daughter Dina. After suffering the loss of every one of her important family relationships and being forced to abandon her studies at the age of fifteen, Olga actively created a new life for herself in the newly independent state of Israel, throwing herself into farming and starting a new family. Though her biological father and brother were still alive in Poland, she did not speak of either to her children, who when asked were told that all of their grandparents were dead. Despite the vast differences in the interpersonal, social and economic circumstances in which she grew up, Dina's story echoes and reverberates with her mother's in a number of ways. She left home at the age of sixteen—just a year older than her mother had been when she was forced to set out on her own—but this time to begin post-secondary studies in education, rather than to have her education cut short. Like her mother, Dina displayed a “pioneering” spirit, helping to found a school in the new Israeli settlement of Lehavim.

Olga and Dina also shared a dominant narrative that interpreted the meaning both of their family and the place of the Holocaust in their lives. In parallel fashion to what we saw in our account of Merleau-Ponty's phenomenology of perception in part one, family systems therapist Michael White argues that family narratives give determinate form to inherently indeterminate and open-ended lived experience (1990, 14–15). The dominant family narrative of the Anisevitches—expressed in key points of the biographies of Olga and Dina—is one of heroic strength and redemption, and of a forward-looking embrace of the future that does not dwell on the past (Bar-On 1995, 183–86). This family narrative resonates with a dominant narrative in Israeli society in the 1940s and '50s of pioneering heroism—a narrative that went hand-in-hand with widespread shame about the Holocaust and denigration of its survivors (Rose 2005, 137–45; Bar-On 1995, 19). As Israeli society began to more explicitly reckon with the Holocaust in the 1970s and '80s, the Anisevitch family narrative incorporated the Holocaust into its own; as Bar-On and Gil'ad argue, Dina “grew up on the idea ‘from Holocaust to redemption,’ seeing the Holocaust as another form of Israeli heroism” (Bar-On 1995, 185). However, as White argues, family narratives can systematically conceal as much as they reveal, serving as the “life support” for problems endemic to the family system (White and Epston 1990, 3). White writes:

[P]ersons experience problems . . . when the narratives in which they are “storying” their experience, and/or in which they are having their experience “storied” by others, do not sufficiently represent their lived experience . . . in these circumstances, there will be significant aspects of their experience that contradict these dominant narratives. (White and Epston 1990, 14-15)

The Anisevitch family narrative of forward-looking heroism begins to show cracks when Olga's brother shows up from Poland, and Dina learns for the first time that she has a living uncle and a Christian grandfather, and a certain gulf opens between Dina and her mother (Bar-On 1995, 175). Perhaps much of what was unsaid in the family narrative—the loss and the grief, the struggle and the terror—lurked in the fear of the dark that had plagued Dina

from childhood into her adult life: her “own” experience is expressive of larger family meanings that she can only partially understand (171).

While FST as theory and practice has for the most part been devoted to intragroup dynamics, its insights can be fruitfully applied to intergroup dynamics as well.¹⁸ We often imagine political group identities (like our individual identities) to be bounded and autonomous, and we commonly locate problems (like individual neuroses) “in” other groups rather than in the larger systems of which they are a part, and thus having nothing to do with “us.” However, in conflictual situations between groups the lived experience and behaviors of members of one group reveal themselves to be systematically linked to the experience and behavior of members of other groups (and vice versa). In the context of Israel-Palestine, we can see the manner in which a dominant Israeli narrative of heroism and overcoming is perpetually troubled by the Palestinian experience that is inevitably tied up with it, lurking on its margins. This perpetual troubling presents itself in microcosmic form in an exchange between Olga Anisevitch and her son Benny, in which the young man describes his experience serving in the IDF:

Benny. Today, when I am called to the reserve army and I face the [First] Intifada, there are questions on my mind: On which side am I? On the side of the Jews or on the side of the cross holders? . . .

Olga, half listening, continues. I made a promise when I was very hungry, in Warsaw, that if I ever had a home, no one would ever leave it hungry. I always kept this promise . . . There were years when a Bedouin boy used to come around and he was like one of us. The children saw that they are people just like us. It’s possible, therefore, that the army, in order to ensure that this child will learn to protect himself, needs to tell him that other one is not exactly like him.

Benny. I have a different idea. I really feel like a conqueror . . . It’s simply disgraceful to behave like that. I walk around with a gun and I say: “Move over—to the right, to the left,” and I can decide whether or not someone is going to die. What am I, God? But in the Second World War, people in my position were God. There is some kind of connection here, and I feel I carry two pictures in my head, one of the Second World War and one of the wars here. These pictures collide all the time, they come and go. It’s very hard for me.

Olga, protesting. I don’t see it that way at all. (Bar-On 1995, 161-62)

The Anisevitch family narrative—and the larger Israeli narrative—of pioneering heroism has the murder, rape, displacement, and ongoing oppression of the Palestinians as its shadow; as Butler argues, we are constituted as much “by those whose deaths [we] disavow” as we are by “those [we] do grieve for” (2004, 46). The Jewish Israelis’ responsibility for the Palestinian *Naqba* and their ongoing oppression cannot be easily squared with either their avowed identity as colonial pioneers or their own recently and ambivalently embraced

¹⁸ See, for example, Bateson (1946).

history as victims of the Holocaust. While aspects of Benny's experience (and that of many Jewish Israelis) contradict his family's (and the larger national) narrative, Olga brushes his concerns aside, ambivalently acknowledging the humanity of an Arab child while proclaiming the necessity of treating the Palestinians as Other so that the Jewish "child" will "learn to protect himself."

FST's concept of symmetrical and complementary relationships shed further light on the group experience and behavior of both Jews and Palestinians in the history of the Israeli-Palestinian conflict. Anthropologist Gregory Bateson, whose cybernetic theory had a major impact on family systems theory, defines symmetrical relationship as those in which the behavior of one party elicits similar behavior in the second party (and vice versa); "[c]ommon examples of simple symmetrical relationship are armaments races, keeping up with the Joneses, athletic emulation, boxing matches, and the like" (1972, 323). We saw how symmetrical behavior can play out on an embodied level in our example of walking together in our discussion of intercorporeality in Part one. In contrast to symmetrical relationships, complementary relationships are those in which the behavior of one party elicits dissimilar but fitting behavior on the part of the other (and vice versa); "[c]ommon examples of complementary relationship are dominance-submission, sadism-masochism, nurturance-dependency, spectatorship-exhibitionism, and the like" (323). We saw how complementary behavior can play out on an embodied level in our example of partnered dancing in Part I. Symmetrical and complementary relationships show the FST concept of feedback loops in action. As Watson explains, "a feedback loop is a systemic process whereby one's behavior is influenced by the system's reactions to one's behavior" (2012, 185). In complementary relationships, for example, a masochistic response to sadistic behavior will evoke further sadistic behavior, which in turn evokes further masochistic behavior, and so on.

On a superficial level, the Israeli-Palestinian conflict can be framed as a symmetrical relationship, in which violence on the part of one party leads to retaliatory violence on the part of the other.¹⁹ However, the deep asymmetries in these groups' respective situations set the stage for a complementary relationship between Jews and Palestinians. Butler's discussion of the interrelated posture of "sovereignty" and of "persecution" draw out the complementary relationship that we can see tacitly at play in Benny's account of his experience in the IDF (as well as, across the Atlantic, in the American gas station attendants' rigid perception of Souad as a "terrorist"). Butler writes on the stance of sovereignty:

The sovereign subject poses as precisely not the one who is impinged upon by others, precisely not the one whose permanent and irreversible injurability forms the condition and horizon of its actions. Such a sovereign subject not only denies its own constitutive injurability but tries to relocate injurability in the other as the effect of doing injury to that other and exposing that other as, by definition, injurable. (2010, 178)

¹⁹ See, for example, Johannes Haushofer et al. (2010).

In behaving as if he was “God,” in Benny’s words, the Israeli soldier effects this stance of sovereignty, eschewing his own vulnerability precisely by abusing the vulnerability of Palestinian “mortals.” As Benny is aware, this was the obverse of what was done to his parents and Jewish ancestors by the Nazis during the Second World War. The posture of sovereignty is, in the case of the Israeli state (and of Olga), contradictorily entangled with what Butler calls the stance of persecution: “a recurrent or timeless feature of a cultural subject who is persecuted or injured by definition and irregardless of historical circumstances” (2010, 178). Butler writes:

If a particular subject considers her- or himself to be by definition injured or indeed persecuted, then whatever acts of violence such a subject commits cannot register as “doing injury,” since the subject who does them is, by definition, precluded from doing anything but suffering injury. (179)

The vulnerability of the Jewish people, devastatingly exploited by the Nazis during the Second World War, is denied in favor of a fantasy of Israeli sovereign impunity, which in turn wreaks havoc upon the vulnerability of the Palestinians. These crimes against the Palestinians are then denied via the Jewish people’s exclusive claim to exceptional victimhood. For the first twenty or so years after the founding of Israel and the Palestinian *Naqba*—from 1948 to 1967—a widespread sense of inferiority and behaviors of fearful self-effacement on the part of Palestinian citizens of Israel complemented the stance of sovereign superiority—and exceptional victimhood—on the part of Jewish Israelis. This recurrent feedback loop began to be interrupted by the 1967 Yom Kippur War and the subsequent re-emergence of Palestinian nationalism, as Palestinian Israelis came back into regular contact with Palestinians living in the newly occupied territories of Gaza and the West Bank.²⁰

Returning to the case of the Anisevitch family, a crack in the family narrative of a pioneering heroism that has left the past behind comes in the person of Orit, Dina’s daughter and Olga’s granddaughter. Mother Olga and daughter Dina have between them what Salvador Minuchin (2012) calls a “diffuse” boundary; it is not always clear where the one ends and the other begins (41). Dina repeats key points from the dominant narrative of her mother as if they were her own—for example, the family motto is “don’t think about what was in the past”—while at the same time speaking in a self-effacing manner when asked to tell her own life story (Bar-On 1995, 193). Without clear boundaries within the various subsystems of their families, individuals cannot achieve the degree of self-differentiation appropriate to mature adult life.²¹ By contrast, Dina’s sixteen-year-old daughter Orit displays the seeds of a notable individuality. The year before Bar-On’s interview, Orit accompanied her grandmother on a trip to Poland. Orit describes visiting the town in which the adolescent Olga was rejected by her gentile father; she “could feel it in the air, what it was like.” The teenage girl’s interest in and sympathy with her grandmother’s past

²⁰ For more on this, see Halabi (2004, 188); Rashid Khalidi (2010, 177–210).

²¹ See Bowen (1978, 161–65).

open up a concrete route for the old woman to grapple with this past in a new way; as we saw above, “a change in one part of the system is followed by compensatory change in another part of the system” (Bowen 1978, 155). Importantly, Orit’s burgeoning individuality is not achieved through a holding herself apart from her family legacy, but precisely by grappling with this legacy on a relational, affective level. As Bowen argues, adults with high levels of individuation “are realistically aware of their dependence on their fellow man,” and are “free to relax ego boundaries” without the fear of losing themselves (1978, 164). It is not despite, but rather through, our intercorporeal vulnerability that we can become most fully ourselves.²²

FST enables us to articulate concretely the ways in which our shared human vulnerability is always developed differentially within larger familial, social, and political systems, and thus to “theorize our interdependency” as parents and children, brothers and sisters, Palestinians and Jewish Israelis, and so on. As I shall argue in part three, it is in vulnerability so understood that the concept’s political potential lies: the point is not simply to recognize that we are all vulnerable—an important, but still rather generic, point—but rather to grapple with the empirical, systematic ways in which our vulnerabilities are intertwined one with the other in multigenerational, complementary, and cyclical manners that are always framed by competing group narratives. It is in the dynamic workings of systems, rather than “in” individuals, that our political problems first and foremost reside. If liberatory political transformation is to occur, it will be through changes in the whole system that in turn allows for compensatory—and sometimes surprising—changes in its individual elements. If Orit’s sensitivity to her grandmother’s past begins to break down the latter’s defensive insistence on her own rigid borders, untouched by parents, her past, or the weight of history, and to allow instead for a new kind of reckoning with the devastation wrought by the Holocaust, might new ways of speaking across entrenched ethnic lines disrupt rigidified identities and patterns of behavior, opening routes—however tenuous—for both individual and collective transformation?

III. THE SCHOOL FOR PEACE AND THE POLITICAL POTENTIAL OF VULNERABILITY

The School for Peace (SFP) offers an example of how experimental changes in the larger system of the Israeli-Palestinian conflict can begin to disrupt multigenerational and complementary patterns of behavior within and across groups, so as to allow new kinds of perceptions and behaviors—and new kinds of personal and political existences—to begin to take shape. With thousands of hours of experience leading “encounters” between Jews and Palestinians (as well as between warring groups in international contexts, such as Protestants and Catholics in Northern Ireland), SFP facilitators have identified a number of typical stages that occur in the dialogue between these two groups (Halabi 2004, 186-87). In what follows, I will draw on examples from two SFP encounters in the 1990s, led by Rabah Halabi and his colleagues: a four-day encounter between thirty Palestinian and thirty

²² I have developed this argument more fully in Laura McMahon (2024).

Jewish high school students at Wahat Al-Salem-Neve Shalom (the Jewish-Palestinian town described in this paper's introduction), and an eight-month long encounter between eight Arab Palestinian and eight Jewish university students at Tel Aviv university. Through these examples, we will see the ways in which long-entrenched complementary relationships of superiority and inferiority, oppressor and oppressed can be negotiated and, to some extent, transformed through difficult, perceptually creative, and systematically-related changes on the part of both groups.

A premise of the SFP is that the encounter groups enact a microcosm of the larger social and political reality in Israel-Palestine (Halabi 2004, 51–52). While it is always individuals that comprise the specific groups of Palestinians and Jews involved in the encounters, these individuals are deeply shaped by their group belonging, and the encounters invariably come to enact a dialogue not merely between individuals but between national groups (51). The SFP encounters thus provide unique opportunities through which to understand, and through which to experimentally transform, this intercultural dialogue. The seeds of this experimental transformation are there from the beginning in the SFP's organization of the encounter. For example, there are always equal numbers of Jewish and Arab participants, though Arab Palestinians make up only about twenty percent of the population within the official territory of Israel. And facilitators open the meetings in both Arabic and Hebrew, insisting throughout that both languages can be spoken (though in practice, the participants tend to default to Hebrew, as happens in Jewish-majority Israel more generally).²³

Halabi and his colleagues report that at the beginning of encounters, there is often a “peculiar” atmosphere characterized by both nervousness and good will (2004, 101). For the teenagers, the first day of the encounter is spent getting to know one another on a personal level, with binational team-building competitions and other “ice breaking” activities, leading to a great deal of good will (101–03). When on the second day they are broken into groups and guided into talking about cultural and political topics, the atmosphere of good will quickly changes, and the binational groupings developed the day before quickly dissolve back into uninationals camps. For the university students, where things are allowed to proceed more organically, this stage begins in about the third week of the semester. In this contentious atmosphere, a number of features of the power relations in Israel-Palestine enact themselves in microcosm. Among the high school students, Jewish participants tended to express a sense of cultural superiority. When discussing the relationships between men and women within Arab and Jewish culture, for example, the Jewish high school students identified themselves with modern, Western values and their Palestinian counterparts with traditional, (Middle) Eastern values; in the words of one Jewish girl, “We progressed and they didn't, that's all” (104). Though some of the Palestinian teenagers resisted this cultural classification—defending, as if for the sake of argument, traditional values—there was a general sense among both groups that if they were to live together in peace, it would be the Palestinian group that would need to change (104–05). We see in this dynamic the complementary relationships of superiority and inferiority typical of Jews and Palestinians for much of the early history of Israel.

²³ On this, see Halabi (2004, 119–40).

However, this *status quo* of complementary strength and weakness, cultural superiority and inferiority, did not remain stable for long. Among the university students, the Palestinian group began to develop and enact a newfound position of strength: they spoke clearly and emphatically about the humiliation of living as a second-class citizen within Israel's official borders, the "disgrace" of the occupation of Gaza and the West Bank, the gross disparity in the distribution of national resources between Jewish and Palestinian towns and villages, and the injustice of the "right of return" for Jews anywhere in the world while Palestinians at home remain stateless (Halabi 2004, 65–66). This enactment of strength in dialogue with the Jewish students was unfamiliar and hence tenuous: Halabi and his colleagues report that the Palestinian university group "didn't wholly feel a connection to its newfound strength; sometimes it even drew back from this new situation, retreating to the cozier and more familiar refuge of being the weak and discriminated against" (77).²⁴ By holding their ground, however, the Palestinian group reversed the power relations typical of the larger external society.

Halabi and his colleagues observed two typical stages in the Jewish group's initial response to the display of strength of the Palestinian group. First, the Jewish group typically experiences acute distress. Jewish Israelis who identify themselves as politically liberal experience a gap between their self-conception and the image that the Palestinians reflect back to them. In the words of one of the Jewish university students,

I feel sentimental towards my grandfather and grandmother's generation, who were pioneers, but on the other hand [there is] the price paid by another group. I wouldn't want to know that I had caused this. This touches on my identity as a human being, as a state. (67)

Next, the Jewish group typically deploys a number of tactics in an attempt to restore the balance of power characteristic of the *status quo* in Israel; "[t]here is a feeling that the conflict is a conflict of the zero-sum type" (107). One tactic is the attempt to steer the conversation away from politics; ignoring politics and focusing on interpersonal relationships can (as Merleau-Ponty says of the psychologically-rigid liberal) enable the fantasy that all human beings are identical rather than shaped, enabled, and disabled by unequal systems. A second tactic is to direct anger *at* the anger of the Palestinians; one of the Jewish high school students came away from a discussion in which Palestinians voiced pointed criticisms furious at "what they did to us" (108).²⁵ A third tactic is to delegitimize the urgent political concerns of the Palestinians by accusing them of merely "parroting" political slogans (69).²⁶ And a fourth tactic is to insist on the moral inferiority of Palestinians,

²⁴ This temptation is an apt illustration of Butler's posture of persecution discussed above. See also Wendy Brown's analysis of this problem in terms of Nietzsche's *ressentiment* (1995, 52-76).

²⁵ See Audre Lorde (1981) on the ways in which the anger of the oppressed is used as a way to dismiss their rational and justified concerns.

²⁶ This tactic has been widespread since the October 7, 2023 Hamas attack, with defenders of Israel's siege on Gaza accusing those criticizing Israel and calling for a ceasefire as "parroting Hamas talking points" rather than making sincere and conscientious arguments. See, for example, Christine Mai-Duc (2023).

referring to “terrorist” attacks as demonstrations that they—unlike the Jewish Israelis—do not “value human life” (Halabi 2004, 107).

However, there is, commonly, a third stage in the Jewish response to Palestinian strength: what Halabi and his colleagues call “a different dialogue” (72). In the high school encounter, this shift is accomplished in large part through a political “simulation” game on the third day, in which groups must negotiate with one another on concrete political issues related to the future of Israeli security, education, symbols and representation, and the character of the state (110–13). In the university encounter, this shift occurs when the Jewish group begins to move “away from its fortified position and its acceptance of the change” in the balance of power that the Palestinian group has dictated earlier in the process, and begin to grapple with their position as “rulers” (72, 77). In both the high school and the university groups, this change takes the form of a *Gestalt* shift with regards to the issue of “grievability.” One Jewish university student spoke of the hypocrisy of the Israeli media’s attention to the deaths of Israeli soldiers in a recent helicopter tragedy, while the deaths of Palestinian children in the occupied territories was largely ignored; Jewish high school students agreed with their Palestinian counterparts that Israel’s national day of mourning should commemorate “Arabs who have fallen as well as . . . fallen Israeli soldiers” (73, 112). There is a qualitative shift in the behavior of the Jewish group, who after their initial response of defensiveness and anger begin to grapple with their own political power, to listen sincerely to the grievances and criticisms of the Palestinians, and, in the words of one Jewish high school student, to acknowledge: “I don’t know what I would do in their place. I don’t know how I would be able to live and to put up with the conditions they have to live with” (116).²⁷ We can see in this “different dialogue” the way in which a change in one part of the system—here, the Palestinians’ outspoken refusal of the inferior political and cultural position generally reserved for them in the larger society—leads to changes in another part of the system—to the Jews’ questioning and beginning to relax their “fortified position” as “rulers.”

One might object that, in a context of entrenched and vastly unequal power dynamics between Palestinians and Israelis, the SFP encounters place undue blame on Palestinian victims for their role in the perpetuation of their own oppression, and an undue burden on Palestinians to discover the means for their own liberation.²⁸ Should not blame be assigned where it is most clearly due, to the state of Israel as a settler colonial project, and to the vast human rights violations on the part of the state of Israel against Palestinians within its borders and stateless Palestinians in the occupied territories? (It is worth noting that this reverses the more common charge in Israel and the West that casts Arab “terrorists” as aggressors and Jewish Israeli civilians as victims). I think that it is possible—

²⁷ It is an expression of widespread psychological rigidity that British MP Jenny Tonge was fired from her front bench position for expressing similar words of political empathy for Palestinians in 2004. Rose (2004).

²⁸ This is, indeed, a principal feminist critique of FST. See Michele Bograd (1988), who argues that attending to the circular causality of feedback loops without a proper attention to entrenched political power relationships between men and women amounts to distributing responsibility for problems across the system rather than assigning responsibility where it is, sometimes, simply due—to an abusive husband or father, for example (Bograd 1988, 124).

and necessary—to simultaneously hold oppressive powers accountable for their actions, and seek to understand the complex dynamics that condition these actions.²⁹ To seek to understand the complex dynamics of an oppressive situation is not to distribute blame equally, but rather to articulate the concrete opportunities for, and challenges to, genuine change.

IV. CONCLUSION: THE UNRAVELING AND RECONSTRUCTION OF PERSONAL AND POLITICAL IDENTITIES

Liberatory political change will necessarily involve the difficult, vulnerable work of challenging psychologically-rigid perception—one’s own as well as others’—that polarizes groups into “good” and “bad,” “victim” and “perpetrator,” in favor of grappling with the histories of intergenerational trauma that shape the vulnerable identities of both sides in complementary, intertwining manners. It also requires rejecting a rigid liberalism that attempts to “see” human beings as identical *qua* human. As Halabi puts it, the goal of the SFP encounters is not simply to overcome negative stereotypes and a history of intense oppression and conflict through the realization of interpersonal harmony, putting aside national differences to “have a plate of hummus together” (2004, 70). It is rather to engage in exercises of political discussion and political imagination head-on in such a way as “to unravel and then reconstruct participants’ identities,” so as to “permit the option of building a more just and humane society” (8). I have argued in this paper that our “identities” are systematically connected, not only within our kin groups but across political groups whose fates are ineluctably intertwined. If this is right, then it is in facing head on our mutual implication in one another’s most intimate existences that our identities can be “unraveled” and then “reconstructed” in manners that are no loss, but rather expand and enrich who we are. We can catch a glimpse of such expansion and enrichment of identity in the fragile but determined coexistence of the residents of Wahat Al-Salem-Neve Shalom, in contrast to the murderous actions of the IDF and Hamas. As Butler (2020) writes in *The Force of Non-Violence*:

Persistence in a condition of vulnerability proves to be its own kind of strength, distinguished from one that champions strength as the achievement of invulnerability . . . Sometimes continuing to exist in the vexation of social relations is the ultimate defeat of violent power. (201)

²⁹ See Butler’s closely related discussion of seeking to understand the conditions of the September 11, 2001 attacks (2004, 1–18).

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