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Joel Michael Reynolds	Date

The Life Worth Living:
Ethics and the Experiences of Disability

By

Joel Michael Reynolds

Doctor of Philosophy

Philosophy

Dr. Rosemarie Garland-Thomson
Reader

Dr. Eva Kittay
Reader

Dr. John Lysaker
Chair of the Examining Committee

Dr. Andrew J. Mitchell
Committee Member

Dr. Cynthia Willett
Committee Member

Accepted:

Lisa A. Tedesco, Ph.D.
Dean of the James T. Laney School of Graduate Studies

Date

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Joel Michael Reynolds
M.A., Emory University, 2014
B.A., Robert D. Clark Honors College, University of Oregon, 2009

Advisor: John Lysaker, Ph.D.

An abstract of
A dissertation submitted to the Faculty of the
James T. Laney School of Graduate Studies of Emory University
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Doctor of Philosophy in Philosophy
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Abstract

The Life Worth Living: Ethics and the Experiences of Disability

By Joel Michael Reynolds

Awaiting execution, Socrates inquires, “Is life worth living with a body that is corrupted and in a bad condition?” “In no way,” replies Crito. My dissertation argues that canonical normative theories have fundamentally misunderstood and mischaracterized the experiences of disability, leading to significant injustices in applied fields such as bioethics. I term this error “the ableist conflation.” This conflation—exemplified in Socrates’ rhetorical question and affirmed unremittingly across philosophical epochs and traditions ranging from Aristotle to Kant, Beauvoir to Foot—presumes that disability is a harm and concomitant with pain and suffering.

Because the goal of ameliorating pain is taken as an ethical and socio-political truism, the ableist conflation leads theorists to preemptively rule out all forms of disability in accounts of human flourishing. It thereby contributes to the contemporary and historical stigmatization of people with disabilities, who are represented as paradigmatically deficient. This is especially disconcerting given that most arguments used to dehumanize and subjugate both people of color and women across the history of philosophy are based in the ableist conflation, whether Aristotle defining females as “mutilated” males or Kant linking black skin directly to intellectual incapacity.

Drawing upon research across the phenomenological tradition—including Heidegger, Merleau-Ponty, Levinas, S. Kay Toombs, and Havi Carel—I develop phenomenological accounts of MS (Multiple Sclerosis) and CRPS (Complex Regional Pain Syndrome). Contrasting these accounts, I develop novel philosophical and diagnostic distinctions between forms of pain and disability. These demonstrate that the ableist conflation is deeply misguided and that the lived experience of people with disabilities, far from being necessarily one of “harm” or “lack,” attests to lives rich in meaning, purpose, and dignity. I conclude by critiquing the ableist conflation at work in contemporary bioethical debates over patients with BIID (Body Integrity Identity Disorder). My research suggests that it is only with a better understanding of the myriad lived experiences of disability that ethicists will construct and apply normative theories that value the full range and experiential worth of human corporeal variation.

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Foremost gratitude goes to the lives and loves that first taught me to both question and value (dis)ability, the nature of experience, and, for that matter, to question the meaning of meaning: Jason, Gail, Alan, Papa Jack, and Grandma Babe. My family has been a support for me without which I would be unmoored, and they are the inspiration for all that I do. In many ways, my research is a way of thinking through and honoring the experiences of love, care, embodiment, and interrelations through which my family survived and, despite long odds, thrived. I hope this project does justice to their precious lives.

My entry into philosophy was occasioned through a one-credit course in which I enrolled on little more than a whim. I had no idea what philosophy was, but a certain “philosopher” named John Lysaker taught the course. The materials intrigued me as had no others, and the following year, I took my first official philosophy course with John, one of many to come. I had no idea that this would be the beginning of a mentorship and friendship that many dream of, but rarely find. John has been the most supportive and, at the same time, most constructively critical guide for which one could wish. I teach with the hope that someday I will be to my students what he has been to me; I write with the hope my pen will attain the lithe acuity and depth of his; and I practice philosophy with the hope it will bear out the type of life he first showed me to be possible. I cannot express my gratitude for his presence in my life except to say that without him, I would rue the life that would have transpired. John has made me not only a better philosopher, but a better person, and for that, there is no adequate economy of gratitude.

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I want to thank the editors at the *Jahrbuch Litertur und Medizin*, Bettina von Jagow & Florian Steger, for allowing me to use re-worked materials from my essay, "Feeding Upon Death: Pain, Possibility, and Transformation in S. Kay Toombs and Kafka's 'The Vulture,'" (Band 6, 135-54). I am also grateful to Mary Rorty and Erin Shephard of the *APA Newsletter on Philosophy and Medicine* for permission to use materials from my essay, "Toward a Critical Theory of Harm: Ableism, Normativity, and Transability (BIID)" (16: 1).

To all those whose presence, insight, and work has informed and shaped this project and, through it, myself, I thank you from the bottom of my heart

For Jason and Gail

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Alyosha:
Brother, let me ask you one more thing: can it be that any man has the right to decide about the rest of mankind, who is worthy to live and who is more unworthy?

Ivan:
But why bring worth into it? The question is most often decided in the hearts of men not at all on the basis of worth, but for quite different reasons, much more natural ones.

—Dostoevsky

INTRODUCTION

> “Let us discuss this, then, starting from the beginning [ἀρξάμενοι].”
>
> —Aristotle, concluding line of the *Nicomachean Ethics*[1]

Awaiting execution, Socrates asks, “Is life worth living with a body that is corrupted and in a bad condition (μοχθηροῦ καὶ διεφθαρμένου σώματος)?” “In no way (Οὐδαμῶς),” replies Crito.[2] With a single word, Crito affirms a judgment that will be repeated throughout the Western canon: the corrupted body, a body we today would call a disabled or ill body, is so unwieldy and undesirable that one would rather not exist with it. One would rather not exist in and as this body, to be clear, only if one has some sense of the worth of life. Only if one has already interpreted and judged the conditions that make life life and not a form of death.[3] It is this hermeneutic against *the impropriety of a range of corporeal variabilities* that draws, in part, the line between worthy and unworthy life for Socrates and Crito.

Despite its immense gravity, this hermeneutic so convincingly grips Socrates that inquiry into its truth is rendered rhetorical. The Socratic deathbed, a synecdoche for the death out of which philosophy, for many, begins, hallows an other-worldly ground through a valuation, if not transvaluation, of the conditions of life. This valuation is one

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[1] Aristotle, *Nicomachean Ethics*, trans. Terence Irwin, 2nd ed. (Indianapolis, Ind.: Hackett Pub. Co., 1999), 1181b25. Reference to the Greek has been made in *The Nicomachean Ethics*, trans. H. Rackham, The Loeb Classical Library (London: W. Heinemann; G. P. Putnam's sons, 1926). I imagine hearing in tandem with this another of Aristotle’s claims: “there is no demonstration of a principle of demonstration [ἀποδείξεως γὰρ ἀρχὴ οὐκ ἀπόδειξίς ἐστιν].” *Metaphysics*, 1011a. Translation modified from *The Metaphysics*, trans. Hugh Tredennick and G. Cyril Armstrong, 2 vols., The Loeb Classical Library Greek Authors (London: W. Heinemann, G.P. Putnam's Sons, 1933).

[2] Plato, *Complete Works* (Indianapolis, Ind.: Hackett Pub., 1997), 47e.

[3] Not that, à la thinkers from Dilthey to Derrida, one could think these two terms apart from each other. That is to say, *sensu stricto*, life is a form of death—it is a question of *what* form of death it is that I am here problematizing.

for which philosophy will become infamous: the life of the body is worth less than that of the mind and the lives of certain bodies and certain minds worth less still. Yet, what do the embodied conditions of life in fact tell us? What does the constitutive variability of our body suggest about how we ought to treat and judge others, their bodies, and the worth of a life? What, to invoke the troubling insight of Dostoevsky's Ivan, are the "much more natural" reasons than worth that in fact determine the worth of a life? Perhaps we should discuss this from the principle, the *arche*, that has historically held sway over philosophy since Socrates' devaluation of the *mochtherou kai diephtharmenou somatos*, the so-called corrupted and bad body. Let us discuss this, then, starting from the beginning.

*   *   *

Night has fallen. But it is day. A severe pain surges through your lower back. The doctor names the cause of this pain: 'Herniated Disk.' The doctor names the vertebrate responsible for housing that disk: 'L4 and L5.' The doctor names the surgery designed to fix you, designed to *take away the pain*: 'Microdiscectomy.' The doctor names lots of names, though unfamiliar and often startling to you. The surgery, suffering a fate to which many such designs succumb, fails. You now hear another name, but this time one which is meant to define your entire being: "chronic pain sufferer." And another: "disabled."

These names, these diagnoses, these etiologies…they seem to constantly betray, for is not the ease with which the "able-body" becomes a "dis-abled-body" astonishing? Is not the ease with which the "healthy disabled" body, to use Susan Wendell's phrasing, becomes a sick or ill "disabled body" also astonishing? It is as if these names, these categories, and these concepts are always on the verge of deceit, always covering over the way in which they fail to capture the very phenomena they claim to pick out.

How are we to hear those words, “You are disabled”? According to the US Department of Human Health and Services, at least fifty-four million people in the United States live with disability. That’s one in every five people. The HHS clarifies: “the reality is that just about everyone – women, men and children of all ages, races and ethnicities – will experience a disability some time during” life.[1]

How are we to hear the words “pain” and “chronic pain”? Pain, the American Academy of Pain Medicine reports, “affects more Americans than diabetes, heart disease and cancer combined,” 100 million, and “a recent market research report indicates that more than 1.5 billion people worldwide suffer from chronic pain.”[2] Is there perhaps more to these facts than attestations, as they are usually interpreted, of the vulnerabilities and dependencies of our bodies? Do they not also speak to the body’s *variability* and differences, to its constantly fluid possibilities? Given that this fluidity is constitutive of being human—and, for that matter, of any organism or biological system—what role do pain and disability[3] play in our understanding of what it means to be human and, by extension, to be political, to be ethical? What do disability and pain reveal about how we should comport ourselves not simply to those for whom it defines their experience and

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[1] “Office on Disability,” U.S. Department of Health and Human Services, accessed 3.10.14, http://www.hhs.gov/od/about/fact_sheets/whatisdisability.html.

[2] “AAPM Facts and Figures on Pain,” American Academy of Pain Medicine, accessed Feb 2013, http://www.painmed.org/patientcenter/facts_on_pain.aspx. Being in pain and being disabled are not all the same, and conflating the two is in fact a common and damaging ableist assumption. I address my use of both of these categories and their crucial differences below.

[3] The term “disabled” (and its variants which historically correlate to a number of problematic figures: the invalid, cripple, freak, idiot, moron, feebleminded, lame, insane, etc.) is itself contested, and when I use the word without scare quotes, I do not mean to indicate that I am neglecting its problematic nature. I will spend two chapters explicitly interrogating its complexity and the multiplicity and contestations the term bears.

identity, but to all persons?[1] Given their import and experiential ubiquity, what role *ought* pain and disability play in ethical theorizing? What role *ought* pain and disability play in the theories that deem themselves worthy of negotiating and directing our havings, doings, and beings? And are pain and disability, as connected by philosophy for millennia, to be thought together in the first place?

The Question

I will begin with pain. While the role of pain in modern liberal theories is often deemphasized in relation to equality or justice, liberal theorists such as Judith Shklar have regarded pain to be the core *minimal* foundation of liberalism.[2] We may disagree about the *summum bonum*, but not the *summum malum*: we all wish to avoid pain. Millean utilitarianism, Aristotelian virtue ethics, Kantian deontology, and care ethics—whether Kittayian, Heldian, Trontian, et al.—all valorize the minimization of pain.

Philosophers such as Richard Rorty have followed the Shklarian line, but with an important caveat: Rorty understands pain to be a sensation and, following Sellars, understands sensations to be non-intentional.[3] Such a Sellarsian understanding of intentionality[4] has had large ramifications, ranging from the thesis of pain's nonlinguistic

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[1] I use the term "praxis" here and henceforth following the gloss John Lysaker offers: "a word for what is an instance of and a concern for the conduct of life." See John T. Lysaker, "Praxis and Form: Thirty Notes for an Ethics of the Future," *Journal of Speculative Philosophy, New Series* 25, no. 2 (2011): 216. Whereas the English "practice" and "practical" connote certain utilitarian themes ("that's not practical") or the planned repetition leading towards a determinate goal ("I was practicing for X"), the Greek *πρᾶξις* can range ambiguously over "doing, action, and practice" in a global sense that doesn't, without further stipulation, function smoothly in the binary "theory-practice." See "Praxis, *n*." in OED, "Oxford English Dictionary," in *Oxford English Dictionary* (Oxford, England: Oxford University Press, 2002). See also "*πρᾶξις*" in "Thesaurus Linguae Graecae," in *Thesaurus Linguae Graecae* (Irvine, CA: University of California, Irvine).

[2] Judith Shklar, "The Liberalism of Fear," in *Liberalism and the Moral Life*, ed. Nancy L. Rosenblum (Cambridge, Mass.: Harvard University Press, 1989).

[3] Richard Rorty, *Contingency, Irony, and Solidarity* (Cambridge; New York: Cambridge University Press, 1989), 40.

[4] Wilfred Sellars, "Empiricism and the Philosophy of Mind," in *Minnesota Studies in the Philosophy of*

character in Elaine Scarry's humanist and widely influential *The Body in Pain*[1] to Robert Brandom's neo-pragmatist deontic scorekeeping framework. In that framework, questions of power and embodiment are excised because sensations cannot *judge* and are thus left out of the normative field of an ideal discursive engagement.[2] In the wake of post-Sellarisan analytic philosophy, while pain may indeed be acknowledged as a potential candidate for *motivating* liberalist goals, it in and of itself carries no normative-justificatory weight.

For example, Rorty argues that the liberalist must rely upon the resources of literature, ethnography, and journalism to further her goals, not upon philosophy, science, or theology. When she so relies, it is because the Shklarian *summum malum* of the avoidance of pain is rendered a *contestable* premise of normative justification that must be decided within the turbulence of cultural politics: I can't apodictically argue you into caring for another, even if we both agree that pain is bad and that that other is in pain. For Rorty, the imaginative work of his preferred resources makes up for the lack of rational-discursive bedrock regarding even something as supposedly foundational as pain.[3]

In contrast to the Sellarsian thesis of sensation's non-intentionality, Merleau-Ponty's arguments for the role of *embodied* or *somatic* intentionality ring loudly.[4] But Merleau-Ponty still treats pain as a type of sensation, even if one that harbors a certain

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Science, ed. Herbet Feigl and Michael Scriven (Unviersity of Minnesota Press, 1956). I am grateful for conversations with Carl Sachs on these points. Carl B. Sachs, *Intentionality and the Myths of the Given: Between Pragmatism and Phenomenology* (London: London: Pickering & Chatto, 2014).

[1] Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World* (New York: Oxford University Press, 1985).

[2] Robert Brandom, *Making It Explicit : Reasoning, Representing, and Discursive Commitment*, ed. Raymond Danowski and Library Raymond Danowski Poetry (Cambridge, MA: Harvard University Press, 1994).

[3] See page 4, footnote 2.

[4] Maurice Merleau-Ponty, *Phenomenology of Perception*, trans. Colin Smith. Trans. rev. Forrest Williams and David Guerriere (London; New York: Routledge, 1962).

sort of intentionality. Pain is specifically the sort of sensation which is constrictive.[1] Levinas, on the other hand, argues that pain—at least when it constitutes "suffering"—cannot be understood as a mere sensation, a mere given, but as an excess of givenness or, in his preferred paradoxical formulation, a givenness of refusal.[2] We experience pain *in its resistance* to our ability to experience. In this respect, pain is not one sensation among others. For Levinas, while pain may indeed be acknowledged as one aspect of the other, it too is taken to be a non-intentional sensation—however unique—insofar as it is a mere given. The admission of another's pain marks a reduction with respect to the absolute call of responsibility.[3] The other qua other claims me under the auspices of Levinasian response ethics; whether or not they are determinably in pain is *not* ultimately a relevant ethical factor for Levinas. The determinateness of a call of pain is posterior to the founding call of response that establishes the subject.

Both in analytic and continental traditions, pain plays the role of a normative *given* without any justificatory weight. That is to say, it is simultaneously assumed that another's expression of pain {A} places a near universal normative claim upon people and that {B} one cannot discursively articulate the ground of that claim within a game of reasons. Whether one holds discursivity to be a condition of normativity (as do many analytic philosophers) or whether one holds discursivity to be *derivative* of the

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[1] The phenomenological characterization of constriction as it relates to a number of "pathologies" is well noted. See, e.g., Kirsten Jacobson, "Agoraphobia and Hypochondria as Disorders of Dwelling," *International Studies in Philosophy* 36, no. 2 (2004): esp. 38-40. Drew Leder speaks of this with respect to hypertension in "Two Bodies" in Donn Welton, *Body and Flesh: A Philosophical Reader* (Malden, Mass.: Blackwell Publishers, 1998), 125. Iris Young speaks of this with respect to the socio-historically situatedness of feminine comportment in "Throwing Like a Girl" in ibid., 259-73, especially the discussion of "inhibited intentionality" from 65-6.

[2] For the purposes at hand, I am conflating pain with suffering. I will distinguish these at length in chapter one.

[3] While I don't know of any who would counter this with respect to *Totality and Infinity*, some might claim that a different account of the role of pain that I sketch here is presented in *Otherwise Than Being*. I address this in chapter 2 below.

establishment of the ethical subject (as do many continental philosophers), the distance between {A} and {B} renders the normative status of pain deeply problematic for both traditions. {B} is understood to fundamentally undercut the power of {A}. What, then, of disability, and why did I begin with pain *and* disability? Why this linkage?

All models of flourishing upon which canonical normative theories are based assume a general minimization of pain. Pain is, in turn, thought as a sort of constraint or lack relative to some hypothetical potential of purposivity and flourishing. All such models of flourishing also assume that corporeal variations we today categorize as "disabilities" (whether defined as primarily physiological or psychological in nature) are, on the whole, constraints or lacks relative to that potential. The central argument of this dissertation is that the omission or disparagement of disability with respect to normative ethics is primarily due, historically, to what I call *the ableist conflation*: the preemptive conflation of disability with pain and suffering. Put otherwise, the conflation of lives lived outside ableist norms with lives lived in pain and suffering.[1]

The ableist conflation names a prevalent facet of historical and contemporary cultural imaginaries, and it also names an assumption that undergirds the majority of reflective thought in the Western intellectual tradition.[2] What I call "the ableist conflation" is, ultimately, a recasting, synthesis, and consolidation of a host of work done in disability studies over the last four decades, the literature of which I engage at length

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[1] I will argue that the conflation of pain with suffering is in fact a sub-conflation at work within the "ableist conflation." Component, constitutive, and consuming pain are phenomenologically distinct and only the latter two are forms of suffering, as I argue in chapter one below. To be clear, I mean conflation in its usual sense: a case where the identities of two or more things sharing some characteristics of one another seem to be a single identity. As I make clear below, this argument is a recasting of claims made by multiple disability activists, disability studies scholars, and philosophers of disability, ranging from Paul Hunt to Susan Wendell to Anita Silvers.

[2] Take, e.g., this satirical post, "This Woman Is Strong, Sexy, And Brave—Even If She Does Have Both Legs," <http://www.clickhole.com/article/woman-strong-sexy-and-braveeven-if-she-does-have-b-1219?utm_campaign=default&utm_medium=ShareTools&utm_source=facebook.>

in the body of the dissertation. When one takes such scholarship seriously, especially that which often goes under the title *critical disability studies*, the entrenchment of the ableist conflation in the history of philosophy should cause serious alarm. In an analogous manner to Charles Mills' damning claim that there exists "a conceptual or theoretical whiteness" that serves as a "pre-theoretical intuition" for the discipline of philosophy, I will argue that the ableist conflation is the primary support for the pre-theoretical, ableist intuitions prevalent across the history of philosophy, East and West.[1] It is still today the most pressing and pernicious issue the field of philosophy of disability faces. I would contend it is also the most pressing issue disability studies more broadly as well as disability rights activism—locally and abroad—faces.[2] That is to say, it is an old, ingrained problem whose grip on the present is, despite notable political and academic victories, still far too tight on the wider global scales of cultural, socio-political, and juridical-philosophical imaginaries.

The ableist conflation powerfully undergirds numerous forms of oppression—epistemic, political, and legal, etc.—against disabled people. It is a prime driver for people with disabilities of what Miranda Fricker calls "epistemic injustice." She defines epistemic injustice in terms of two types: testimonial and hermeneutic injustice. Fricker explains, "testimonial injustice occurs when prejudice causes a hearer to give a deflated

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[1] Charles Mills, "Non-Cartesian 'Sums': Philosophy and the African-American Experience," *Teaching Philosophy* 17, no. 3 (1994).

[2] J. McMahan, "Causing Disabled People to Exist and Causing People to Be Disabled," *Ethics* 116, no. 1 (2005). Arguments that tie "decency" to "disability" are subtle forms of this. Example from recent government documents and recent news articles include: Social Security Advisory Board, *The Unsustainable Cost of Health Care* (United States of America Government); H David, "The Unsustainable Rise of the Disability Rolls in the United States: Causes, Consequences, and Policy Options," (National Bureau of Economic Research, 2011); Daniel P White, "The Uncontrollable Increase in United States' Disability Rolls and the Inevitable Exhaustion of the United States' Disability System," (2013). Such arguments are often couched in terms of *fiscal* sustainability: E.g., take this quote from a Fox News segment: "Tanner said there must be a serious effort to put people back to work because the continued growth of these entitlement programs is unsustainable." Mike Emanuel, "Census Figures Show More Than One-Third of Americans Receiving Welfare Benefits," *Fox News* Aug. 29, 2014.

level of credibility to a speaker's word; hermeneutical injustice occurs at a prior stage, when a gap in collective interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences."[1] In short, the ableist conflation produces both systemic and individual epistemic disadvantages for people living with disabilities. The epistemic error of the ableist conflation contributes to such injustices by supporting the ignorance or devaluation of the accounts of experience given by people with disabilities, whilst valuing the projective, typically empirically unfounded assumptions of able-bodied people.

The Ableist Conflation

> "Our dominant understanding is that disability is something to be avoided…because…we understand disability to confer pain, disease, suffering, functional limitation, abnormality, dependence, social stigma, and economic disadvantage and to limit life opportunities and quality."
>
> —Rosemarie Garland-Thomson[2]

Despite the growing number of bioethicists and ethicists that address or engage disability critiques and despite decades of disability activism and critical disability studies scholarship spanning the humanities and social sciences, the ableist conflation of disability with pain, suffering, and death continues across multiple philosophical and intellectual literatures. Bioethics, in particular, is still often structured by an understanding of disability as an individual tragedy or misfortune due to genetic or environmental insult. Following disability studies' literature, I will henceforth refer to

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[1] Miranda Fricker, *Epistemic Injustice: Power and the Ethics of Knowing* (Oxford; New York: Oxford University Press, 2007).

[2] Rosemarie Garland-Thomson, "The Case for Conserving Disability," *Journal of Bioethical Inquiry* 9, no. 3 (2012): 340.

this idea as the medical model of disability.[1] To be fair, several bioethicists do engage alternative, non-medical conceptions of disability. Yet, those conceptions are often conglomerated into a mere “position”—as if there were some subset of people who simply have a different view about disability and as if ethicists, after fulfilling the due diligence of mentioning that view, can go on with metaethical, normative, or applied business as usual. This scholarly attitude is reflected in practical domains. For example, the extent and role of education about disability in medical training is still today a point of contestation.[2] Unsurprisingly, people with disabilities report significantly higher inadequacies than people without disabilities in patient-provider communication.[3]

I claimed above that this pervasive misunderstanding of disability is not simply due to a general assumption of able-bodiedness, but more specifically due to what I term *the ableist conflation*: the assumption that disability is a harm and thereby coextensive with pain and suffering. On this logic, disability is both a *symptom* and *cause* of existential dis-ease and dis-order. On this logic, it makes sense to serially list death, suffering, and disability. The ableist conflation is that which rationalizes the horrific locution, “I’d rather be dead than disabled.”[4] Let me now explain the ableist conflation in more detail.

Whether embedded in social, institutional, ideological, or other mediums, the ableist conflation is comprised, at minimum, of the following four inferences:

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[1] S. Kay Toombs, *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient*, Philosophy and Medicine (Boston: Kluwer Academic Publishers, 1992); "The Lived Experience of Disability," *Human Studies* 18 (1995).

[2] A. Elizabeth McKim, "Making Poetry of Pain: The Headache Poems of Jane Cave Winscom," *Literature and Medicine* 24, no. 1 (2005).

[3] Diane L. Smith, "Disparities in Patient-Physician Communication for Persons with a Disability from the 2006 Medical Expenditure Panel Survey," *Disability and Health Journal* 2, no. 4 (2009).

[4] Joel Michael Reynolds, "'I'd Rather Be Dead Than Disabled:' The Ableist Conflation and the Meanings of Disability," *The Review of Communication* (Forthcoming).

> {1} Disability is considered a lack or deprivation of a (natural) good.
> {2} Deprivation of potential goods is considered a harm.[1]
> {3} Harm is understood to cause or be a form of pain and suffering, whether physical or psychological in nature.
> {4} Given 1-3, disability is concomitant with [*weak form*] or causes [*strong form*] pain and suffering.

This is the basic formula, I contend, that best explains the medical model of disability and best explains the widespread cultural disparagement of disability, from the prevalence of inspiration porn and inspiration profiteering to the frequency of disability hate crimes (which have *increased* in the US since the ADA).[2]

A few general observations are in order. Firstly, it should be obvious that {1} simply follows from ableism. I will here define ableism as the normative assumption that the "normal" able-body is, *ceteris paribus,* in and of itself better than abnormal forms by virtue of being normal.[3] To use Rosemarie Garland-Thompson's apposite phrase, whether the "velvet eugenics" of justifying human germline editing or the vulgar eugenics of forced sterilization or sanctioned murder, the ableist conflation is constitutively *eu*-genic in assuming that certain forms of life are intrinsically worse than others and in working to shape the world based on those assumptions.[4] Wherever the ableist conflation is at work, one will find active and passive devaluations of disability and of non-normate forms of existence.

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[1] Thomas Nagel, "Death," in *The Metaphysics of Death*, ed. John M. Fischer (Standford: Stanford University Press, 1993).

[2] Alison Kafer, *Feminist, Queer, Crip* (Bloomington, Indiana: Indiana University Press, 2013); Mark Sherry, *Disability Hate Crimes: Does Anyone Really Hate Disabled People?* (Burlington, VT: Ashgate, 2010). Inspiration porn refers to instances where people with disabilities are viewed as inspirational only by virtue of their disability and, through so doing, reduced solely to their disability or, more accurately, impairment.

[3] Joel Michael Reynolds, "The Ableism of Quality of Life Judgments in Disorders of Consciousness: Who Bears Epistemic Responsibility?," *American Journal of Bioethics Neuroscience* 7, no. 1 (2015).

[4] Rosemarie Garland-Thomson, "Human Biodiversity Conservation: A Consensual Ethical Principle," *The American Journal of Bioethics* 15, no. 6 (2015); "A Habitable World: Harriet Mcbryde Johnson's "Case for My Life"," *Hypatia* 30, no. 1 (2015). On the extent of stigmatization of disability, see Sherry.

Given 1-4, disability and pain *signify* similarly, and one would expect a person to communicate about them in similar ways.[1] People pity and say, “I’m so sorry,” to someone in pain, just as those without disability education do to many with disabilities (and typically regardless of whether they are “in pain” at all). People often valorize and take inspiration from those who overcome pain, just as those without disability education do to many with disabilities when enjoying and propagating inspiration porn.[2] The countervailing logics of pity and inspiration make perfect sense if grounded by the ableist conflation. However, I have only provided the bare-bones version of it. There are many others.

For example, the variation of the ableist conflation that best explains eugenic logic is, at least schematically, as follows:

> {1} Disability is considered a lack or deprivation of a (natural) good.
> {2} Deprivation of potential goods is considered a harm.[3]
> {3} Harm is understood to cause (physical or psychological) pain and suffering.
>   {a} Pain and suffering are to be avoided.
>   {b} The aim of politics and ethics is to ameliorate pain and suffering.
> {4} Given 1-3, disability *causes* pain and suffering.
>   {a} Given 1-4, disability is intrinsically negative and to be avoided.
>   {b} Given 1-4a, individuals and the state are in certain cases justified in ending or otherwise curtailing the lives of people with disabilities.

This is an especially notable form of the ableist conflation insofar as it prescribes *actions* that a society or an individual should take to lessen or alter the existence of people with disabilities in the world.

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[1] It should be noted that, among other things, disability is left underdefined in this formulation of the ableist conflation. According to the cultural logic at issue here, it is not immediately clear whether needing glasses or chronic depression constitutes disability, while few would argue that paraplegia or cystic fibrosis does not. See Reynolds, "'I'd Rather Be Dead Than Disabled:' The Ableist Conflation and the Meanings of Disability."

[2] Paul K. Longmore, *Telethons: Spectacle, Disability, and the Business of Charity* (Oxford: Oxford University Press, 2015).

[3] Nagel.

The infamous conclusion of the United States' 1927 *Buck v. Bell* Supreme Court case puts this form of the ableist conflation in crystal clear terms: "The public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices…in order to prevent our being swamped with incompetence. It is better for all the world, if…society can prevent those who are manifestly unfit from continuing their kind…Three generations of imbeciles are enough".[1] For Justice Oliver Wendell Holmes, Jr., certain forms of disability not only trump liberal egalitarianism, they call upon a liberal society to end the future of their existence. A most illiberal inference, indeed.[2] To demonstrate the breadth and depth of deployments of the ableist conflation, I will now focus on two recent examples whose argumentation are leveraged and underwritten quite explicitly by its logic. These will be based upon claims made by psychologist Steven Pinker and philosopher Peter Singer,

Steven Pinker's Promethean Bioethics

On August 1st, 2015, Steven Pinker wrote in the Boston Globe:

> Some say that it's simple prudence to pause and consider the long-term implications of [biomedical] research before it rushes headlong into changing the human condition. But this is an illusion. First, slowing down research has a massive human cost. Even a one-year delay in implementing an effective treatment could spell **death, suffering, or disability** for millions of people. Second, technological prediction beyond a horizon of a few years is so futile that any policy based on it is almost certain to do more harm than good.[3]

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[1] *Buck V. Bell (Carrie Buck V. James Hendren Bell, Superintendent of State Colony for Epileptics and Feeble Minded)*, Oliver Wendell Holmes, Jr. (1927).

[2] Garland-Thomson, "Human Biodiversity Conservation: A Consensual Ethical Principle."

[3] Steven Pinker, "The Moral Imperative for Bioethics," Boston Globe, Aug 1, 2015. https://www.bostonglobe.com/opinion/2015/07/31/the-moral-imperative-for bioethics/JmEkoyzlTAu9oQV76JrK9N/story.html. Emphasis added. This article was then reported at multiple bioethics news outlets, including *BioEdge*.

Pinker finds that death, suffering, and disability are similar enough to be listed together as articulations of experiences no one wants and *obviously* so. Imagine making sense of one's experience when one is labeled "disabled" under such circumstances. By creating hermeneutical injustice, the ableist conflation effects a total testimonial injustice in a case such as this. Pinker's equivocation of death, suffering, and disability creates a set of interpretative conditions under which the experiences of disability are flattened and made purely negative, and this leads to the inability of first-person testimony regarding disability to be taken seriously in any other form. On Pinker's logic, the credibility of a person living with a disability who disagrees with the aspiration of eliminating disability would have a *total* and not just deflated level of credibility.

Pinker's claim is in step with many transhumanist and posthumanist writers. They actively seek the total eradication of "disability" from the human species, conflating a whole range of corporeal variabilities categorized as "disabilities" not only with pain and suffering, but with disease and illness.[1] To be fair, Pinker does not explicitly claim in the quote above that disability is in and of itself a type of suffering, as the ableist conflation stipulates. Yet, whether one understands the "or" conjunctively or disjunctively, the perlocutionary force of his series "death, suffering, or disability" could not be clearer: these phenomena are identical in that *no one wants to experience them*.

Such an understanding is all-too-common for people living with disabilities, and disability studies scholars working within academic fields ranging from bioethics to literary studies have spilled much ink for decades arguing against it. To repeat a point from above, I hope here to contribute to these debates by providing a philosophical

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[1] "Transhumanist FAQ," http://humanityplus.org/philosophy/transhumanist-faq/, accessed June 6, 2015. On the relation of post- and trans-humanism to disability and disability studies, see Scott DeShong, "On (Post)Human (Dis)Ability," *Subjectivity: International Journal of Critical Psychology* 5, no. 3 (2012).

account of how such a view was constructed in the first place and why, even when reasonably weakened, it is held onto by too many—and by certain philosophers in particular—with such tenacity. In another section from the same piece, Pinker writes,

> Have you had a friend or relative who died prematurely or endured years of suffering from a physical or psychiatric disease, such as cancer, heart disease, Alzheimer's, Huntington's, Parkinson's, or schizophrenia? Of course you have: the cost of **disease** is felt by every living human. The Global Burden of Disease Project has tried to quantify it by estimating the number of years lost to premature **death** or compromised by **disability**. In 2010 it was 2.5 billion, which means that about a third of potential human life and flourishing goes to waste. The toll from crime, wars, and genocides does not come anywhere close.

Disease, disability, and premature death are here treated interchangeably, unlike the grammatical ambiguity of the quote analyzed before. A life with disability is a life compromised. Disability names a life in which both the flourishing and sheer potentiality of life itself are *wasted*. In term of quantitative comparison, disability—combined here through its essential characteristics with disease and premature death—is more grave than crime, war, and genocide. Disability, as Pinker understands it, is a form of constitutive pain and suffering. Disability names the *obviously* undesired, unfulfilled, and unflourishing. Pinker not only commits the ableist conflation, but he then employs its logic to argue against ethical reflection on the advances and future of biomedical technologies. Disability, like disease and death, is so bad that ethical concerns about the implications of biomedical technology prove imprudent. Worry about risk on your own time, Pinker exclaims, but we need to immediately continue reducing disability, disease, and death. There is a total hermeneutic and testimonial injustice at work here, and, perhaps above all else, the rhetorical force of the ableist conflation is to blame.

Peter Singer's Common Sense Ableism

One can also find the ableist conflation at work in Peter Singer's remarks concerning disability. Because numerous scholars have already done so, I will not engage his arguments in favor of the euthanasia of severely intellectually disabled infants (whether in vitro or, as he argued earlier in his career, within twenty-eight days of birth). I will instead focus on how the ableist conflation functions in a passage from *Practical Ethics* on the relation of disability to human well-being or flourishing. To be charitable, I take a passage from the most recently revised version. This version contains edits presumably based upon his multiple interactions with a host of disability rights advocates and disability studies scholars.

Making what he clearly thinks is a perfectly common sense argument, Singer writes:

> It is one thing to argue that people with disabilities who want to live their lives to the full should be given every possible assistance in doing so. It is another, and quite different thing, to argue that if we are in a position to choose, for our next child, whether that child shall begin life with or without a disability, it is **mere** prejudice or bias that leads us to choose to have a child without a disability. If disabled people who must use wheelchairs to get around were suddenly offered a miracle drug that would, with no side effects, give them full use of their legs, how many of them would refuse to take it on the grounds that life with a disability is **in no way** inferior to life without a disability? In seeking to raise research funds to overcome and prevent disability, people with disabilities themselves show that the preference for a life without disability is no mere prejudice. Some disabled people **might say** that they make this choice only because society puts so many obstacles in the way of people with disabilities. **They claim** that it is social conditions that disable them, not their physical or intellectual condition. This assertion takes the simple truth that social conditions make the lives of the disabled much more difficult than they need be, and **twists it** into a sweeping falsehood. To be able to walk, to see, to hear, to be relatively free from pain and discomfort, to communicate effectively – *all these are,* **under virtually any social conditions**, *genuine benefits*. To say this is not to deny that people lacking these benefits may triumph over their disabilities and have lives of astonishing richness and diversity. Nevertheless, we show no prejudice against people with disabilities if we prefer, whether for ourselves or for our children, **not to be faced with hurdles** so great that to surmount them is in itself a triumph.[1]

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[1] Peter Singer, *Practical Ethics*, 3rd ed. (New York: Cambridge University Press, 2011), 46-7, all emphases are mine.

Though the magnitude of scholarly irresponsibility here strikes me as indefensible nearly across the board (especially with respect to engagement with empirical evidence concerning the topics evoked and also with respect to even a cursory attempt to ground one's claims in premises that go beyond common sense—which, given the demographic makeup of the philosophic profession, is *able-bodied common sense*), I will limit myself to just four points.

First, Singer's hypothetical scenario about a "miracle drug" ends with an empirical question to which he provides no answer and for which he provides no data. The fact that he feels he doesn't even need to provide meaningful data concerning whether people who use wheelchairs would take this "miracle drug" communicates the extent to which he assumes disability—in this case understood in terms of wheelchair use—to be a form of pain and suffering relative to the ability to ambulate. *Even if* it were the case that the majority of wheelchair users reported that they would take this drug, his inference doesn't follow. Were the majority to say so, this could be because of the structures of ableism which he—in his mind, apparently—is trying to address, not necessarily because of any intrinsic qualities of "being a wheelchair user."

Furthermore, the very formulation of his hypothetical is question-begging. Such a miracle drug would only be produced if there were demand for it, and the demand for such a drug would be predicated upon assuming wheelchair use to be inferior to ambulation. The subject of the question is already assumed to be in a relation of lack that only an answer in the affirmative can rectify. To risk belaboring the point, the assumptions behind each of the components of the question render it as dubious as asking, "If you were thirsty, would you drink water?" This is why Singer's hypothetical functions as a rhetorical question and why he feels no need to do or engage any research. *Of course* I'd take the miracle drug to no longer use a wheelchair… *Of course* I'd drink water if I were thirsty…

Second, Singer generalizes from people with disabilities who raise research funds "to overcome and prevent disability" to people with disabilities in general. Again lacking quantitative or qualitative data, he concludes from this that selecting against disability cannot be "mere prejudice." Singer's argument appears to be, "action X against group Y cannot be merely prejudicial if (some of?) those in group Y take action X." This is patently specious.

Thirdly, Singer quickly dismisses as a "sweeping falsehood" the most important tool of the disability rights movement and the institutional rise of disability studies, the social model of disability. Singer either misunderstands or mischaracterizes the social model, since the claim that social conditions *disable* is always coupled with the effects of psycho-physical *impairment*. No one, as far as I am aware, claims that impairing factors are entirely irrelevant or do not, at least in some cases, carry existential woes. If one omits the role played by the concept of impairment, as Signer does, it is strictly false to say that social model advocates think that that social conditions alone disable (since that claim fundamentally relies upon the role of impairment).

Fourthly, Singer blatantly commits the ableist conflation as one reaches the acme of his argument. "To be able to walk, to see, to hear, to be relatively free from pain and discomfort, to communicate effectively – all these are, under virtually any social conditions, genuine benefits." We here get a list of human corporeal norms, and the implication is that these are both biologically and also statistically normal abilities. Yet, it has been argued at length in multiple fields that claims concerning biological and statistical normality do not in and of themselves carry *normative* weight. Singer, however, fails to engage or even mention the literatures in question or the philosophical stakes such disputes raise.[1]

These norms are then listed along with a lack of pain and discomfort. For Singer, to be able-bodied is to be free of pain and, correlatively, *to be disabled is to be in pain*. Singer's qualification, "under virtually any social conditions," adds an empirical element to his prescriptive claim, but, yet again, he finds no need to provide evidence. That Deaf people would vehemently disagree that "to hear" is a "genuine benefit," that some in the Autistic community and other communities of people with intellectual disabilities would vehemently disagree that "to communicate effectively [effective relative to what?]" is a "genuine benefit"—none of these well-documented and well-researched rebuttals are meaningfully addressed.

If there are multiple social conditions wherein his claims are contradicted *by those actually living* in such conditions, it is unclear what "virtually any" means in the phrase "under virtually any social conditions." Under virtually any social conditions relative to Peter Singer's life experience? Under virtually any social conditions that the *majority* of people deem beneficial? What majority? The able-bodied majority? So, the majority that has historically and consistently mischaracterized the experiences of the lives of the disabled?[2] Lives who, thanks to longstanding judgments, policies, and assumptions about

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[1] Guy Kahane and Julian Savulescu, "The Concept of Harm and the Significance of Normality," *Journal of Applied Philosophy* 29, no. 4 (2012). See also Joel Michael Reynolds, "Toward a Critical Theory of Harm: Ableism, Normativity, and Transability (Biid)," *APA Newsletter on Philosophy and Medicine* (Forthcoming).

[2] "The Ableism of Quality of Life Judgments in Disorders of Consciousness: Who Bears Epistemic Responsibility?."

lives lived with disability, have ostracized, demonized, and even sanctioned the murder of people living with disabilities?

Singer's arguments are patent, textbook cases of both testimonial and hermeneutic injustice. Most disturbingly and most damningly as a philosopher of repute, it appears that Singer surreptitiously and indefensibly identifies his own able-bodied state and experiences with what he is describing as *the* model of corporeal flourishing. In this passage, one encounters able-bodied privilege at home—a home where its intuitions are taken as prima facie grounds for both understanding and also shaping the world. At least in the passage under discussion, Singer capitulates to common sense and to the ableist conflation, leaving critical thought and empirical inquiry to the side. Having now shown the ableist conflation at work in contemporary examples, I will now turn to highlight its appearance in canonical normative ethical theories within the Western intellectual tradition.

Ableism in the History of Philosophy

Within the history of philosophy, disability has been understood before all else as a lack or privation. In an example to which I will return more than once over the course of the dissertation, Aristotle writes,

> Blindness (*tuphlotes*) is a privation (*steresis*), but one is not blind at any and every age, but only if one has not sight at the age at which one would naturally have it. Similarly a thing suffers privation when it has not an attribute in those circumstances, or in that respect and in that relation and in that sense, in which it would naturally have it.—The violent taking away (*biaia aphaeresis*) of anything is called privation.[1]

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[1] Aristotle, *The Complete Works of Aristotle: The Revised Oxford Translation*, ed. Jonathan Barnes, 2 vols., Bollingen Series (Princeton: Princeton University Press, 1984), 2:1615/022b27-22. In the spurious *Sense and Sensibilia*, it is also commented that "of persons destitute from either sense, the blind are more intelligent than the deaf and dumb" (437a15-17). For my take on the indefensibility of Aristotle's claims, at minimum with respect to blindness, see Joel Michael Reynolds, "On Being Outside the (Normate) Body: Merleau-Ponty's Aveugle and Crip Phenomenology," *Chiasmi International* (Forthcoming).

In the *Politics*, Aristotle argues, “as for the exposure and rearing of children, let there be a law that no deformed child shall live” (περὶ δὲ ἀποθέσεως καὶ τροφῆς τῶν γιγνομένων ἔστω νόμος μηδὲν πεπηρωμένον τρέφειν).[1] No argument is given for this claim—it is taken as grounded upon an understanding of disability (in this case, that which is *peperomenon*) that is obvious enough as to warrant no explanation.

In many ways agreeing with Aristotle, Kant will later claim, “infirmity (*Schwäche*) of the mind is just such a crippled state of mind, as infirmity of the body is a crippled state for the body. Infirmities are not hindrances of the powers of mind, but a lack, but the latter exists when the condition for the regular use of the powers of mind is lacking.”[2] To the extent that one does not meet Kant’s norms for mental ability, one is lacking and lacking fundamentally as a “human.” For example, one is, in such a state, without that which grants moral dignity, among other things.[3] It is telling that there are serious scholarly arguments over whether it is possible in any respect to grant people with intellectual disability moral status within Kant’s moral framework.

Or take Mill’s famous normative judgment about happiness and satisfaction: “better to be Socrates dissatisfied than a fool satisfied.”[4] Fool, in late 19th century English, denotes what today would be called a type of “intellectual disability,” and in that

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[1] 1335b20-21. Aristotle, *The Complete Works of Aristotle: The Revised Oxford Translation*.

[2] Immanuel Kant, *Lectures on Anthropology*, The Cambridge Edition of the Works of Immanuel Kant in Translation (Cambridge: Cambridge University Press, 2012), 113/25:554.

[3] I address those who argue otherwise vis-à-vis Kant below.

[4] John Stuart Mill, *The Collected Works of John Stuart Mill*, vol. X (Indianapolis, IN: Liberty Fund, 2006), 212. Take John Locke as another example from modern philosophy: “But if, through defects that may happen out of the ordinary course of nature, any one comes not to such a degree of reason, wherein he might be supposed capable of knowing the law, and so living within the rules of it, he is *never capable of being a free man,* he is never let loose to the disposure of his own will (because he knows no bounds to it, has not understanding, its proper guide) but is continued under the tuition and government of others, all the time his own understanding is incapable of that charge. And so *lunatics* and *ideots* are never set free from the government of their parents.” John Locke, *Two Treatises of Government*, trans. Peter Laslett, Cambridge Texts in the History of Political Thought (England; New York: Cambridge University Press, 1988), ¶60.

light, it is clear that Mill is in fact pronouncing a variation of Socrates' rhetorical question.[1] A lack of intelligence (even if it is thought to result in satisfaction!) is *worse* than not having that lack. Furthermore, Mill claims that if the "fool" judges his life to in fact be as satisfactory, "it is because they only know their own side of the question. The other party to the comparison knows both sides." This is a textbook case of epistemic injustice, a point to which I return below.[2]

Having now offered several contemporary and canonical examples of the ableist conflation at work, I want to take a step back to further assess its broader theoretical and political stakes. Thinking through the intersections of pain and disability produces a number of puzzling questions, but in this dissertation I focus on two problematics that, by my lights, are fundamental for understanding the role of disability in the history of philosophy: {1} how does the linking of pain and disability function, i.e., what conceptual, affective, or empirical, et al., structures support that linking, and {2} how would ethical theorizing—whether primarily metaethical, normative, or applied—be altered if this linking were undone?

Stakes, Topoi, and Itineraries

The conceptual linkage of pain with disability, i.e., the ableist conflation, explains in part the *affective* cultural responses to disability. Hate crimes towards persons with disabilities and the history of institutionalization of all manner of peoples with disabilities—not to mention current, often deplorable practices developed specifically for the aging—are two obvious examples of this affective influence. In light of the fact that the justification of medically mediated deaths in the ICU and elsewhere (such as in

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[1] See the entry on "fool, n.1 and adj." in OED.

[2] Fricker; Josh Dohmen, "A Little of Her Language," *Res Philosophica* 93, no. 4 (2016).

hospice care or in prisons) turn on a specific understanding of pain and an understanding that more often than not ties that pain to what we call "disability," the stakes of the ableist conflation prove both wide and deadly, today and historically.

An initial caveat is in order. When Adrienne Rich warns of the "idolatry of pure ideas," she attests to the danger of discourse unhinged from social location and identity.[1] How do I—as a disability ally, son, grandson, and sibling—speak and think about disability without betraying one of the central premises of disability studies and disability activism: "nothing about us without us"? "I come here," as Rich beautifully writes, "with notes but without absolute conclusions."

Yet, there is one absolute conclusion I do indeed come with: ableism is everyone's problem, and it must be dismantled. This dismantling is the responsibility of some more than others, namely, those who are able-bodied and thereby constantly privileging from ableism. Furthermore, as Elizabeth Barnes notes and as is hopefully becomingly increasingly obvious as disability studies spills into more and more fields: "disability is a topic that's personal for everyone. The last time I checked, most non-disabled people are pretty personally invested in being non-disabled…When it comes to disability, I'm not objective. And neither are you. And that's true whether you're disabled or (temporarily) non-disabled."[2] To this I would add Margrit Shildrick's exhortation that "the responsibility for enquiry and analysis falls, then, not on disabled people alone but on all those who participate in the relevant structures."[3] Ableism, like racism, sexism,

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[1] Adrienne Rich, "Notes Toward a Politics of Location (1984)" in Myriam Díaz-Diocaretz and Iris M. Zavala, *Women, Feminist Identity, and Society in the 1980's: Selected Papers*, Critical Theory (Amsterdam; Philadelphia: Benjamins, 1985).

[2] Elizabeth Barnes, *The Minority Body* (New York, NY: Oxford University Press, 2016), ix.

[3] Margrit Shildrick, *Dangerous Discourses of Disability, Subjectivity and Sexuality* (Basingstoke; New York: Palgrave Macmillan, 2009).

cisgenderism, classism, and other ideological trappings, must be discussed, addressed, and opposed by all. My hope is that the following will offer something of value to those discussions and those projects of social justice.

Having now laid out a provisional introduction of the problematic and arc of my dissertation, I will turn to quickly outline its chapters. The methodology, the *way* of approaching *logoi,* I utilize will not proceed dialectically from doxic accounts of the good to an articulation of that which all goods seek (Aristotle).[1] Nor will it proceed from a reductive analysis of certain ethical principles to a supreme principle (Kant).[2] Nor will it proceed from a chief ethical principle that results in a rule which allows one to implement it (Mill).[3] Instead, after constructing a critical schematic of various theories (doxas) of the phenomena in question, I proceed from a hermeneutic phenomenology to the prescriptive *insights* such a phenomenology offers. In the words of Peirce: “Every attempt to understand anything, — every research, — supposes, or at least *hopes*, that the very objects of study themselves are subject to a logic more or less identical with that which we employ.”[4] Far from seeking a full understanding, I suppose and hope that an experiential, phenomenological logic proves the best entry-point and method to understand these phenomena and an entry-point that is especially rich with respect to their ethical implications.

Because I, with varying levels of depth, engage a very wide array of literatures—from religious studies to biology to literature and from law to sociology to nursing—I run

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[1] For Aristotle, this is *eudaimonia*. See Aristotle, *Nicomachean Ethics*, 1094a-98b.

[2] Immanuel Kant, *Grounding for the Metaphysics of Morals with on a Supposed Right to Lie Because of Philanthropic Concerns*, trans. James W. Ellington, 3rd ed. (Indianapolis: Hackett Pub. Co., 1993), 5/392.

[3] John Stuart Mill and Jeremy Bentham, *Utilitarianism and Other Essays*, Penguin Classics (New York: Penguin Books, 1987), 275, 83.

[4] Charles S. Peirce, *Reasoning and the Logic of Things : The Cambridge Conferences Lectures of 1898* (Cambridge, Mass.: Harvard University Press, 1992), 257.

the risk of leaving specialists displeased at various steps in the project. Given both my topoi and my aims, this is an unavoidable danger. Yet, it is both unavoidable and also welcome insofar as my problematic accounts for a theoretical myopia that spans the humanities and social sciences, a myopia instilled in what goes under the moniker "the Western intellectual tradition."

Still, a further comment on the positioning of this work is in order. I understand this project to ultimately reside at the intersection of ethics and philosophy of disability, with particular ramifications for the applied fields of bioethics, health communication studies, and nursing studies. Philosophy of disability, in turn, I take as a subfield within the broad, interdisciplinary work of disability studies and, more specifically, as a vital component of critical disability studies. The institutional history of disability studies as fundamentally multi-disciplinary and interdisciplinary field is a history that continues to reflect the complexity of its object of study. But if disability studies demands breadth, disability theory does even more so, for disability theory—which is historically a *critical* enterprise—seeks to do more than simply describe. It seeks to critique, change, and create novel ways of thinking and acting.[1] By my lights, it seeks to ultimately transform praxis. I will now turn to outline the chapters that follow.

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[1] This, I think, is why Shelley Tremain provocatively speaks of disability studies as "counterdisciplinary" field. She explains, "academics who conduct their work under the rubric of disability studies have begun to problematize the foundational assumptions of many disciplines and fields of inquiry, as well as the methodologies that they employ, the criteria of evaluation to which they appeal, and the epistemological and social positioning of the researchers and theorists invested in them. From within both autonomous programs and home disciplines, disability theorists and researchers have engaged in a diversity of investigative and critical pursuits. For example, they have shown the cultural and historical specificity of dominant Euro-American notions of corporeal attractiveness; they have analyzed how disability colluded with race in the formation of the modern nation-state, have plotted histories of disabled people's resistance, traced genealogies of eugenic policies that culminate in contemporary reproductive technologies, critiqued representations of disabled people in the media and literature, and considered the intersection between disability and queer sexualities." Shelley Tremain, *Foucault and the Government of Disability*, Corporealities (Ann Arbor: University of Michigan Press, 2005), 2.

Chapter Outlines

With the goal of understanding how the ableist conflation has held such sway across Western thought, I schematize dominant understandings of pain in chapter one, detailing how pain functions in religious, neurobiological, humanist, existential, and medical theories. This is not merely a descriptive procedure, for the goal of these surveys is to produce a schematic that exposes the underlying theoretical structure of each theory taken as a whole.[1] Ultimately, I aim to to uncover structures of the phenomena in question as well as the prescriptive *insights* therein.

In chapter two, I contrast these theories with a phenomenology of pain through the figure of a person living with Complex Regional Pain Syndrome (CRPS) Type I. I argue that while an analytic and diagnostic distinction is necessary between component, constitutive, and consuming pain, dominant models of pain all afford one a way to regain one's sense of agency. In chapter three, I contrast individualist, social, and post-social theories of disability. I argue that only social theories of disability afford self-regulation and assist in purposive action. I then contrast these theories with a phenomenology of "disability" through the figure of a person living with Multiple Sclerosis (MS) in chapter four. I argue that while differences between conditions categorized as instances of "disability" are staggering, historically dominant models of disability systematically relegate all people with disabilities to forms of languishing, not flourishing, and function to exteriorize one living with disability. I then suggest that many philosophical

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[1] As an *expositional* device, the schematic is at once descriptive and critical. I then develop a hermeneutic phenomenological treatment of the theme in question before returning to assess both how well or poorly the schematic comprehends the theme and how well or poorly my phenomenological reconstruction captures the breadth represented in the schematic. If one defines *critical phenomenology* as phenomenological research that is cautious or skeptical of the accuracy or completeness of its first-person mooring, then in the latter cases I engage in a critical phenomenology.

discussions of disability go awry by failing to distinguish between multiple forms of disability, and I offer several conceptual distinctions towards that end.

In chapter five, I argue the problem of the ableist conflation is ultimately grounded in its implicit conception of ability. I develop a model of what I call *the charmed pendulum of ability* as a way of thinking ability as access as opposed to ability as personal control. Those who are more familiar with philosophy of disability and critical disability studies will encounter more novel claims, I think, in the fifth and final chapter.

I conclude the dissertation by analyzing the last central component of the ableist conflation: the concept of harm. I analyze the concept of harm as deployed by bioethicists against therapeutic amputation for people with BIID (body integrity identity disorder). I then close by addressing how a dismantling of the ableist conflation such as I present in this dissertation might inform ongoing work in continental philosophy (especially scholarship engaged with phenomenology, both classical and contemporary), critical disability studies, feminist philosophy, and ethics, both continental and analytic.

PAIN

1 THEORIES OF PAIN

> For it would be better to die once and for all than to suffer pain for all one's life.
> Ἰώ: [...] κρεῖσσον γὰρ εἰσάπαξ θανεῖν // ἢ τὰς ἁπάσας ἡμέρας πάσχειν κακῶς
>
> —Aeschylus[1]

> Though what is painful is borne for a short time, no one could continuously endure even the Good Itself if it were painful to him.
> τὸ δὲ λυπηρὸν ὀλίγον μὲν χρόνον φέρουσιν, συνεχῶς δ’ οὐδεὶς αὐτὸ ἂν ὑπομείναι, οὐδ’ τὸ ἀγαθόν, εἰ λυπηρὸν αὐτῷ εἴη
>
> —Aristotle[2]

Today is a not a good day.

Light—its expanse, its warmth—is an adversary. Motion—that energy breaking in and pulling back, that dynamism we equivocate as power—is in cuffs. You *are* experiencing. You *are* experiencing *something*. You search for words. You have heard of something called a “headache.” You have experienced this before, but typically after long nights at Dionysus’ fickle side. This cannot be that. You *know* that. Perhaps this is called something else...a “migraine headache”?[3] Perhaps. Whatever it is called, the world is different. Is there a word for that? Wouldn’t that word first need to exist in the old world, the world before everything was different? Or wouldn’t it need to span these worlds, going back and forth, around and around and back again? Can a word pirouette like that? Can pain *do* that?

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[1] Aeschylus, *The Complete Aeschylus*, 2 vols., Greek Tragedy in New Translations (Oxford; New York: Oxford University Press, 2011), 1: 351, verses 750-1.

[2] Aristotle, *Nicomachean Ethics*, 8.6: 1158a24-5.

[3] I pick the example of a headache here on purpose because it walks the line between an experience nearly everyone has and, when chronic, an instance of a “disability.” See J. Borkum and R. W. Evans, "Disability and Chronic Migraine," (2014).

I argued in the introduction that the most pressing issue for philosophy of disability is the ableist conflation. However, I did not fully explain what I meant by "ableism." Definitions of this term abound, but I define it according to two component presumptions.[1] The first component is the presumption of a standard body.[2] More technically, this is an ontological presumption that holds there to be psycho-somal norms based upon medically and socially pathologized typologies. The second component is the relegation of non-standard, non-normative bodies to undesirable domains of existence. This is an existential or modal presumption insofar as it defines the *way* lives are lived that fall on the hither side of the ontological presumption of a standard body. In a sentence, ableism is "assumption that the 'standard' or 'normal' able-body is, *ceteris paribus*, in and of itself better than nonstandard or abnormal forms."[3] The ableist conflation is thus a specific form of ableism.[4] I find the widespread view that disability is assumed to be undesirable simply because it is considered non-normative unconvincing; rather, it is the more specific linking of disability with pain or suffering that, initially and for the most part, produces the particular cultural characteristics of its putative

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[1] I say "presumption" and not "assumption" because assumptions are held whether or not one is confident about that which is assumed, whereas presumptions are held about things of which one is sure. For numerous glosses of the term "ableism," see Fiona Kumari Campbell, *Contours of Ableism: The Production of Disability and Abledness* (New York: Palgrave Macmillan, 2009). In a shorter piece, Campbell defines it as "a network of beliefs, processes, and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, as the species-typical, and, therefore, as essential [sic] and fully human." Fiona Kumari Campbell, "Legislating Disability" in Tremain, 127.

[2] See Robin Lynn Zebrowski, "We Are Plastic: Human Variability and the Myth of the Standard Body" (Ph.D. Dissertation, University of Oregon, 2009).

[3] Reynolds, "The Ableism of Quality of Life Judgments in Disorders of Consciousness: Who Bears Epistemic Responsibility?," 59.

[4] Perhaps the other side of the ableist conflation is the conflation of lives lived outside ableist norms with lives that suffer nothing and are thus outside the purview of moral consideration. E.g., Jeff McMahan takes such a stance with respect to the "congenitally severely mentally retarded," specifically in relation to their putative inability to engage in "prudential relations." See Jeff McMahan, *The Ethics of Killing: Problems at the Margins of Life*, Oxford Ethics Series (New York: Oxford University Press, 2002). A trenchant criticism of McMahan's views is presented in E. F. Kittay, "At the Margins of Moral Personhood," *J. Bioethical Inq.* 5, no. 2-3 (2008).

undesirability.[1] In order to understand how the ableist conflation came to be, I will first turn to analyze pain.

While the fields of inquiry most directly concerned with pain are the medical sciences, one is hard pressed to find any theory that meaningfully structures human life that does not take its role seriously, whether via elevation, neutralization, or deflation. In light of the breadth of theoretical considerations pain has historically evoked, this chapter provides a survey of dominant theoretical models of pain, including religious, neurobiological, humanist, existential, and medical models.[2] I turn in the following chapter to a phenomenology of pain, upon which I develop a distinction between component pain, constitutive pain, and consuming pain. In the end, I argue that that pain functions *regulatively*: it orients one towards actions that address the cause or existence of pain.[3] More specifically, pain always functions as a command to reorient oneself with the aim of reestablishing homeostasis and, thereby, one's prior, expected abilities. The

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[1] I am thus taking issue with some formulations of "ableism" as presented in Fiona Kumari Campbell, "Inciting Legal Fictions: 'Disability's' Date with Ontology and the Ableist Body of Law," *Griffith Law Review* 42 (2001); *Contours of Ableism*. The prevalence of an attitude of *pity* towards people with disabilities—as opposed to, say, hostility—is further socio-cultural evidence of my claim. Granted, there are undoubtedly cases where the undesirability of disability is not due to the ableist conflation. When one responds with *disgust* to a non-phenotypical form of embodiment, it would be hard to claim that this is primarily and for the most part due to a linking of that embodiment to pain or suffering. My argument is that whatever prevalence such responses may have, the primary response to disability is one that operates relative to the ableist conflation—this is borne out most obviously when one looks to evidence in economic, literary, political, and ethical literature regarding arguments over the value of disabled lives (evidence I cite extensively in chapters 2 and 3 below). Having said this, I will argue in chapter four below that hostility and pity are *formally* similar in their exteriorization of disability from the one displaying hostility or pity.

[2] Histories of pain are increasingly common. Due to the aims of my dissertation, I cannot engage a comprehensive account of such histories (whatever their scope), but I would highlight the following resources: Joanna Bourke, *The Story of Pain: From Prayer to Painkillers* (New York, NY: Oxford University Press, 2014); Javier Moscoso, *Pain: A Cultural History* (Basingstoke; New York: Palgrave Macmillan, 2012); Roselyne Rey, *The History of Pain* (Cambridge, Mass.: Harvard University Press, 1995); Keith Wailoo, *Pain: A Political History* (Baltimore: Johns Hopkins University Press, 2014); Kenneth D. Keele, *Anatomies of Pain* (Springfield, Ill.: Charles C. Thomas, 1957). It may appear that by surveying various models, I ascribe to a "pain culture" view of pain, viz., that of a social constructivist and historicist. For such an account, see Sarah Aldrich and Chris Eccleston, "Making Sense of Everyday Pain," *Social Science & Medicine* 50, no. 11 (2000). I will argue below that although social, historical, and any other number of factors are indeed determinative, that does not preclude the possibility that a phenomenon such as pain has general structures.

[3] I.e., etiological or symptomatic approaches are each responses to pain's regulative function.

unique characteristic of suffering, by contrast, is its resistance to this regulative functionalization.[1] Tellingly, chronic pain and what I will define below as "suffering" do not fit well into any dominant theories of pain, except as exceptions.[2]

A word on what I mean by using the term "theory" when I speak of various theories of pain and, in chapter three, theories of disability. My use is captured well by Thomas Nail when discussing his theory of the border. "The purpose of a theory or concept of [a phenomenon] is not to explain or predict every detail of empirical [phenomena of that sort]; a theory…aims to describe the conditions or sets of relations under which" those phenomena occur (11). To this I would only add, a theory aims to describes the conditions or sets of relations under which a given phenomenon is experienced as *meaningful* or ought to be so experienced. For those well acquainted with the multiple literatures discussed below, it will be clear that, in the end, I offer a theory *of* theories concerning pain. I do so in order to understand how the multiplicity of theories of pain and the range of meanings to which they relate might all nevertheless work to support the ableist conflation.

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[1] To foreshadow, the phenomenology of disability I present in the second chapter will lead me to argue that disability is linked to suffering only when viewed as a deregulation, that is, when conceptualized as a loss of ability as control. I will later suggest that the philosophical roots of the conception of ability as personal power derive from ideologies of privilege or, what is the same, ideologies of assumed access. Because privilege informs prescription just as prescription confers privilege, it is no surprise that canonical normative theories have excluded *numerous* unprivileged.

[2] If space were not limited, I would structure a full discussion of dominant models of pain as follows:

- NEGATIVE (downregulating):
    - Deflationary (Buddhism, Stoicism)
    - Retributive (Abrahamic-Genesaic, Christological-soteriological, juridical-legal)
- POSITIVE (upregulating):
    - Alethic-Enlivening (existentialist, self-mutilation, BDSM)
    - Alethic-Revelatory (humanist, tragic)
    - Redemptive (Pauline Christianity, mystics, flagellants)
    - Bolstering (Nietzschean, military-industrial, sport-exercise)
- NEUTRAL (either downregulating or upregulating):
    - Adaptive (evolutionary, neurobiological, historical materialist)
    - Gnoseological (medical, phenomenological, political)

§1.1 Religious (Abrahamic)

Because I am working primarily within the Western philosophical tradition, I here treat what I am calling the "religious model of pain" only with respect to the Abrahamic traditions: Judaism, Christianity, and Islam. A further benefit of solely engaging the Abrahamic traditions is that it allows me to focus primarily on the Genesaic cosmogony (which the Qur'an/Koran largely follows). Given that each of these traditions begins in the near East, not what is today ambiguously referred to as "the West", there is a certain geographic irony in such an opening qualification. My focus, of course, must be understood in terms of a historical trajectory and thus both constructed and contestable.[1]

A selective archive of pain's etymology is an effective entry-point. The English "pain" originates from the classical Latin *poena*: "penalty, punishment, satisfaction, revenge, unpleasant consequence" and in post-classical Latin also "suffering, affliction (4th cent.)" The Latin, in turn, originates from the Attic Greek *ποινή*: "blood money, fine, penalty, satisfaction, reward." The Indo-European base of this root appears in multiple languages with the same basic sense: pain is the *price one pays for something*.[2] This *for* structure is constitutive of pain's sense: etymologically, pain is always in a dynamic

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[1] The stakes of such a contestation are presented well in, e.g., Edward W. Said, *Culture and Imperialism*, 1st ed. (New York: Knopf: Distributed by Random House, 1993), 318ff. One might quickly object that if I were to consider certain Eastern religious traditions that treat pain and suffering as illusionary, my "religious model" would turn out quite differently. Although I cannot fully substantiate the claim in this dissertation, I will argue at the end of this section and also in section 1.1.6 below that that my conclusions about the functional role of pain in these models captures what is at stake in deflationary models of pain as well. In short, pain still functions as a command to reorient oneself relative to a given order in deflationary models—it's just that the command in such a case is to *ignore* or sublimate that pain. One might respond that with sufficient bodily-mental practice, certain religious practioneers say they no longer feel or sense pain (such as in fire-walking practices). But if one takes that to be the case, it is not a counterexample, for my argument does not cover examples where pain is neither sensed nor felt. See Lucile Armstrong, "Fire-Walking at San Pedro Manrique, Spain," *Folklore* 81, no. 3 (1970).

[2] OED, "poena, n." "Avestan *kaenā* vengeance, reparation and, with a different ablaut grade, Old Church Slavonic *cěna*, Russian *cena*, and Lithuanian *kaina* all in sense 'price.'"

relationship that cannot be understood in terms of its mere happening. By definition, *pain has an etiology*.

In the Abrahamic traditions pain is not understood as a necessary condition of being human, but as a price humans have paid due to an act of transgression. The latter *causes* the former to enter into the world. The Genesaic cosmogony makes this clear[1]:

> The Lord God took the man and put him in the garden of Eden to till it and keep it. And the Lord God commanded the man, "You may freely eat of every tree of the garden; but of the tree of the knowledge of good and evil you shall not eat, for in the day that you eat of it you shall die (*muth*: תָּמוּת)" (2:15-17).[2]

Unlike the P account in Genesis 1 where God[3] offers only positive directives, the first commandment in the J account is dual. The *sole* action the human[4] cannot take is contrasted with the human's relative freedom, but the *poine*, the price, of defying that injunction is death. The cosmogony of J installs power absolutely; the possibility of the

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[1] For a very short, but helpful introduction to some of the issues Gen. 1-11, in particular, presents, see John Rogerson, *Genesis 1-11* (London; New York: T&T Clark International, 2004), esp. 18-26. He includes some discussion of the critical readings utilizing the Documentary or Wellhausen Hypothesis (DH/WH) that distinguish between the Yahwist (J), Elohist (J), Deuteronimist (D), and Priestly (P) sources. This hypothesis dates back to the 18th century but was made foundational due to Julius Wellhausen's 1876/77 *Die Composition des Hexateuch und der historischen Bücher des Alten Testaments*. For a recent monograph on the DH, see Joel S. Baden, *The Composition of the Pentateuch: Renewing the Documentary Hypothesis*, The Anchor Yale Bible Reference Library (New Haven: Yale University Press, 2012).

[2] Wayne A. Meeks and Jouette M. Bassler, *The Harpercollins Study Bible: New Revised Standard Version with the Apocryphal/Deuterocanonical Books*, 1st ed. (New York, NY: HarperCollins, 1993). Hereafter referred to as NRSV. The Qur'anic/Koranic account is nearly identical: "We said: 'Adam, dwell with your wife in Paradise and eat of its fruits to your hearts' content wherever you will. But never approach this tree or you shall both become transgressors.'" *The Koran*, trans. N. J. Dawood, 5th rev. ed., Penguin Classics (London, England; New York, NY: Penguin Books, 1990), 2:34, see also 7:19. See also 20:120: "Thus did Adam disobey his Lord and stray from the right path." Due to this disobedience, the human is elsewhere described as contentious or as a disputer (خَصِيمٌ) (36:77 and 2:204).

[3] As a whole, the DH relies upon the different usages of the name of God as one clue as to which documentary source is which. The names at issue are Elohim, YHWH, YHWH Eloheinu, and El Shaddai. I will utilize the term "God" for simplicity.

[4] With the exception of the clearly gendered punishment, I will speak not of "man" but of humans with respect to the Genesaic account. As Robert Alter notes, the Hebrew term *'adam* (אָדָם) does not indicate a male. With respect to Gen. 1:26, Alter writes, "The term *'adam,* afterward consistently with a definite article, which is used both here and in the second account of the origins of humankind, is a generic term for human beings, not a proper noun. It also does not automatically suggest maleness, especially not without the prefix *ben*, 'son of,' and so the traditional rendering 'man' is misleading, and an exclusively male *'adam* would make nonsense of the last clause of verse 27." Robert Alter, *Genesis* (New York: W.W. Norton, 1996), 5. See also the translation by the JPS (Jewish publication society) in Jewish Publication Society, *Tanakh: A New Translation of the Holy Scriptures According to the Traditional Hebrew Text*, 1st ed. (Philadelphia: Jewish Publication Society, 1985).

an-archic, of an absolute rebellion against the *theos*, is the price, the pain, of death. An absolute injunction for an absolute insurrection.

> To the woman he said, “I will greatly increase your pangs [*itstsabon*: עִצָּבוֹן] in childbearing; in pain [*etseb*: בְּעֶצֶב] you shall bring forth children, yet your desire shall be for your husband, and he shall rule over you.” And to the man he said, “Because you have listened to the voice of your wife, and have eaten of the tree about which I commanded you, ‘You shall not eat of it’, cursed is the ground because of you; in toil [*itstsabon*: עִצָּבוֹן] you shall eat of it all the days of your life; thorns and thistles it shall bring forth for you; and you shall eat the plants of the field. By the sweat of your face you shall eat bread until you return to the ground, for out of it you were taken; you are dust [*aphar:* עָפָר], and to dust you shall return” (3:16-19, NRSV).

God’s response to the transgression offers an anthropological rationality that explains both gender differences and economic realities. In each case, pain is a *price* one pays for a wrong committed and a price that is essentially experienced as *to-be-avoided*. Tellingly, the Genesaic account does not offer Adam and Eve a way to rectify their transgression. Moreover, Adam and Eve only figuratively pay the price stated in Gen. 2, for they do not die.[1] They live on, but they live on in the only way non-mythic accounts of humans live on—as mortals, which is always to say, as creatures who experience pain.[2] There is a single root in classical Hebrew of the words translated as “pangs,” “pain,” and “toil” in the quote above: *atsab* (עָצַב). It means “an earthen vessel; usually (painful) toil; also a pang (whether of body or mind): grievous, idol, labor, sorrow.”[3] The dry earth or dust

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[1] Due to the humanistic backdrop of my investigation, I will not here consider accounts which treat this separation from God as a sort of death or as even worse than death.

[2] Recall that there are three impetuses for Eve’s decision. (That it is taken to be *Eve’s* decision, when Adam was with her the whole time, is a problematic I cannot broach here.) She chooses the tree because it offers sustenance, aesthetics, and wisdom. It is not accidental that it is only upon an understanding that the tree would *feed* her, that it would *please* her, and that it would, thirdly and finally, also make her more *wise*. I do not read the order of these functions as accidental. It is only upon the reproduction of human life, to borrow the Marxian idiom, that the tree appeals to Eve in the first place. Secondarily, it is pleasuring, which one need not take as a mere matter of *aesthesis*, but as a more general question of enlivening, of a flourishing beyond the exigencies of subsistence. That is to say, that the tree brings pleasure is a good, but the condition of the possibility of both recognizing and enjoying that pleasure is the baseline necessity of reproducing life. It is only as the final and third consideration that Eve takes up the serpent’s bait: wisdom is good, to be sure, assuming it follows upon the reproduction of material life and the joys of pleasure.

[3] James Strong, *The New Strong's Exhaustive Concordance of the Bible: With Main Concordance, Appendix to the Main Concordance, Hebrew and Aramaic Dictionary of the Old Testament, Greek*

(*aphar)* out of which the human is formed is precisely conceived as a sort of vessel because the human only becomes a living creature upon receiving the breath of life *into* its earthen, dusty vessel (Gen. 2:7-8). God's punishment links the creation of the human as an *atsab*[1] to its experiencing of *atsab*. The human comes to experience itself in relation to its materiality, and this relation is conceived precisely as one of *pain*. When the human experiences itself *human-ly,* it does so through pain.[2] *'Adam*—as being *'adamah*, as being made up of *aphar* and as an *atsab*—experiences *atsab*, experiences *itstsabon* and *etseb*. The price (death: *muth*) of transgression is to bring the human to experience itself as itself, which is to say, in its pain.[3]

Note also that the thought that one could want to pay this price or that this pain has a *use* beyond mere retribution is inconceivable in the Genesaic account, and this marks a notable difference from the conception of pain in later theologies, whether explicitly theodical or not. It is only after this mythical, primordial, and essentially unwanted pain first occurs that pain can enter into redemptive ratiocinations. For example, the author of Luke, held by most scholars as the last of the three synoptic gospels to be written, has the resurrected Jesus offer a soteriological-Christological interpretation of his suffering: "Was it not necessary that the Messiah should suffer these things?" (Lk. 24:26, cf. 24:46).[4] This is based upon an interpretation of Isaiah 53, and this

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Dictionary of the New Testament (Nashville, Tenn.: T. Nelson, 1996), 6093.

[1] As the punning makes clear of *'adam* off of *'adamah*: "from the soil".

[2] To be clear, I am here translating the pun from Hebrew into English without heeding the English etymology.

[3] This formulation is, of course, heterodox insofar as I am not reading the prelapsarian relation of the human to itself and to creation as prelapsarian at all.

[4] This line does not occur in any of the other gospels. See Kurt Aland, *Synopsis of the Four Gospels: Completely Revised on the Basis of the Greek Text of the Nestle-Aland 26th Edition and Greek New Testament 3rd Edition: The Text Is the Second Edition of the Revised Standard Version*, English ed. (New York: United Bible Societies, 1982), 335.

soteriology *requiring* Jesus to suffer is a prevalent theme across the Christian New Testament.[1]

To take another example, that suffering is something in which one ought to rejoice is a crucial theme for Pauline theology (Rom. 5:6, 2 Cor. 12:7-10, Col. 1:24). In other places, Paul either explicitly minimizes suffering in relation to future glory or equalizes it with the comfort received through Christ (Rom. 8:18-23, Phil. 3:8-12, 2 Cor. 1:5-10).[2] The Genesaic cosmogony leads one to suggest that none of the theological *usefulness* or postlapsarian *necessity* of pain or suffering would make sense unless pain had first been brought into the world through *an error.* Pain is fundamentally exterior to purposivity of the Genesaic cosmogony.

Put otherwise, it is only after the Fall that pain could be brought into theological jurisprudence without denying cosmological benevolence, even though *pain* is simultaneously rendered essential for the human. Genesis unfolds this paradoxical logic deftly: pain enters the world after mortals do, even though, as the etymology of *astab* suggests, it is definitive for their material form. Still, mortals *pay for* this fault, the proof of which constitutes their very existence *as* mortals and the removal of which is impossible without the removal of their very constitution (i.e., via their death). Pain

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[1] See, e.g., 1 Peter 2:19-25: "For it is a credit to you if, being aware of God, you endure pain (λύπας πάσχων) while suffering unjustly…if you endure when you do right and suffer for it, you have God's approval. For to this you have been called, because Christ also suffered (ἔπαθεν) for you…when he was abused…he entrusted himself to the one who judges justly. He himself bore our sins in his body on the cross, so that, free from sins, we might live for righteousness; by his wounds you have been healed." As the notes to Luke 24.26-27 point out, the soteriology based upon Isaiah 53 appears often (Lk. 9:22, 43b-45, 12:50, 13:32-33; 17:25, 18:31-34 and in Acts 3:18, 17:3, and 26:23. Some scholars hold Acts to be written by the author of Luke).

[2] E. P. Sanders speculates in his seminal work on Paul that a "history of attitudes towards suffering in Palestinian Judaism…would, I think, reveal that generally human suffering was considered to be divine punishment for transgression, except during the periods of religious persecution." E. P. Sanders, *Paul and Palestinian Judaism: A Comparison of Patterns of Religion*, 1st American ed. (Philadelphia: Fortress Press, 1977), 23. Paul's views on suffering are in concert with prevalent views in Rabbinic theology of at least the Tannaitic period. *Ibid*, 105-06. On the overall role of suffering in Pauline soteriology, see esp. *ibid*, 466-474.

marks the entrance into mortality and into the mortally deferred *recovery* of a prior painlessness, a painlessness which would, paradoxically, mark the non-mortal. A strange logic, indeed.

Pain reminds us both of what we are and what we seek to be, viz., *not* what we are. Pain reminds us that what we are is *what we wish we weren't*. Pain signals the ontological divide between transgression and redemption. For the religious imaginary taken by such an account, pain signals right from wrong in a far less abstract sense than one might think. To support such a point, one can look to the reactions of certain religious individuals to epidemics among religiously ostracized groups. The Westboro Baptist Church is one such example. Reactions from such groups not only disregards the suffering of the ostracized groups in question, but actually rejoice and revel in that suffering as proof of divine justice. The vitriol appears almost inexplicably intense and extreme outside of an explanation such as this.

To summarize, I began by arguing that pain is a sign by which one knows one committed a wrong before God as the thetic order.[1] By "thetic" I mean that which is a principle—that which is a *principium* in the sense of both being an origin and foundation. When Aristotle argues in the *Metaphysics* that "there is no demonstration of a principle of demonstration (ἀποδείξεως γὰρ ἀρχὴ οὐκ ἀπόδειξίς ἐστιν)," I would gloss this as the claim that that which is thetic, any given theticism, is founding and ultimately so.[2] Pain, then, is integral, if not central, to the moral feedback loop of a thetic order, whether God, Reason, Nature, Morality, the Good, or what have you.

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[1] As ultimately a question of theticism, under different hegemonic regimes "God" can easily become "nature" or "consciousness," et al. See Reiner Schürmann, *Broken Hegemonies*, trans. Reginald Lilly, Studies in Continental Thought (Bloomington, IN: Indiana University Press, 2003).

[2] *Metaphysics*, 1011a. Translation modified from Aristotle, *The Metaphysics*.

As the other models and the whole of section 1.2 below will make even clearer, pain is the most epistemically obvious signal a theticism could employ because of its (presumed) de facto *negativity*. That is to say, aside from notable exceptions with which I deal below, pain is fundamentally experienced as that which is *to-be-avoided*. Moreover, without alternative explanations such as modern medicine would later provide, the religious-cosmological explanation of pain is sounded in the moral register out of which religion first speaks: debt.[1] I said earlier that pain has an etiology by definition, but, to be more precise, it is an *economic* etiology. Pain signifies an experiential price to be paid.

While this economic etiology explains how pain functions, it stops short of elucidating what pain *means*, what pain's *sense* is for a religico-Abrahamic imaginary. Pain points backwards to a wronging of and before God for which one must pay. It simultaneously enjoins one to seek the righting of that wrong. Pain is both proscriptive and prescriptive. Although it does not in and of itself offer content vis-à-vis its prescriptive obligation, it orients one to the possibility of harmony with the *theos* in question. It is, in that sense, a condition of the possibility of redemption and future promise, whatever its parameters. Nietzsche, critiquing Christianity, said it most clearly: "the discipline of suffering, great suffering—do you not know that only *this* discipline has created all the enhancements of man so far?"[2]

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[1] David Graeber, *Debt: The First 5,000 Years* (Brooklyn, N.Y.: Melville House, 2011). It is for this reason that although I have focused on the Abrahamic traditions almost solely through the Genesaic cosmogony, I am content to term my discussion as a "religious model" of pain, which is not to say there aren't exceptions, but that those exceptions would be atypical. E.g., Graeber, when speaking of the transition from late second millennium Vedic poems to the Brahmanas, notes that the conclusion made by the Brahmans was quite simple: "human existence is a form of debt." Ibid, 56.

[2] Friedrich Wilhelm Nietzsche, *Beyond Good and Evil: Prelude to a Philosophy of the Future*, trans. Walter Arnold Kaufmann (New York: Vintage Books, 1966), 154. Or, to take another paradigmatic statement critiquing Christianity, "To see others suffer does one good, to make others suffer even more…without cruelty there is no festival." *On the Genealogy of Morals; Ecce Homo*, trans. Walter Arnold Kaufmann (New York: Vintage Books, 1967), 67.

Accordingly, a final formulation of religious theories of pain is now possible: via an economy of debt, *pain is theologically regulative*.

§1.2 Neurobiological

The neurobiological theory of pain relies, of course, upon an evolutionary-biological account. There are two basic systems in which pain plays a crucial evolutionary role: (1) the avoidance system and (2) the restorative system.[1] The avoidance system is based upon the quick acting A-δ fibers that lead an organism to move itself away from the localized cause of pain; the restorative system, on the other hand, enlists the slower C nerve fibers to kick in after the A-δ fibers and to last long after the acute occurrence of pain.[2] These duller, less localized nerve signals lead an organism to limit the mobility of the damaged area such that it can become repaired. Pain thus serves two primary evolutionary roles: the prevention of initial harm through avoidance and the securing of repair through immobilization. In turn, both of these roles serve the larger purpose of the preservation of bodily integrity in order to maintain the life of an organism. At the most general biological level, *pain is a necessary condition of the ontogenetically adaptive and allostatic capabilities of an organism*. Because adaptive, pain is thus always positive, except when it is absent (e.g., congenital analgesia) or when it becomes a syndrome and thereby maladaptive (CRPS, allodynia, etc.).[3]

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[1] Meyer et al., "Peripheral Mechanisms of Cutaneous Nociception" in Patrick D. Wall et al., *Wall and Melzack's Textbook of Pain*, 5th ed. (Philadelphia: Elsevier/Churchill Livingstone, 2006), 3-34.

[2] For a scientific discussion of this, see the previous footnote. For a general explanations of this, see Patrick D. Wall, *Pain: The Science of Suffering*, Maps of the Mind (New York: Columbia University Press, 2000), 40-43. For a philosophically oriented explanation, see Nikola Grahek, *Feeling Pain and Being in Pain* (Cambridge, Mass.: MIT Press, 2007), 141-66.

[3] It is arguable whether pain asymbolia, which I discuss below, fits either of these categories. Either way, pain is necessary for the optimal adaptation of an organism to its environment.

It may sound at this point as though pain is merely a question of a stimulus-response chain, but neuroscientific research shows that this is incorrect. Kenneth Craig, e.g., argues that the affective aspects of pain are actually more important biologically, but due to the fact that the majority of testing related to the neurophysiological aspects of pain have historically been performed on non-verbal laboratory animals, it is no surprise that research in this area is lacking.[1] Although there are indeed determinable sensory-discriminative aspects to pain, the affective-cognitive aspects are central.[2] This suggests that thought experiments that focus on acute, noxious stimuli (holding one's finger over a candle, e.g.) are bound to mislead.[3] Focusing, say, on the way in which the fear of a noxious stimuli can *exacerbate* the pain it elicits would prove more promising. Some interpret the case of pain asymbolia (those for whom pain is experienced, but without unpleasantness, i.e., feeling pain without being in pain) to suggest that these two aspects are dissociable, while others disagree, but both camps maintain that both the sensory-discriminative and affective-cognitive aspects are necessary for pain to in fact be *painful*.[4]

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[1] Wall et al., 232-33. As Melzack and Wall themselves put it, "The impact of the pain revolution is revealed by the contents of this handbook. The further we move from a stimulus-driven concept of pain, the better we recognize the validity of baffling pain syndromes that often have no obvious pathology to explain the presence of pain or its terrible intensity. They include neuropathic pains, backache, fibromyalgia, pelvic, urogenital, and other pains (Chaps. 5–18), which become increasingly comprehensible when we extend our diagnostic search to consider multiple causal mechanisms."

[2] The language of this distinction goes back at least to Ronald Melzack, *The Puzzle of Pain*, Penguin Modern Psychology: Motivation and Emotion (Harmondsworth: Penguin Books, 1973).

[3] What's more, as Don Gustafson nicely summarizes, "Not even acute pain examples (a burn of the hand or blow to the thumb, etc.) cited by philosophers and others are conceived as simple sensations in current pain sciences." Don Gustafson, "Categorizing Pain," in Murat Aydede, *Pain: New Essays on Its Nature and the Methodology of Its Study* (Cambridge, Mass.: MIT Press, 2005), 237.

[4] As an example of an argument that they are dissociable, see Grahek. For an example that they are not, see Colin Klein, "An Imperative Theory of Pain," *The Journal of Philosophy* 104, no. 10 (2007).

In early Greek and Egyptian writings, pain is associated with object intrusion, whether of a material or immaterial sort.[1] Plato understands pain as an affection in the sense of an intrusion *on* the body or soul.[2] The idea that pain is *emotional-affective*, however, goes back at least to Aristotle, for whom pain is a modality of touch and on a continuum with its opposite affect: pleasure.[3] By the time of Galen, the idea of animal spirits moving through ventricles (nerves) took hold, and the emotional-affective aspects of pain were downplayed relative to stimulus-response patterns of the nervous system.[4] This line was followed by Avicenna in the middle ages and taken up again in the early modern period by da Vinci, Vesalius, Eustachius, and Descartes.[5] Through the 19th century and into the early 20th century, the roots of the Galen model held and arguments over pain were between whether pain was a question of specificity or intensity, i.e., whether pain is a sense modality of its own or whether it is a sufficiently intense stimulation of another sense modality. It is only in the last few decades and especially since the advent of PET and, more recently, fMRI technology, that the Aristotelian, emoto-affective view of pain has regained currency.[6] Pain is now understood as an event involving a complex, multimodal gestalt of sensory-affective components.

I refer to the current section as the *neuro*biological model of pain because it is in large part due to the technological advances of PET scans and fMRIs that previously "subjective" questions of affect have become a topic in pain research.[7] This

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[1] Keele, 2. In what follows, I am drawing on both on Keele and Gustafson's summary of Keele in "Categorizing Pain," Aydede.

[2] Plato, *Timaeus*, 64d.

[3] Aristotle, *On the Soul* 3.2: 426b and *The Parts of Animals* 3.4: 666a.

[4] Galen, *De Usu Partium*, 5.9.

[5] Descartes most famous claim about pain comes in *L'homme*, published 14 years after his death.

[6] See, e.g., Wall's claim that "Pain is not just a sensation but, like hunger and thirst, is an awareness of an action plan to be rid of it." Wall, 177.

[7] E.g., see, Donald D. Price, "Psychological and Neural Mechanisms of the Affective Dimension of Pain,"

neuropsychological research has grounded first-person reporting of pain in third-person, technologically mediated analysis in novel and impactful ways. However, upon adding the affective-cognitive dimensions of pain into pain research through neuropsychology and neurobiology, the primary understanding of pain from evolutionary biology remains intact: pain orients an organism to avoid potential or actual noxious stimuli and, secondarily, to allow for the healing of damage done by that cause.

A final formulation of the neurobiological theory of pain is now possible: via complex, intermodal sensory-discriminative and affective-cognitive interactions, *pain is adaptively regulative*.

§1.3 Humanist

There are a number of texts that I could address in order to formulate a "humanist model" of pain, but because of the immense import it has had in the literature I address in the rest of the dissertation, I focus here on Elaine Scarry's *The Body in Pain*. Although Scarry stops sort of explicit moralizing, she frames her discussion of pain through examples of torture and war, and she expects this selection to have a *prima facie*, though not necessarily universal, moral import:

> The deconstruction of creation is present in the structure of one event which is widely recognized as close to being an absolute of immorality (torture), and…the deconstruction of creation is again present in the structure of a second event regarded as morally problematic by everyone and as radically immoral by some (war).[1]

Scarry defines the act of torture as "extreme and prolonged physical [or psychological] pain" (59). The ultimate pain-producers—torturers—are placed squarely in the realm of the immoral:

Science 288, no. 5472 (2000).

[1] Scarry, 22.

> For the torturers, the sheer and simple fact of human agony is made invisible, and the moral fact of inflicting that agony is made neutral by the feigned urgency and significance of the question…Almost anyone looking at the physical act of torture would be immediately appalled and repulsed by the torturers. It is difficult to think of a human situation in which the lines of moral responsibility are more starkly or simply drawn, in which there is a more compelling reason to ally one's sympathies with the one person and to repel the claims of the other. [Being appalled by torture is] a basic moral reflex…torture is such an extreme event that it seems inappropriate to generalize from it to anything else or from anything else to it. Its immorality is so absolute and the pain it brings about so real that there is a reluctance to place it in conversation by the side of other subjects. (29, 35, 60, cf. 143).

War and torture are the most extreme forms of pain in the public imaginary, and it is not accidental that Scarry turns to such extreme examples. The very structure of the project undertaken in *The Body in Pain* suggests that Scarry is, above all else, interested in establishing or—at the very least—buttressing human solidarity. The aim of *The Body in Pain* is to bring the unmaking of the world caused by torture and war by means of pain to light in such a way that one cannot support either and works instead towards communitarian practices of making the world.

As Paul Gilroy writes, “The reconstruction of pain, disease, humiliation, grief, and care for those one loves can all contribute to an abstract sense of human similarity powerful enough to make solidarities based on cultural particularity appear suddenly trivial.”[1] By employing pain as the prime example of the unmaking of the world, Scarry proffers an intuitive and universal human phenomenon for a maximum persuasive punch. In its immoral obviousness, pain—albeit *undue* pain—functions both as a *call* for justice and as a *foundation* for ethical solidarity. The existence of pain attunes us to ethical deliberation so as to ameliorate it wherever we can.

Scarry also argues that pain is a subjective experience: no one can have *my* pain. Yet, “when one speaks about ‘one’s own physical pain’ and about ‘another person’s

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[1] Paul Gilroy, *Against Race: Imagining Political Culture Beyond the Color Line* (Cambridge, Mass.: Belknap Press of Harvard University Press, 2000), 17.

physical pain,' one might almost appear to be speaking about two wholly distinct order of events."[1] She further assumes pain to require discursive articulation, for the "breakdown of language" in the extreme pain of torture only makes sense if pains, cries, groans, and screams are taken as "non-linguistic." While I criticize such understanding of pain at length in the next chapter, both with respect to its putative subjectivity and its potential breakdown, I mention it here because it is integral to Scarry's argument about the destruction of a world. Scarry simultaneously leverages the subjective incommunicability of pain and its normative indubitability. A sufficient explanation of how such a gap is possible is never provided. The fact that I *feel* the pain of others, despite not feeling of the pain *of* the other, seems to operate in an empyrean of analogical experience. Despite this explanatory lacuna, Scarry is confident that the pain of others is sufficient to motivate reasons for action. On a humanist model such as Scarry's, via the presumed epistemic obviousness of its undesirable nature and the presumed ability to be affected by the pain of another, *pain is normatively regulative.*

§1.4 Existential

I hurt myself today / To see if I still feel / I focused on the pain / The
only thing that's real…what have I become?
—Trent Reznor[2]

As with humanist theories, there are a plethora of options from which to frame an existential theory of pain, but I will focus here on Sartre because among philosophers whose work is dominantly categorized under "existentialism," he offers the most

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[1] Scarry, 4. This is a constant refrain. Cf. Woolf. Cf. Arthur W. Frank, *At the Will of the Body: Reflections on Illness* (Boston: Houghton Mifflin, 1991), 29.

[2] Trent Reznor, "Hurt," performed by Johnny Cash, *Cash Unearthed*, Disc 5, American Recordings: 2003.

sustained analysis of pain. He also offers an analysis of pain that takes it to be phenomenologically distinct from suffering.[1]

In a section on “The Body” in *Being and Nothingness,* Sartre introduces his discussion of “what we call ‘physical’ pain” as a way to understand the proprioceptive coenesthesia of consciousness, of “the manner in which consciousness *exists* spontaneously and in the non-thetic mode.”[2] Sartre argues that although “it is undeniable that pain contains information about itself,” this knowledge is non-reflective.[3] If I have pain in my eyes as I am reading, I do not sense pain *in* my eyes, that is, as in or emanating from the area below my eyebrows and above my cheekbones; rather, I experience “the-eyes-as-pain or vision-as-pain; [this pain] is not distinguished from my way of apprehending transcendent words [the words on the page that are brought together to make some meaning in the act of reading].”

This means, however, that pain *just is* my consciousness. Pain is neither “in” my consciousness, nor is it “about” something. “It is simply a matter of the way in which consciousness *exists* its contingency...the pain is neither absent nor unconscious; it simply forms a part of that distanceless existence of positional consciousness for it-self…[pain] is not in space. But neither does it belong to objective time; it temporalizes itself, and it is in and through this temporalization that the time of the world can appear.”[4] Pain is a modality of experience, not a sensation. It is not intentional. I.e., it is not fundamentally

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[1] I follow Kaufmann in situating “existentialism” among *at least* the following names: Dostoevsky, Kierkegaard, Nietzsche, Kafka, Jaspers, Sartre, and Camus. I would not add Heidegger for reasons explained later. I am less confident about including Rilke and Ortega, as Kaufmann does, but I would add Gabriel Marcel, Paul Tillich, and Simone de Beauvoir. See Walter Arnold Kaufmann, *Existentialism from Dostoevsky to Sartre*, Meridian Books (New York: Meridian Books, 1956).

[2] Jean-Paul Sartre, *Being and Nothingness: An Essay in Phenomenological Ontology*, trans. Hazel E. Barnes. (New York: Washington Square Press, 1984), 436.

[3] Ibid, 437.

[4] Ibid, 436, 440.

experienced as *about* something, but as the very way in which a thing or set of things appear.

This phenomenology of pain reveals, for Sartre, the very constitution of human existence: a for-itself or, as Sartre also puts it, “the nothingness of *this in-itself*.”[1] An existence “condemned to freedom.”[2] It is a modality that reveals the vulnerability of human existence as a being condemned to such existence, a vulnerability or vacuity that crosses every existential structures, whether temporal, spatial, or what have you. Pain reveals the condemnation of our freedom and simultaneously the freedom of that condemnation. Sartre writes,

> What then is this pain? Simply the translucent matter of consciousness, its *being-there*…the pain exists beyond all attention and all knowledge since it slips into each act of attention and of knowledge since it is this very act in so far as the act is without being the foundation of its being (438).

Sartre further distinguishes between pain as it is lived and explicit or thetic “pain-consciousness.” The latter is “a project toward a further consciousness which would be empty of all pain; that is, to a consciousness whose contexture, whose being-there would be not painful” (438). For Sartre, lived pain is not the same as this thetic consciousness of pain because lived pain does not have the convenience to distance itself from itself—a distance intentionality, being “conscious of”, requires.

Such a distinction notwithstanding, pain is understood as proof of both the obstinacy of the world and our freedom—a price we pay, not to God as in the religious theories discussed above, but to *existence*. Pain reminds us of the fundamental ambiguity of our condition. Pain attunes us to the nature of our existence. It is regulative with respect to our understanding of the phenomenon of pain itself as well as to how it relates

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[1] Ibid, 791.
[2] Ibid, 623.

to our existence more broadly. To repeat from above, by regulative, I mean that it *guides* one's understanding and being-in-the-world: it is a tool by which we seek the constitution of our existence.[1] On existential theories, *pain is existentially regulative.*

§1.5 Medical

While one aspect of the overall goal of medicine has always been the alleviation of pain, pain has a complex relation with the ambitions of medicine and increasingly so since the 19th century.[2] While medicine has historically been "bedside," with the rise of the clinic and, in particular, the emergence of the field of anesthesia in the mid-19th century, palliation began to give way to pathologization.[3] As increasing technological advancement allowed health care providers (HCPs), as they are now oft called, to achieve unparalleled physiological accuracy across a broad range of diagnostic measures, the aim of the medical profession shifted its focus *in practice* for the first time from a Maimonidean to a Hippocratic mandate, or, in short, from care to cure.[4] This is not to say that, historically, medical practices ignored pathologization or, more broadly, diagnosis. I am only claiming that the *primary* focus shifted along with the unequaled diagnostic capabilities brought about by technology. It is the widespread trust in the ever-increasing technological ability to uncover physiological pathologies that has in many cases actually *exacerbated* the suffering of those whose conditions do not have such a pathology.

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[1] Immanuel Kant, *Critique of Pure Reason*, trans. Paul Guyer and Allen W. Wood, The Cambridge Edition of the Works of Immanuel Kant (Cambridge; New York: Cambridge University Press, 1998), A670-71/B98-99.

[2] Bourke, 131-58.

[3] Michel Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception* (New York: Vintage Books, 1994). Martin S. Pernick, *A Calculus of Suffering: Pain, Professionalism, and Anesthesia in Nineteenth-Century America* (New York: Columbia University Press, 1985).

[4] The central line of the Maimonidean oath reads, "May I never see in the patient anything but a fellow creature in pain." S Y Tan, "Medicine in Stamps: Moses Maimonides (1135-1204): Rabbi, Philosopher, Physician," *Singapore Med J* 43, no. 11 (2002). See M. L. Meldrum, "A Capsule History of Pain Management," *JAMA* 290, no. 18 (2003).

The entangling of for-profit pharmacological ventures with medical practice has only further entrenched the emphasis on discrete material pathologies, and, equally troubling, the multiplication of such pathologies.[1] Furthermore, the anesthesiological specialization in the minimization of pain during surgical procedures in the mid-19th century later found its non-surgical correlate with another new specialization in the late 20th century: pain specialists and, since the late 1970s, pain clinics. If you suffer from a condition that requires sustained pain management, your primary care physician will now send you off to such a specialist for, alas, it is not their specialization to care for such a person. In the United States, at least, that shift has been profoundly affected by the fact that chronic pain doctors currently operate in the wake of the early 1990s rise of policy-driven and legally buttressed pharmacovigilance, one incubatory ramification of the Nixon-era "war on drugs" that presidents from Raegan to Clinton maintained with damning confidence.[2]

To complicate the matter even further, while in the 19th century, pain without lesion—that is, pain without any physiologically determinable etiology—was considered

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[1] Joseph M. Gabriel and Daniel S. Goldberg, "Big Pharma and the Problem of Disease Inflation," *Internationl Journal of Health Services* 44, no. 2 (2014).

[2] Daniel S. Goldberg and Ben Rich, "Pharmacovigilence and the Plight of Chronic Pain Patients: In Pursuit of a Realistic and Responsible Ethic of Care," *Indiana Health Law Review* 83 (2014). For example, doctors whose focus is on making the life of a person with chronic pain more manageable now face prohibitive conditions on opioid analgesic disbursement *regardless* of the particularities of the patient—actions that range from licensure to criminal prosecution. See Melanie Thernstrom, *The Pain Chronicles: Cures, Myths, Mysteries, Prayers, Diaries, Brain Scan, Healing, and the Science of Suffering*, 1st ed. (New York: Farrar, Straus and Giroux, 2010), 164-67. When overlaid with the fundamental materialism of the medical sciences (i.e., the assumption that phenomena under medical purview must have *physical* manifestations—specifically, manifestations that are *quantifiable* by current technological-diagnostic procedures) the question of pain's subjectivity, a given in the clinical literature on pain, is interpreted to mean that when no physiological etiology of pain can be found, a HCP is not out of bounds to assume that the patient is lying. See a *manual* on assessing whether or not a patient is lying, in this case in the context of mental illness: Richard Rogers, *Clinical Assessment of Malingering and Deception*, 3rd ed. (New York: Guilford Press, 2008).

anomalous[1], it is now well documented that a number of quite common pain conditions occur without lesion. This includes lower back, abdominal, and pelvic pain, tension and migraine headaches, fibromyalgia, and causalgiform disorders such as complex regional pain syndrome.[2]

What is remarkable is the constancy of pain's meaning for medicine *despite* these otherwise vast changes: diagnostically, pain is understood as a sign or symbol that leads to a physiological cause of that pain, historically thought to be typically due to tissue insult, injury, or irritation. Although pain researchers have increasingly recognized that this stimulus-response and sensation-/materialist- based understanding of pain is false[3], clinical practice still treats pain largely in such a manner.[4] Whether pain is a sign of an acute trauma or a non-acute condition such as a disease or syndrome, the semiosis of pain assists (or is assumed to assist) in leading a HCP to the correct diagnosis, to the proper form of treatment, and, ideally, to the cure. Despite its complexity as a phenomenon and as a variable component of medical aims, on a medical model *pain is diagnostically regulative*. Pain provides medical practice with *gnosis*, with knowledge, and thereby orients both the ends and means of patient-provider relations.

§1.6 Conclusion: The Regulative Role of Pain

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[1] Daniel S. Goldberg, "Pain without Lesion: Debate among American Nuerologists, 1850-1900," *19: Interdisciplinary Studies in the Long Nineteenth Century* 15 (2012).

[2] These conditions are not necessarily coextensive with chronic pain conditions *with* lesion or with a clear post-onset etiology: osteoarthritis, rheumatoid arthritis, diabetic neuropathy, postherpetic neuralgia, etc.

[3] E.g., see Gustafson's summary of research spanning from the mid-70s up to the last decade by Wall, Melzack, Craig, Price, and Chapman in Aydede, 234-38. I discussed this in section 1.1.2 above as well.

[4] Even explicit efforts to *improve* the undertreatment of pain fall in this trap. See W. Meissner et al., "Quality Improvement in Postoperative Pain Management: Results from the Quips Project," *Dtsch Arztebl Int* 105, no. 50 (2008). Regarding this project, another study has questioned whether or not its efforts, which employ numerical rating scales (NRS), provide any better outcome parameters than simply asking for binary (yes/no) responses: J. Rothuag; T. Weiss; W. Meissner, "How Simple Can It Get? Measuring Pain with Nrs Items or Binary Items," *The Clinical Journal of Pain* 29, no. 3 (2013). See also .

> What means are there of determining which is the acutest of two pains, or the intensest of two pleasurable sensations, except the general suffrage of those who are familiar with both? *Neither pains nor pleasures are homogeneous*, and pain is always heterogeneous with pleasure. What is there to decide whether a particular pleasure is worth purchasing at the cost of a particular pain, except the feelings and judgment of the experienced
> —Mill[1]

> Reflection tends to make of pain something *psychic.*
> —Sartre[2]

In each of the five models of pain I presented, it is striking that pain in each case plays a *regulative* role. I am now in a position to present a schematic of the models of pain discussed above:

Theories of Pain

Theory	**Religious-Moral**	**Neurobiological**	**Humanist**	**Existential**	**Medical**
Domain	Theology	Biology	Axiology	Ontology	Symptomatology
Function	Judgment	Adaptive	Normative	Disclosive	Diagnostic
Power	Injunctive	Organic	Valent	Reflective	Etiological
Effect	Allostatic Reg.	Allostatic Reg.	Allostatic Reg.	Allostatic Reg.	Allostatic Reg.

The **theories** I name ultimately operate within the parameters of their respective **domains**. The religious-moral theory of pain, for example, operates within the parameters of theology, which is why distinctively theological concepts such as sin or divine creation prove crucial for its understandings of pain. The **function** names how the domain utilizes the phenomenon in question. For example, the humanist model operates within the domain of axiology, of an account of values, and pain is used to account for *valuation* of human life in that model; hence, it has a *normative* function. Predictably, **power** names how the function in question is actually experienced in the meaning of pain determined by the model. The power of the medical theory of pain is etiological because the diagnostic function of the medical model's understanding of pain is experienced as *giving*

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[1] Mill and Bentham, 282.
[2] Sartre, 440.

a cause to one's pain. The **effect** is the primary consequence the theory of pain in question has not simply on the subject, but on the world of the subject. The effect deals with the intersubjective and cultural aspects that a model's understanding of the phenomenon in question effects. On all theories of pain, one is ultimately oriented towards being not-in-pain, and one is oriented in such a way that one is assisted in regaining homeostasis, one's sense of self, and one's ability expectations. The effect, then, of all models of pain discussed herein is to allostatically regulate a life. As I argue at length in the next chapter, this regulation fails and fails spectacularly when the pain in question is either constitutive or consuming.

In each domain that proffers a meaning for pain, pain functions to reorient one back to oneself. That is to say, pain functions as a command to reorient oneself with the aim of reestablishing one's abilities. In each case, however its semiosis is specifically conceived, it both commands and orients one relative to the domain under which it is interpreted. In religious theories, pain signals the very authority of the thetic; it forms and constitutes injunctive power. In the neurobiological theories, it signals the tendency towards ontogenetic persistence; it forms and constitutes organic power. In humanist theories, it signals a foundation of human solidarity and an obligation to buttress it; it forms and constitutes valent power. In existential theories, it signals a central aspect of existence itself as a free project for one conscious and in good faith of one's existence; it forms and constitutes reflective power. In medical theories, it signals the cause of a corporeal disturbance and thus a key to knowledge of that cause; it forms and constitutes etiological power.

Another way of describing the regulative function of pain is that the *form* of pain, regardless of its content or lack thereof, is always in the shape of an imperative.[1] Although it is, without habituation to the contrary, always experienced first and foremost as to-be-avoided, this can be overridden in a number of cases, such as self-mutilation and various bondage practices and the changes in second-order judgment the habituated practices of such things can effect. These are not counterexamples. On the contrary, they provide supporting evidence, for self-cutters describe cutting as a way to feel, as a way to *regain* control over themselves, especially the lack of non-negative affective variation.[2]

To recast it another way, there is a single overarching feature of pain's regulative role to which each of these theories attests: *pain is a command to reorient oneself.* To be sure, the ends towards which one will reorient oneself in the face of pain will be diverse

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[1] Although I disagree with a number of specific claims therein, see Colin Klein, *What the Body Commands: The Imperative Theory of Pain* (Cambridge, MA: MIT Press, 2015).. I address more literature in philosophy of mind on pain in footnote 2 below.

[2] See Marilee Strong, *A Bright Red Scream: Self-Mutilation and the Language of Pain* (New York, N.Y.: Viking, 1998). Robert J. Stoller, *Pain and Passion: A Psychoanalyst Explores the World of S&M* (New York: Plenum Press, 1991). Moreover, except in the ephemerality of a moment or in the abstractions of philosophers interested in the possibility of qualia, pain is never *just* a sign and never *just* a sensation. Phenomenologies of pain, as I will argue below, repudiate that possibility. My invocation of the term "imperative" is not meant to explicitly align my account of pain with imperativism in philosophy of mind. I find that due to the aims of such literature—which is, ultimately, interested in pain insofar as it is revelatory concerning questions of *consciousness*—the social, political, and historical (et. al.) aspects of pain are lost. Moreover, when reference is made to the "phenomenology" of pain, it sometimes borders on a malapropism for "experience." Reference is not made to the phenomenological tradition nor are concerns of methodology addressed. I thus find much of the "phenomenology of pain" occurring in philosophy of mind literature to be little more than investigations of experiences described under the constraints of *common sense*. In other words, I find little *phenomenology* of pain whatsoever. Defenders of imperativism about pain include David Bain, Richard Hall, Manolo Martínez, and Colin Klein. See David Bain, "Pains That Don't Hurt," *Australasian Journal of Philosophy* 92, no. 2 (2013); Manolo Martínez, "Imperative Content and the Painfulness of Pain," *Phenomenology and the Cognitive Sciences* 10, no. 1 (2011); Richard J. Hall, "If It Itches, Scratch!," *Australasian Journal of Philosophy* 86, no. 4 (2008); Klein, "An Imperative Theory of Pain."; "Imperatives, Phantom Pains, and Hallucination by Presupposition," *Philosophical Psychology* (2011). The primary alternative position is representationalism which, broadly, conceives the reporting of pain to represent some fact (or perceived fact) about the world. In other words, the phenomenal experience of pain is such by virtue of that experience's representational content. Defenders of various forms of representationalism regarding pain include Bryan Cutter, Michael Tye, George Pitcher, Armstrong. See B. Cutter and M. Tye, "Tracking Representationalism and the Painfulness of Pain," *Nous-Supplement: Philosophical Issues* 21, no. 1 (2011). George Pitcher, "Pain Perception," *The Philosophical Review* (1970). D. M. Armstrong, *A Materialist Theory of the Mind*, Rev. ed., International Library of Philosophy (London; New York: Routledge, 1993).

for a host of reasons. Those ends will always be relative to the domain or domains in which and by which one interprets one’s pain as well as the salient interpretative differences operative within that domain. For example, with respect to medicine, e.g., cultural, historical, class-based, and genetic cohort related groupings (“race,” “sex,” etc.) can significantly affect the interpretation of pain.[1] As Rosemarie Garland-Thompson notes,

> The suffering body so essential to both benevolent and religious discourses transforms into the unfit body with the increasing medicalization of pain and the pathologizing of embodied differences…The introduction of anesthesia in 1846 began to pry pain away from suffering, which is the more elastic, encompassing concept...pain becomes discrete and—most important—medicalized when antisepsis, sanitation, and vaccination emerge with modern allopathic medicine’s domination and consolidation of its authority in the late nineteenth century…as pain is pathologized, suffering is sentimentalized…To freely choose— to ‘‘prefer’’—to live with or to die because of disability can be overwhelmingly difficult in a culture with such strong incentives to reject a disabled identity and life with a disability. Our preferences can never be innocent when the prevention and elimination of disability and the bodies marked by it are the goals of medical, scientific, benevolent, economic, and religious ideologies.”[2]

One will, under a medical theory of pain, still ultimately seek its cause. If one is convinced by my arguments so far, it is striking that with respect to models that have wildly different premises and conclusions, pain’s *function* is the same. Now that I have provided a provisional inquiry into dominant models of pain, I will turn to present a phenomenology pain through the figure of a person living with CRPS Type I.

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[1] This is a plethora of literature on this topic, ranging from highly specific (studies done relative to a single triage unit) to quite general (historical, cross-cultural analyses). I offer a representative sample of such research: C. Sargent, "Between Death and Shame: Dimensions of Pain in Bariba Culture," *Social Science and Medicine* 19 (1984); LJ Staton et al., "When Race Matters: Disagreement in Pain Perception between Patients and Their Physicians in Primary Care.," *J Natl Med Assoc* 99, no. 5 (2007); Jeanette McNeill, "Unequal Quality of Cancer Pain Management: Disparity in Perceived Control and Proposed Solutions," *Oncology Nursing Forum* 34, no. 6 (2007); Arthur Kleinman, *Social Origins of Distress and Disease: Depression, Neurasthenia, and Pain in Modern China* (New Haven: Yale Univeristy Press, 1986). Maryann S. Bates and Lesley Rankin-Hill, "Control, Culture and Chronic Pain," *Social Science & Medicine* 39, no. 5 (1994).

[2] Rosemarie Garland-Thomson, "The Cultural Logic of Euthanasia: "Sad Fancyings" in Herman Melville's "Bartleby"," *American Literature* 76, no. 4 (2004): 784, 89, 99.

2 A PHENOMENOLOGY OF CRPS I

§2.1 A Note on Method

When I speak of a "phenomenology of pain," what *type* of phenomenology do I mean? Even within Husserl's oeuvre, multiple scholars have argued for a distinction between, at minimum, transcendental, constitutive, and genetic phenomenology.[1] In the phenomenological tradition more generally, one can mark further distinctions, including hermeneutical, existential, generative, and realist phenomenologies, including what some term "postphenomenology."[2] The phenomenology of chronic pain I present below follows within the tradition of hermeneutic or descriptive phenomenology. As Graeme Nicholson puts it,

> Phenomenology became hermeneutical when it argued that every form of human awareness is interpretive, when it was not content to regard interpretation as just one specific form of awareness directed to one particular range of objects — for instance, texts. If *all* the intentions of our perception and imagination are already marked through and through by language, and, moreover, if the phenomenologist him- or herself can no longer claim an intuitive access to mental life, but is always interpreting it, then we are in hermeneutics. This mutation of phenomenology was inaugurated by one book, Martin Heidegger's *Sein und Zeit* (1927).[3]

I share with Heidegger the contention that inquiry cannot be presuppositionless (*voraussetzungslos*). We find ourselves on the way, already imbricated in the thick of things. We find ourselves *thrown*.

Because of this, phenomenological investigation is tasked with attention to *the way in which* we find ourselves on the way. Phenomenological investigation is thus

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[1] Donn Welton, *The Other Husserl: The Horizons of Transcendental Phenomenology* (Bloomington: Indiana University Press, 2000).

[2] Lester E. Embree et al., *Encyclopedia of Phenomenology*, vol. 18, Contributions to Phenomenology: In Cooperation with the Center for Advanced Research in Phenomenology (Dordrecht; Boston: Kluwer Academic Publishers, 1997). Evan Selinger, *Suny Series in the Philosophy of the Social Sciences: Postphenomenology : A Critical Companion to Ihde*, Postphenomenology: A Critical Companion to Ihde (Ithaca, NY, USA: Ithaca, NY, USA State University of New York Press, 2006); Lisa Guenther, *Solitary Confinement: Social Death and Its Afterlives* (Minneapolis: University Of Minnesota Press, 2013).

[3] Graeme Nicholson, "Hermeneutical Phenomenology" in Embree et al., 18.

always in part a question of comportment. The way in which I encounter phenomena affects that encounter and thus the phenomena themselves. Heidegger, in his 1927 lecture course *Basic Problems of Phenomenology*, presents a tripartite methodology for hermeneutical phenomenology (though he terms it there simply “phenomenology”): description, reconstruction, and destruction.[1] Approaches to the first stage, description, have historically not employed the genre of narration (among others) because that genre involves, even prizes, idiosyncrasies. Narration neither explicitly seeks nor valorizes the essence or essential structures of objects, much less canonical objects of phenomenology such as time-consciousness. It is also not limited to speaking from the experience of the *I*, instead drawing upon multiple perspectives. Both the content and form of narrative is far wider than that to which classical phenomenology restricted itself.

When it comes to a phenomenon like chronic pain, broader descriptive methods such as those deployed in narrative are indispensable. The extended diachronicity of chronic pain is a key component that distinguishes it from other forms of pain. This is not, however, merely a point about the temporality of pain as it relates to phenomenological inquiry. As I argue further below, the self-understanding of one’s pain is constitutive of the character of that pain. Remarkably, one can experience a pain more or less depending on the story one tells oneself about it—or the story one is told. A phenomenology of chronic pain that left out its story would not capture its target phenomenon.

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[1] Martin Heidegger, *The Basic Problems of Phenomenology*, trans. Albert Hofstadter, Studies in Phenomenology and Existential Philosophy (Bloomington: Indiana University Press, 1982), 19-23, esp. 23. The stage of reconstruction is a malapropism because since analysis has not been carried out on the phenomenological description, there is nothing to reconstruct. One, on the contrary, carries out an extraction or, more accurately, a *decoction* of that description, followed by a destruction of the concepts upon which the decoction itself relies. It could even be said that, so far from the Husserlian programmatic, a successful phenomenology for Heidegger ends in ruins.

The "problems of narrative configuration," Ricoeur argues, "border on those of the refiguration of time by narrative"—the structures of narrative modify temporality just as the structures of temporality modify narrativity.[1] Stories change time; time changes stories. They are so in ways that render a phenomenological description ignorant or avoidant of narrative elements lacking. I thus blend elements of personal narrative with more traditional phenomenological description in the account below.

§2.2 Bearable, but Unbearable

Today

I opened my eyes this morning to a blur.[2] *Pain surged everywhere, but especially in my head. Mouth: dry. Hands: numb. Feet: less numb, and more lacking presence. As my eyes open, I worry that I will not be able to get out of bed. Upon waking, I don't know whether today will be "one of those days." I have an appointment in forty-eight hours with my pain doctor. At the last appointment, my pain meds were cut. The plan is to bring my dosage down at least 30% in four or so increments. There was no explanation for this except that the doctor said she was concerned the dosages were "too high." TOO HIGH? Too high relative to what? I know opioids are addictive. I know there is an opioid "epidemic." But these are statistics. I am a person. I am a chronic pain sufferer of over twenty years. I am not an instance to which the fears of those facts relate. Prior to the*

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[1] Paul Ricœur, *Time and Narrative*, 3 vols. (Chicago: University of Chicago Press, 1984), 2: 100. See also ibid., 1: 121-74.

[2] In the phenomenological description that follows, I have drawn especially upon the following resources: Alphonse Daudet, *In the Land of Pain*, trans. Julian Barnes, 1st American ed. (New York: Knopf, 2002); Thernstrom; Victor Kestenbaum, *The Humanity of the Ill: Phenomenological Perspectives*, 1st ed. (Knoxville: University of Tennessee Press, 1982); Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York: Basic Books, 1988); Leslie Jamison, *The Empathy Exams: Essays* (Minneapolis, MN: Graywolf Press, 2014); Sarah Coakley and Kay Kaufman Shelemay, *Pain and Its Transformations: The Interface of Biology and Culture* (Cambridge, Mass.: Harvard University Press, 2007); Audre Lorde, *The Cancer Journals*, Special ed. (San Francisco: Aunt Lute Books, 1997).

cut, I was able to get out of bed at least a few days a week. What will I be like after the next cut? The fear of further pain and its debilitation is unbearable. I do not know what I will be able to do in an hour, much less tomorrow, and if I lack the surety of the sole medication that gives me a vestige of the ability to function, then what? The fear of tomorrow makes today's pain worse.

5 Minutes Later

Nausea sets in. If I vomit, I'll lose all my meds. My jaw pain (I have TMJ) will intensify, as will my neck pain, and that circuit will set my head in a vice. A vice clinched by a feedback-loop of pain. I must not vomit. No movement. No nothing. "Just focus on not vomiting," I tell myself between long breaths. Where is the Zofran? (Better than Promethazine, the doctor said.) If I move, I'll…

I text my partner to bring it to me…I take the Zofran with a sip of water. I feel an immediate rush of nausea. "Hold it…hold it…hold it," I say to myself over and over again. I can do this. While the nausea circles me, the pain both arrests me and acts as a backdrop. The constant throbbing, cutting, the fog that clouds all my thoughts and memories and plans…this is the background against which I measure everything, against which experience. Experiencing is a fancy term for measurement. Tacit and express, background and fore—pain can play both roles. I never know when spikes will occur; I never know when the light of the sun will become an enemy, when the voice of my partner and lover of thirty years will act as a chainsaw running through my head or when the touch of my own children will set fire across my skin. I never know.

3 Hours Later

I vomited. I vomited 5 times. I am dry heaving. I am losing consciousness. Couldn't drink water the last few hours. Ambulance. Emergency Room. My partner is trying to list out my medications. The nurse is "uncomfortable" administering my regular pain meds. My partner nearly yells. The head nurse is contacted. We get a different nurse. This nurse treats us differently—I am now a "problem" patient. My partner is now a family member who "interferes." They surely put something in my medical notes about the incident. My primary care doctor is unavailable, as is my pain doctor: it's a Saturday. I would have protested going to the ER: what can they do that I can't at home? All they can do is be late. All they can do is be actively obstinate about administering my legally prescribed medications. All they can do is treat me like an "addict."

2 Days Later

I walk into my pain doctor's office. I feel ashamed. I feel she will judge me. Hasn't she always? Why was I in the ER, again, she'll ask. I'm a "chronic pain sufferer." I have diagnoses in my medical file that don't have pathologies. My medical files probably say "I complain"—what if they use the word malingering!?—because, well, I haven't been out of pain for twenty years. What does the recording of those words do to a person? I am not a patient to my pain doctor; I'm a problem. Unlike her "easy" patients, she sees me because I make her money. Because, perhaps, if she didn't see me, she'd feel guilty. But she wants me to be gone. She wants me to stop complaining. She's given up figuring out what's wrong with me. I am a problem patient. Her specialty is pain management…management! How do you manage the unmanageable? How do you manage persistent chronic pain resulting without an etiology? I am unmanageable. ***I*** *am.*

That is the message I hear between the lines, between the diagnoses, between the baited breaths of failed medical intervention seeking, incessantly, a cure.

10 Days Later

This morning I could hear the TV from the living room. Someone asked, "What are you looking forward to in life?" I didn't hear the answer. Maybe I blocked it out. I rarely experience my own future like that anymore. I experience others', and I substitute theirs for mine. It's not that I can no longer imagine; it's that my present is too strong. My present is the future lost to pain now. My present is my history evaporated in pain now. Except…except when I see my children. Except…when I hear the words "I love you" from my partner. Except…in those moments when another breaks me out of the circuit of pain. Daudet said it best, "Very strange, the fear that pain inspires nowadays – or rather, this pain of mine. It's bearable, and yet I cannot bear it."[1] *Bearable, and yet I cannot bear it. That I am alive and that I even talk and walk does not mean all that others take it to mean. They do not know what it means to experience life as bearable and yet unbearable.*

30 Days Later (The Next Pain Appointment)

The pain specialist has a new PA. He didn't bother to read my case history. He walks in with the nerve to say, "What brings you in today?" WHAT BRINGS ME IN? Is this some kind of sick joke? Where should I begin? Let the puppet show commence.

Of course, I can list the biggest diagnoses without thinking—one never forgets those words, "You have X." But what is this PA, who clearly didn't even read my file, able to understand of my history? Two decades of experiences and complications. Two decades of pain, the singular history of which cannot be conveyed in haste, if at all. Two

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[1] Daudet, 9.

decades of unknowns, misknowns, and someday-we-will-knows. He wants a summary and solution. And I am anything but.

Incident 1

The moss was wet as I hit my back on stone and wood. 28 years old. In a hurry. I had mentioned to the landlord to clean the stairs. I had mentioned it three times. The pain was intense, focused on my lower back, but also in my neck. It was not sharp or burning, but dull and throbbing. It hurt to walk, to sit upright, even to sleep if I moved in the wrong way. The pain often made it hard to focus. I had to take a number of days off. I took a while to go to the doctor because I didn't have insurance. My boss is mad enough to fire me.

Diagnosis: Herniated Disk (L4, C6)

Incident 2

I never felt the spider bite. Must have been distracted. Didn't I register the bite somehow? But after a sudden onset of fever, headache, and stiff neck, I involuntary checked my body and noticed a small bite-mark with a mild rash. Sickness came quickly. I had no idea a spider could bring on such a thing.

Diagnosis: Viral Meningitis

Incident 3

My jaw had never hurt. I was extremely active—always outdoors. But the left side of my jaw was so sore. Was I grinding my teeth? It lasted for weeks and continued to get worse.

I saw a dentist. "It's not grinding." Off to an oral surgeon… The MRI brought news I was not expecting.

Diagnosis: Temporomandibular Joint Disorder (TMJD)

Incident 4

No matter how much I sleep, I always feel tired. My muscles ache indiscriminately, but I don't have a fever. Is this related to the TMJ? Could it be an aftereffect of the viral meningitis or my back injury? I have headaches very often. Sometimes they are mild, but other times they put me in bed. It's hard to concentrate. I've been to two primary care physicians, a naturopath, and an allergist. No one can figure out what's going on. This has been going for years. Finally, a doctor connects the dots (which amounts to an admission of not understanding how the dots are actually connected).

Diagnosis: Fibromyalgia

Incident 5

I have been seeing a chronic pain doctor for 20 years now. I have been diagnosed and treated for herniated disks, viral meningitis, and TMJD. I have also been diagnosed with fibromyalgia and degenerative disk disease, though there is no "real" treatment for those. Among other things, I lately developed carpal tunnel, chronic migraine headaches, numbness and/or tingling in my extremities. I cannot lift a gallon of milk anymore; a half-gallon is at times a struggle. I have to concentrate to walk. I often cannot even get out of bed due to the pain. I feel isolated. I feel as though doctors are tired of seeing me and have lost hope of helping me. I finally saw a specialist at the Mayo Clinic. He thinks *there is more to the story. This is an unusual diagnosis for someone like me, he says. Other doctors will disagree. I don't even qualify for "disability" in my state, because my partner makes "too much." Medical expenses aren't a factor—only gross income.*

Diagnosis: Complex Regional Pain Syndrome (CRPS) Type 1

Today, Again

I do not "have" pain in the same way that I do not "have" a body. If I hold my finger over a flame, it is an entirely different experience from the pain in which I live. The pain in which I live can also involve acute, intensifying flare-ups, but these are themselves set against the background constancy of pain. Smiling hurts. Movement hurts. Interacting with others hurts. Pain as a background condition. I do not live in the same world as those who experience pain events. I do not experience pain events; I experience a world in pain. I experience a different world. All my projects are unsteady under its immeasurable weight. The litany of diagnoses, the surfeit of medical events from doctor's appointments to ER trips, seem endless. I live the chronicity of my pain. This chronicity constitutes my present. How am I to explain living with, in the here and now, a chronic condition such as pain? How does one live the chronic? How does one live pain?

§2.3 The Structure of Chronic Pain Through CRPS I

> Far from being broken, the fantasy link between knowledge and pain is reinforced by a more complex means than the mere permeability of the imagination; the presence of disease in the body…[is] challenged as to [its] objectivity by the reductive discourse of the doctor…the figures of pain are…redistributed in the space in which bodies and eyes meet. What has changed is…the relation of situation and attitude to what is speaking and what is spoken about.
>
> —Foucault[1]

> "When we suffer, we suffer and we know we suffer because we live our illness in the first person pronoun, without mediation, without reflection, without the influence of generalities. These come later…"
>
> —David Peña-Guzmán[2]

A number of problems emerge in even a cursory engagement with the description of chronic pain presented above. How does the chronicity of pain relate to its synchronicity? How does one's conceptualization of pain affect one's experience of pain?[3] Can one analytically distinguish between pain characteristics and non-pain characteristics? Is pain a natural kind?[4] If pain is a discrete phenomenon, is it a sensation or a mode of sensing? Is it a distinct cognitive state? An affective state? An existential situation? Is pain "private"?[5] If pain is a discrete phenomenon of whatever sort, is "chronic pain" as well? How is the experience of pain affected by factors of socio-cultural, historical, racial/ethnic, sex/gender, dis/abled difference? How, that is to say, do

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[1] Foucault, x-xi.

[2] David M. Peña-Guzmán, "Pathic Normativity: Merleau Ponty and Canguilhem's Theory of Norms," *Chiasmi International* 15 (2013): 367. As I argue below, I think that the only form of pain that (asymptotically) reaches the level of immediacy, without mediation, is consuming pain. I cite this epigraph nevertheless to highlight the intuitiveness of the unmediated nature of suffering.

[3] I say "how," because research overwhelmingly suggests one's conceptualization of pain does affect one's experience of pain. E.g., See Douglas E. DeGood and Brian Kiernan, "Perception of Fault in Patients with Chronic Pain," *Pain* 64, no. 1 (1996); Bates and Rankin-Hill; Michael E. Geisser, Michael E. Robinson, and Joseph L. Riley Iii, "Pain Beliefs, Coping, and Adjustment to Chronic Pain: Let's Focus More on the Negative," *Pain Forum* 8, no. 4 (1999).

[4] On this topic, see Jennifer Corns, "Pain Is Not a Natural Kind" (Ph.D., City University of New York, 2012).

[5] Arguments in both philosophical and clinical literature often refer to Wittgenstein's arguments against private *language* in Ludwig Wittgenstein, *Philosophical Investigations: The German Text, with a Revised English Translation*, trans. G. E. M. Anscombe, 3rd ed. (Malden, MA,: Blackwell Pub., 2003), §124. See, e.g., Mark D. Sullivan, "Pain in Language: From Sentience to Sapience," *Pain Forum* 4, no. 1 (1995).

social conditions and concrete interactions affect pain experience, including empathy responses?[1] How do the effects of increasing pathologization in our global, (neo)liberal, late capital world affect pain experience? How do the effects of the history of the "anatomo-clinical gaze"?[2]

These questions far outstrip the scope of this project. Indeed, some are foundational questions for entire fields or subfields. Relatedly, it is even debatable whether a sufficient phenomenology of pain has ever been developed. In 1950, Ortega y Gasset remarked that "no one has undertaken" a "strict phenomenology of pain."[3] In what

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[1] Studies suggest that for some people, observing pain in another activates emotional and sensory brain regions associated with pain (in addition to their reporting of an actual noxious somatic experience). See Jody Osborn and Stuart W. G. Derbyshire, "Pain Sensation Evoked by Observing Injury in Others," *PAIN* 148, no. 2 (2010); Frederique De Vignemont and Tania Singer, "The Empathic Brain: How, When and Why?," *Trends In Cognitive Sciences* 10, no. 10 (2006); Philip L Jackson, Pierre Rainville, and Jean Decety, "To What Extent Do We Share the Pain of Others? Insight from the Neural Bases of Pain Empathy," *Pain* 125, no. 1 (2006). Studies also suggest that the ability to form a cohesive narrative and have it *affirmed* by HCPs provides support. Maggie Evans, Ali Shaw, and Debbie Sharp, "Integrity in Patients' Stories: 'Meaning-Making' through Narrative in Supportive Cancer Care," *European Journal of Integrative Medicine* 4, no. 1 (2012).

[2] There is research suggesting that time spent in a pain research facility itself intensifies pain experience. See Inge E. Lamé et al., "Quality of Life in Chronic Pain Is More Associated with Beliefs About Pain, Than with Pain Intensity," *European Journal of Pain* 9, no. 1 (2005). The fact that in many cases chronic pain relates to medically unexplained symptoms (MUS) has significant deleterious effects, and such effects are simply not well recognized in clinical settings (though they are well recognized in clinical and theoretical psychology). See Monica Greco, "The Classification and Nomenclature of 'Medically Unexplained Symptoms': Conflict, Performativity and Critique," *Social Science & Medicine* 75, no. 12 (2012); Peter Salmon, "Conflict, Collusion or Collaboration in Consultations About Medically Unexplained Symptoms: The Need for a Curriculum of Medical Explanation," *Patient Education and Counseling* 67, no. 3 (2007); Sarah Nettleton, "'I Just Want Permission to Be Ill': Towards a Sociology of Medically Unexplained Symptoms," *Social Science & Medicine* 62, no. 5 (2006); Véronique De Gucht and Stan Maes, "Explaining Medically Unexplained Symptoms: Toward a Multidimensional, Theory-Based Approach to Somatization," *Journal of Psychosomatic Research* 60, no. 4 (2006).

[3] José Ortega y Gasset, *Man and People*, 1st ed. (New York: Norton, 1957), 141. Agustín Serrano de Haro, whose article I address in detail below, notes that Ortega must have been unaware of F. J. J. Buytendijk, *ÜBer Den Schmerz; Aus Dem HolläNdischen ÜBersetzt* (Bern: H. Huber, 1949). The assumption, to be clear, is that the phenomenologies of pain found in the earliest thinkers in the phenomenological tradition such as Brentano, Stumpf, and Husserl were not "strict" in Ortega's sense and not "more than an example" in my sense. See Saulius Geniusas, "The Origins of the Phenomenology of Pain: Brentano, Stumpf and Husserl," *Continental Philosophy Review* 47, no. 1 (2014). Geniusas presents the problematic of these early phenomenological thinkers in relation to pain as addressing the question: "Is pain a sensation or emotion?"—but with an eye to determining the phenomenality of sensation vs. emotion, not to that of pain itself. Recent candidates for a "strict phenomenology of pain" include Abraham Olivier, *Being in Pain* (Frankfurt am Main; New York: Lang, 2007); Christian Grüny, *ZerstöRte Erfahrung: Eine PhäNomenologie Des Schmerzes*, Wittener Kulturwissenschaftliche Studien (Würzburg: Königshausen &

follows, I aim to disclose structures of the lived experience of chronic pain, i.e., to articulate the general features that co-constitute and give shape to the particularity and, *a fortiori*, singularity of a given person's experience of chronic pain.[1] I will suggest, at minimum, four structures of chronic pain: foreboding, beholdenness, diagnostication, and regulative disorientation. I conclude the chapter by arguing for the analytic and therapeutic importance of a distinction between component, constitutive, and consuming pain.

§2.3.1 Foreboding

One of the more salient features revealed by the phenomenological description of chronic pain in section 2.2 above is how pain becomes the background condition *against which* experiences are measured. Mariet Vranken writes, "Pre-scientifically, pain is that mode of being in which the body becomes the center of one's life-world (Lebenswelt)."[2] One does not awake and think about one's agenda or long-term projects. The background condition of purposive action has *itself* become a disturbance both in the current moment and in the ability to forge a future. This is not to say it is simply a question of distraction or purposive frustration. With chronic pain, the emotional-affective valence is explicitly one of *foreboding*. "As my eyes open, I worry that I will not be able to get out of bed." Foreboding is a structure or general feature of chronic pain. I use the term "foreboding" here because unlike anxiety, which has no object, and fear, which has an object, foreboding operates ambiguously between these two poles.[3] Not only does one not know

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Neumann, 2004).

[1] By singularity, I aim to pick out the way in which one's experiences are indexed to (though, as I'll argue, not reducible to) one's unique experience.

[2] Mariet A. E. Vrancken, "Schools of Thought on Pain," *Social Science & Medicine* 29, no. 3 (1989). It is not at all clear to me that pain alone holds this role. It is not just that pain places the body in attentional relief; it is the way in which it does so that, I think, makes it unique from other types of sensation.

[3] This would be called "worry" by Christopher Eccleston and Geert Crombez, "Worry and Chronic Pain: A

whether or not one should be concerned in the first place, one does not know precisely *what* one is concerned about. Yet, while this precision is indeed lacking, one does know the general cause of one's concern: pain.

At issue is not just the type of pain that might come (e.g., it might get worse or be of a different sort) but the specific manner in which that pain to come will affect one.[1] Put more simply, the fact that one knows neither what will come nor how it will come intensifies one's fear. This means that foreboding *redoubles* itself. Through the shift in concern from the potential *quantitas* and *qualitas* of pain to the *modus* of its eventuality, this redoubled foreboding feeds the circuit of pain one is already experiencing. The painfulness of pain is *exacerbated* through the particular dimensions of its affective-emotional interpretation, which always takes into consideration its potential effects on purposive action.[2]

These interpretive dimensions are at once general and singular. They exist at the overlap of dynamic socio-cultural, politico-historical, and ethico-juridical systems, on the one hand, and their singularization by the particularity of a given being, on the other. The meaning of pain emerges between the political and the personal. It is here where narrative and historical aspects come to the fore and prove essential for an accurate reconstruction of the existential structures of the phenomena in question.

Misdirected Problem Solving Model," *PAIN* 132, no. 3 (2007).

[1] This accounts for the fact that qualitative data suggests that "the limitations imposed by pain often form the focus of people's coping efforts, rather than the pain per se." See A. Miles et al., "Managing Constraint: The Experience of People with Chronic Pain," *Social Science & Medicine* 61, no. 2 (2005).

[2] As noted above in section 1.1.2, this first-person evidence is corroborated in third-person research in the sciences. G. Crombez et al., "When Somatic Information Threatens, Catastrophic Thinking Enhances Attentional Interference," *Pain* 75 (1998); Mike Osborn and Jonathan A. Smith, "The Fearfulness of Chronic Pain and the Centrality of the Therapeutic Relationship in Containing It: An Interpretative Phenomenological Analysis," *Qualitative Research in Psychology* 5, no. 4 (2008).

The inertia of twenty years of chronic pain, of multiple days bed-ridden, and of multiple clinical encounters where one's experience and voice has been disregarded—this inertia buttresses the amplification of foreboding. In light of that chronicity, could one overstate the effect of the doctor's perceived lack of concern? No. Such a factor *further* intensifies. "Will the pain worsen?" opens onto "What effects will that worsening have?" which opens onto "I will have no recourse to relief." The dread that the sheer reporting of one's pain in its full severity might further prove oneself to be *unmanageable*, to be beyond help in the eyes of one's greatest hope for assistance, is horrifying.[1]

Foreboding also assists in accounting for the unique temporality of chronic pain: the dulling of the past and future and the circling back to the ambiguous present. "I rarely experience my future anymore."[2] It is not that one's imagination has diminished, however blurred or fogged one's mental alacrity may be; it is that the attentional *and* affective dimensions of one's orientation are forced into myopia.

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[1] Not to mention the requirement to *repeat* this reporting at each appointment in order to continue to receive the medication. This is a double-edge sword, the other side of which is the possibility of the doctor not *believing* one's claims about one's pain. Benjamin J. Newton et al., "A Narrative Review of the Impact of Disbelief in Chronic Pain," *Pain Management Nursing* 14, no. 3 (2013). Studies suggest that this is notably worse for women: Anne Werner and Kirsti Malterud, "It Is Hard Work Behaving as a Credible Patient: Encounters between Women with Chronic Pain and Their Doctors," *Social Science & Medicine* 57, no. 8 (2003). Class and locale are also relevant factors: Melissa A. Day and Beverly E. Thorn, "The Relationship of Demographic and Psychosocial Variables to Pain-Related Outcomes in a Rural Chronic Pain Population," *PAIN* 151, no. 2 (2010). Unsurprising, so is race: Mary-Jo DelVecchio Good, *Pain as Human Experience: An Anthropological Perspective*, Comparative Studies of Health Systems and Medical Care (Berkeley: University of California Press, 1992); Gillian Bendelow, "Pain Perceptions, Emotions and Gender," *Sociology of Health & Illness* 15, no. 3 (1993); Raymond C. Tait and John T. Chibnall, "Racial/Ethnic Disparities in the Assessment and Treatment of Pain: Psychosocial Perspectives," *American Psychologist* 69, no. 2 (2014). Moreover, as Leslie Jamison notes, "I've come to understand that the distinction made here between 'real' and 'unreal' doesn't just signify physical versus mental but also implies another binary: the difference between suffering produced by a force outside the self or within it…these explanations place blame back on the patient and suggest not only that the harm inflicted is less legitimate but also that it's less deserving of compassion or aid." Jamison, 41.

[2] Age and perceived life expectancy are two factors that alter this temporality. See Jane C. Richardson, Bie Nio Ong, and Julius Sim, "Is Chronic Widespread Pain Biographically Disruptive?," *Social Science & Medicine* 63, no. 6 (2006); Jean Améry, *On Aging: Revolt and Resignation* (Bloomington: Indiana University Press, 1994).

§2.3.2 Beholdenness

The temporal ek-stases of past, present, and future do not merely function differently. The very character of one's being as ekstatic is itself different. One experiences oneself as beholden, another structure of chronic pain. To be beholden is not simply to be held by someone or something, but also to be observed (as in being "under watch") and to be retained (as in a lawyer on retainer). One is monitored and on call, but *by whom*? This is not known. It could be the doctor, the medical system, the legal system, one's body—all of those are in principle "watching" one and one is constantly "on call" for them. One cannot but interiorize such mechanisms over the years that define many chronic pain sufferers.

Beholdenness is not the same as thrownness (*Geworfenheit*)—it is not the general condition of finding oneself already formed by and complicit in systems one did not create and, in large part, cannot alter. Beholdenness names that one is at the same time {a} monitored, {b} on call, and {c} forced to respond when called upon. What occurs, for example, when nausea strikes? One's body "calls in," and one perforce responds. The question of *who* responds is brought to the fore.

"I do not 'have' pain in the same way that I do not 'have' a body."[1] How does one describe the relationality of pain to "oneself" if "having" fails? If the "in" of "in pain" can find no locale, no borders? Beholdenness names this ambiguity: one is forever "on reserve" by the pain, even when explicitly called upon. Being called to duty does not

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[1] This ambiguity of embodiment is well documented. The most famous investigation of this relation is arguably Maurice Merleau-Ponty, *Phenomenology of Perception*, trans. Donald A. Landes (Oxon; New York: Routledge, 2011); *Phénoménologie De La Perception* (Paris: Gallimard, 1945). For more recent book-length study, see Drew Leder, *The Absent Body* (Chicago: University of Chicago Press, 1990). Yet, beholdenness speaks to more than just the way in which I *live* my body, the way I am not bodied as much as *I body*. Rather, this paradox of bearing, of burden, speaks to the porosity of the *sense* of self in chronic pain.

annul being "on reserve"—it is a modality of it. One is never off the hook. The respite of localization or compartmentalization is cordoned off. The emphasis of beholdenness is not simply in terms of some variation from a norm, but of constitutive *variability*. It is the unique relationality of this variability of oneself to oneself and to the world that I am here naming beholdenness.

One is beholden by the pain that structures the very contours of one's experience and, simultaneously, the pain that breaks through, transforms, or realigns that experience. In other words, that by which experience is measured as well as the very continuity of that measurement *exceeds one's control*.[1] This accounts for the paradoxical formulation: "unbearable, yet bearable." One can point of fact handle it; one isn't dead or strictly unconscious. One still goes on *living*. And yet, in a way one does not. It's overwhelming, too much, crushing…*unbearable*. The teeter-totter of the paradoxical structure of the "bearable-unbearable" produces fatigue, weariness, and burnout. Beholdenness captures this in its fundamental and *tiring* ambiguity: that which I am called upon to bear is *itself* indeterminate even in my very bearing it.[2] Beholdenness is characterized by capriciousness, ambiguity, and weariness—a product of the fundamental ekstatic variability one experiences in the lived chronicity of pain.

§2.3.3 Diagnostication

Habitually localizing pain to discrete sources and qualifying pains according to the McGill Pain Questionnaire, one becomes a diagnostician. One's "normal" action is preemptively altered based upon anticipation of future symptoms or limitations. This

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[1] Still, this is not to suggest that nothing be done by oneself or by others. I speak to this in section 1.3 below.

[2] While the significant conditions by which I bear and am called upon to bear are not under my control, any action I take is monitored and may, unpredictably, affect me: "Smiling hurts. Movement hurts—movement itself. Interacting with others hurts." See J. W. S. Vlaeyen and G. Crombez, "Fear of Movement/(Re)Injury, Avoidance, and Pain Disability in Chronic Low Back Pain Patients," *Manual Therapy* 4, no. 4 (1999).

relates to Christine Miserandino's *Spoon Theory*.[1] Her short story, now famous enough that it has its own Wikipedia page and numerous chronic pain or chronic illness-based communities who use the term as an identity marker ("Oh, you're a spoonie too?"), revolves around the metaphor of spoons as an intangible marker of psycho-physical energy. The "average" person might begin with, say, fourteen spoons for a given day. For a spoonie, however, even minor daily activities might take a spoon. Shower—one spoon gone. Make breakfast—another. Schedule appointments and run errands—two more. What counts as "normal" activity is very different for a spoonie and can be hard for non-spoonie's to understand.

Furthermore, a spoonie might have less spoons at the start, and one may not be able to transfer spoons from one day to another. When one is out of spoons, *one is out*. Tracking one's spoons is a form of diagnostication, a process of constant self-evaluation of not just one's energy levels, but all of one's feelings, movements, and even thoughts. Regulating all of one's activities in light of one's pain, detailing the events and diagnoses that lead to it, remembering life before it—these are all part and parcel of the structure of diagnostication.

Diagnoses constitute a narrative life of their own, a subplot that can, in effect, subtend the real plot, the fully-fleshed life. Both self- and other-generated diagnostication is temporally transverse: one seeks out new etiologies and diagnoses by reinterpreting past data, and one anticipates future diagnoses based upon present data. A crucial

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[1] Christine Miserandino, "The Spoon Theory," http://www.butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/.

component that exacerbates this process is that in the case of the many chronic pain patients, one must simultaneously prove one's (invisible) pain to be real (to others).[1]

Thus the frustration: "What brings me in? Is this some kind of sick joke?"[2] Diagnostication renders the pain legitimate under the anatomo-clinical gaze. Eccleston et. al. writes, "when pain is no longer useful as a symptom, identity is challenged, weakened and at risk for both chronic pain patients and pain professionals."[3] Lack of diagnoses, by virtue of delegitimizing the reported pain, *delegitimizes the person*. Diagnostication institutes not merely medical authority, but the phenomenal authority of experienced symptoms and the authority of the one who experiences them. The experience of chronic pain is an experience of adjudication by diagnostication, an experience of *a continual tribunal* before which the cohesion of one's self dissolves or solidifies. Diagnostication thus contributes to the intensity of one's beholdenness and foreboding. Each co-constitute each.

§2.3.4 Disorientation

I will now argue for a fourth structure of chronic pain: disorientation. Unlike the first three structures, disorientation is *centripetal*. By centripetal, I mean that it acts upon the other structures of foreboding, beholdenness, and diagnostician. It alters and often exacerbates their force. Chronic pain renders the forces that determine one's life

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[1] Robert Kugelmann, "Complaining About Chronic Pain," *Social Science & Medicine* 49, no. 12 (1999); Anne Werner, Lise Widding Isaksen, and Kirsti Malterud, "'I Am Not the Kind of Woman Who Complains of Everything': Illness Stories on Self and Shame in Women with Chronic Pain," ibid.59, no. 5 (2004).

[2] That it is a PA (a person who is obviously not one's doctor) does not make a difference. That space, the medical office where one has met that doctor for twenty years, has a history. The newcomer who fails to take the time to learn that history trespasses and betrays the trust built there. Note also that the intersubjective position of the supplicant and patient is functionally similar. The supplicant is bent over (*sub-plicāre*) by virtue of their petitioning, their asking or begging (*petit-iō*). The patient, who is as *patiēns*[2] already under the weight of (*sub-ferre*) suffering undergoes further suffering by virtue of their entreaty, the drawing-up of negotiations (*en-trahĕre*) with the practitioner.

[3] Chris Eccleston, Amanda C. De C. Williams, and Wendy Stainton Rogers, "Patients' and Professionals' Understandings of the Causes of Chronic Pain: Blame, Responsibility and Identity Protection," *Social Science & Medicine* 45, no. 5 (1997).

constitutively capricious. In this respect, chronic pain effects disorientation in one's ability to regulate one's activities and projects, even to the point of disrupting one's sense of self. Regulative disorientation can intensify foreboding and beholdenness and demand more reflective diagnostication.

I said earlier that the *for* structure is constitutive of pain's sense, that pain is always in a dynamic relationship that cannot be understood in terms of its mere happening and that, by definition, *pain has an etiology*. Given my analysis of various models of pain, it is now clear that pain has an etiology *in order to* function regulatively. Without a cause, pain loses its regulative signification because it no longer has a historical basis from which it can *orient* one's action. This is the case whether that action is conceived at the level of the organism, as in the biological model, or at the level of the divine, as in the religious model, or at whatever level with respect to the other models, *mutatis mutandis*. Chronic pain disrupts this regulation; it disallows one a home, even a home "in" oneself, with respect to one's body. All orders by which one might seeks orientation are unsecure. To repeat, it is not a simple combination or addition, not merely co-constitutive, but is coalescent and intensificatory of the other three structures. Regulative disorientation means one cannot take anything for granted. One is in eternal limbo. Regulative disorientation is primarily characterized by nomological disarray. The law by which and under which one understands oneself, one orients oneself—this law is unknown and capricious.

§2.4 Of Pains and Sufferings

> The incarnation of the self and its possibilities of gratuitous pain must be understood in function of the absolute accusative characteristic of the self, a passivity prior to all passivity at the bottom of matter

becoming flesh.
—Levinas[1]

Freedom follows the subject's urge to express itself. The need to lend a voice to suffering is a condition of all truth. For suffering is objectivity that weights upon the subject; its most subjective experience…objectively conveyed.
—Adorno (Neg. Dia. 17-18)

I am now in a position to clarify the initial error of the ableist conflation: the conflation of pain with suffering. Although some trade on the common sense intuition that pain is not "enjoyable," a small amount of reflection proves this false. Exercise, partying to exhaustion, eating spicy food or past being sated: these are all instances where we inflict pain onto ourselves quite willingly and happily.[2] On the other hand, no one wants to *suffer*.[3] Why? Based upon the phenomenology of chronic pain in section 2.2 and the phenomenological analysis in 2.3, I contend that there are three distinct categories of pain, none of which are reducible to the other:

Component Pain	**Constitutive Pain**	**Consuming Pain**
Feeling Pain, Being In Pain	Suffering, Constitutive Suffering	Extreme Suffering

I will now address each of these categories in turn.

§2.4.1 Component Pain

Feeling Pain: Whether or not philosophers of mind and/or cognitive scientists agree on the implications of pain asymbolia, humans, in terms of praxis, distinguish

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[1] Emmanuel Levinas, *Otherwise Than Being or Beyond Essence*, trans. Alphonso Lingis, Martinus Nijhoff Philosophy Texts (Hague; Boston: M. Nijhoff; Kluwer Boston, 1981), 196, fn. 21.

[2] One could counter that these are cases of "discomfort" and not pain; I'm unpersuaded that such a distinction holds phenomenologically. One could alternatively counter that pain is in these cases desirable, enjoyable, perhaps such that it should not count as an "instance" of pain. Again, I'm unconvinced on phenomenological grounds. The *pain* of the activity is integral to the activity itself; it is part of the energeia of such activities, not a mere means.

[3] I hold this to be the case even with those who self-mutilate/self-flagellate or engage in BDSM or other such practices. People who willingly inflict long-term and extreme suffering on themselves appear to be doing so *in order to palliate* their suffering or for some other end. It is not suffering for suffering's sake—the telos of these practices is aimed directly at a goal *other* than the suffering in and of itself. See Strong; Stoller.

between the mere sensation of pain and being in pain. Pain as a sensation (feeling pain) and pain as an existential quality (being in pain) are not the same. Ordinary language offers an insight here: "It hurt, but it wasn't that bad—I wasn't really in pain" or "I'm fine; it's just a knick."[1] This demarcation is made most often as a way of marking off pain that *affects* the conditions of one's facticity and pain that does not.[2] Merely feeling pain need not mean one is in pain.

Being in Pain: unlike feeling pain, being in pain means that the pain has entered into one's projects, even if temporarily. It indicates the fact that it is non-trivial. Being in pain names a situation wherein the emotional-affective and cognitive-projective factors of one's being are notably *altered* by one's pain. When a person is sick enough to go to the doctor and is asked, "How much pain are you in?"—such a question is ultimately less about the level of the *sensation* of pain and more about the extent to which the pain is inhibiting action (it's functional effect on life activity), notwithstanding the logic of the McGill or Faces Pain Scale. One neither simply feels pain after a tonsillectomy, nor does one simply feel pain during pregnancy or amputation: one is in pain.

§2.4.2 Constitutive Pain

Suffering: Suffering is marked out by the extent to which the projects of a being are substantively foreclosed by the pain which they experience. Suffering is when a determinable component of the future and a person's sense of self is determined by their being in pain. Note that this definition of suffering allows one to explain how a person

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[1] By referring to "ordinary language," I am in part invoking the theoretic weight given to ordinary language within the tradition of ordinary language philosophy in twentieth-century Anglophone philosophy (Wittgenstein, Austin, Ryle, etc.)

[2] It is precisely between within the distinction of component pains (feeling pain, being in pain) that one can situate what Sheena Hyland has called "mild corporeal pain," which she defines as "ordinary, non-pathological bodily stresses and strains–experiences that are commonly referred to as 'aches and pains.'" Lisa Folkmarson Käll, *Dimensions of Pain: Humanities and Social Science Perspectives*, Routledge Studies in the Sociology of Health and Illness (Abingdon, Oxon; New York: Routledge, 2013).

who reports that they are suffering can nonetheless become temporarily distracted. Distraction functions to pull one out of one's suffering even if one is *conscious of* the same level of pain before, during, and after that distraction. If one understands distraction as a temporary diminishment of suffering, it is not surprising that it can function both through innocuous examples (laughter, music, good company, etc.) or through noxious ones (self-mutilation). In the latter cases, the infliction of pain by cutting or other such means actually *opens* up the field of one's otherwise foreclosed projects. This is intuitively paradoxical to many, but this is exactly what is reported by those who take this action: cutting allows one to give a physical form to one's pain, exposing what one otherwise feels as hidden and incommunicable.[1] In doing so, self-mutilation is experienced as the *diminishment* of suffering through an *amplification* of pain, viz., through creating a condition wherein one can be in pain. This definition of suffering also allows one to explain *why* foreboding can intensify the self-reporting of pain levels with respect to methods like the McGill pain scale. Foreboding names one way in which the future and sense of self of a person is determined by their being in pain.

***Constitutive Suffering**:* Constitutive suffering names conditions where suffering has become *integral* part of the person's sense of self, whether because of the combination of its intensity with extended duration, due to the gravity of a given trauma, or due to severe loss, among other possible reasons. It becomes part of one's existential background. This explains the intuitive difference one would make between suffering during the recovery from open-heart surgery vs. the suffering of chronic pain or PTSD. The latter are cases of constitutive suffering. Chronic pain, as should be obvious by now, is a type of constitutive suffering. Even if, miraculously, one's chronic pain were to

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[1] Idem.

cease, it has become the default position. It would mark the background against which the new non-suffering state would be compared. If someone were tortured for twelve hours, that would be suffering (and not simply being "in pain"), but not *necessarily* constitutive suffering.[1]

§2.4.3 Consuming Pain

Extreme Suffering**:** this term indicates that one experiences *nothing* or nearly nothing but one's pain. As I explain below, torture is a species of such suffering, but I'll argue it is unique enough to warrant its own category. The poet Jane Cave lies in her bed with a migraine headache so strong that it is as if she is entombed "in perpetual night."[2] Claustrophobic darkness encroaches upon her, drowning out, along with the last specks of light crawling through the shaded windows, sense itself. "To languish on is worse than death," she cries, knowing that only the utter inertness of death could conquer the suffering which grips her. Why is she thus entombed? Whence has this suffering derived its power? She knows full well: "its dire excess" dissolves her sight.[3] There is an excessivity of nothingness. If all one experiences is one's pain: one experiences extreme suffering. *Extreme suffering is the suffering of suffering itself.* It is an experience about which we often create or repurpose new words (*pathein* in the context of Attic tragedy, Holocaust/Shoah, genocide, etc.).

As I will argue in more detail in section 2.4 below, I disagree with those who side with Elaine Scarry and Virginia Woolf that language pales before pain. Such a thought

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[1] It would precisely depend on what happens after that, viz., whether the experience of being tortured became an integral part of one's self. To be clear, in most cases of torture, I imagine it *would*. See Scarry.

[2] Jane Cave Winscom, *Poems on Various Subjects, Entertaining, Elegiac and Religious. By Miss Cave, Now Mrs. Winscom. The Fourth Edition, Corrected and Improved, with Many Additional Poems, Never before Published*, ed. Gale Group Eighteenth Century Collections Online (Bristol1795), 166-67.

[3] This feature of suffering—that is, its excessivity—is sounded by Dickenson as well when she speaks of "pain – so utter – It swallows substance up –". Emily Dickinson, *Complete Poems*, 1st ed. (Boston: Little, 1960).

makes sense only on an indefensibly narrow understanding of language, one that sees the groan and cry as inarticulate and nonlinguistic (Scarry 1985, 5). Pain only signifies in an explicitly linguistic context when arrested, not in excess. That is to say, the fully pained body, the body stricken with pain, *speaks loudly*. It groans, cries, moans, yelps, and screams. So-called "nonlinguistic" expressions of pain could be considered far *more articulate* about disclosing the actual situation of a sufferer.

To be sure, these significations, these groans and cries, offer very little by way of any diagnostics with an etiological aim as opposed to a purely palliative one. A doctor or nurse or other medical practitioner ultimately must know where, why—and, in a research setting, *how*—these groans signify a quantifiable and determinate cause. "This place here." "With respect to this tissue here." "Because of this neurological event that happened there." When this is impossible or difficult, the patient may suffer more. When one seeks such etiological knowledge at the expense of their present suffering, the patient may suffer more. That balance is an ethical one. But the perlocutionary effects of the cry "speak" clearer than any grammar allows.

Torture: when one is tortured, one is not simply in extreme suffering, for one knows that the *goal* of such suffering is suffering; that is, the fact that one's suffering is *intended* to be insufferable is itself used as a way to intensify that suffering.[1] Moreover, as Elaine Scarry has shown, torture's goal and, in some cases, effect is to destroy the self-

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[1] I find that the importance of the distinction between torture and the other types of pain I have is crucial. It is in part the ambiguousness of the term "pain" that offers it such political force—force which, in many cases, is unwarranted, misplaced, or misused. For example, Elaine Scarry's *The Body in Pain* has had a very wide readership and, for better and worse, influenced the conceptualization of pain across multiple disciplines. The examples of pain upon which she draws are, however, from torture. The problem with this approach is that torture is in many respects unique phenomenologically. It does not, as the phenomenology of CRPS I presented earlier demonstrates, correlate to the constitutive suffering of chronic pain. Moreover, it certainly does not correlate to feeling pain, being in pain, or even suffering *simpliciter*. Whatever similarities it may have with other forms of experiences that one typically seeks to avoid, these recede amidst the potency of its differences.

integrity of person, their very sense of being a "self." Torture seeks the destruction of one's world. In torture, one is carved out from the inside by the inside. The very affectivity by which one exists is turned against oneself into a weapon. More than any other phenomenon, torture destroys, and destroys completely, the conditions for a subject to exist. It is, all other things being equal, the worst possible experience for a being.[1] Torture is that species of extreme suffering wherein one knows one's suffering is both intended and avoidable.

In extreme suffering (as well as its more specific form in torture), *one suffers one's suffering*. To help one clarify what it might mean to suffer suffering itself, I will turn to Levinas' essay "Useless Suffering."[2] To begin, I do not read it as an essay on suffering, but an essay on the suffering of suffering. He begins by noting that suffering indeed presents itself in the common sense way we usually talk about pain: it is a fact, a datum, of consciousness—it is a sensation. As he puts it, "Suffering is surely a *given* in consciousness, a certain 'psychological content', like the lived experience of colour, of sound, of contact, or like any sensation." Yet, a simple given, like the sensation of the

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[1] It is at the extreme of torture that claims about the differential constitution of subjectivity are especially put to the test. "If the subject did not differ from itself," Nancy writes, "it would not be what it is: a subject relating itself to itself. A = A signifies that A in itself 'is its difference from itself, and that it derives its equality, its being-equal to itself, only from this difference. (A...is not a logical symbol; it is the initial of every initial: it is a proper name, a face, a voice...The A of speculative idealism is both the first notation of an algebra of ontological identity and the name of the singular in its singularity.)" Jean-Luc Nancy, *The Birth to Presence*, Meridian (Stanford, Calif.: Stanford University Press, 1993), 11. This insight does not solely relate to humanistic concerns—it applies equally to non-human animals and the "environment." The differential relation of oneself to oneself is mediated, imbricated, in difference. Torture is the collapse of all differentiation.

[2] Emmanuel Lévinas, "Useless Suffering," trans. Richard B. Cohen, in Robert Bernasconi and David Wood, *The Provocation of Levinas: Rethinking the Other*, Warwick Studies in Philosophy and Literature (London; New York: Routledge, 1988), 156-67. This essay has also been translated by Michael B. Smith and Barbara Harshav in Emmanuel Levinas, *Entre Nous: On Thinking-of-the-Other*, European Perspectives (New York: Columbia University Press, 1998), 91-101. 'La Soig'france inutile' first appeared in Giornale di Metafisica 4 (1982), 13-26, and was reprinted in Les Chaiers de la Nuit Surveille, Numero 3; Emmanuel Lévinas, ed. Jacques Rolland (Paris: Editions Verdief, 1984), 329-38. Citations will appear in-text hereafter based on Cohen's translation.

color red, is not yet an experience of red.[1] Thus, the next claim that Levinas makes about suffering is quite radical. He writes, "but in this 'content itself, it [suffering] is in-spite-of-consciousness [*malgré-la-conscience*], unassumable. It is unassumable and 'unassumability' [*L'inassumble et l' « inassumabilitié »*]."[2] While we might be able to get a grasp, then, on an unassumable content, a sort of asymptotal content, why then does Levinas add "unassumability"? The root "-ility" or "*ilité*" is a variant of the suffix "-ity" and "-ty" which designates being in the state or condition or having the quality of something. So suffering is a given which refuses itself, and this paradoxical experience is the state of suffering suffering. The manner or *how* of the unassumable is itself unassumable.

It is one thing to say, e.g., that a sensation refuses itself to understanding, to consciousness. I feel love for you, but when I try to make this love clear to myself, when I try to analyze it, understand it, reason about it, explain it…I fail. Moving from phenomenological description to reconstruction in such a case can produce refraction. To say that it is "unassumability," however, is to say that the very character, the quality of that "given that refuses itself in its giving" is *also* refused. The refusal of the given cannot itself be analyzed as a quiddity, in terms of *what* it is, in terms of its type or kind. I

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[1] To treat them both as instances of red is to ignore these phenomena. That pain is given as a sensation does not yet tell us how pain is *experienced* as a phenomenon, or, put otherwise, it does not yet tell us *how* pain is given or what pain is given as. As Merleau-Ponty will argue in his *Phenomenology of Perception*, the wooly red of this carpet here versus the red of Rothko's 1961 "Orange, Red, Orange" are not the same. Merleau-Ponty, *Phenomenology of Perception*. References to "red" and other colors abound, but in reference to "woolly carpets," see 5 and 365; on this point more generally, see especially 15-17, 204-05, 376, 436-38, and 524.

[2] Phenomenology seeks to uncover givens we pass over due to the natural attitude, to our usual assumptions about things and due to our entrenched ways of seeing things, but phenomenology—or at least classical phenomenology—cannot speak to what is not given to us at all. That is, some would say, the purview of speculative metaphysics. So, what precisely does Levinas mean when he says that suffering is unassumable and unassumability? If we listen to the word "assume," to "*assumer*," we get "taken to or upon oneself; appropriated; adopted as a basis for reasoning, taken on." That which is unassumable is precisely that which refuses being taken even in being given; it is that which pushes back in its giving.

neither am able to reconstruct the phenomenon of suffering, i.e., *what* is given, the *thing* given, nor am I am able to reconstruct its mode of giveness, i.e., any details or characteristics about it whatsoever. Extreme suffering is, Levinas' phenomenology seems to suggest, a non-phenomenon, an impossible phenomenon. Lisa Guenther's work on the dissolution of subjectivity in solitary confinement provides support for this thesis.[1]

Levinas continues, "'unassuambility' does not result from the excessive intensity of a sensation, from some sort of quantitative 'too much', surpassing the measure of our sensibility and our means of grasping and holding" (156).[2] Suffering "results from an excess, a 'too much' which is inscribed in a sensorial content" (156). Unassumability names an excess *within* sensation, not an excess beyond or outside of sensation. Although an imperfect example, I find that one can get a glimpse of this point by referring to strong, acute pain. What happens in the moment one's finger lingers too long over the flame? Although the surging of the pain is absolutely immense, although all one's concentration collapses and intensifies onto, comparatively, a point—the excessiveness of the sensation is internal to sensation itself, not external.[3]

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[1] Guenther.

[2] The reference here is to the mathematically sublime (opposed to the dynamically sublime) as Kant defines it in Section 25-6 of the second book of the "Analytic of the Sublime" in the third critique, where he terms the mathematical sublime as that which exceeds the capacities of measurement of the senses. "That is [mathematically] sublime which even to be able to think of demonstrates a faculty of the mind that surpasses every measure of the senses" (Immanuel Kant, *Critique of the Power of Judgment*, trans. Paul Guyer, The Cambridge Edition of the Works of Immanuel Kant (Cambridge; New York: Cambridge University Press, 2000), 250/134. By contrast, "nature considered in aesthetic judgment as a power that has no dominion over us is dynamically sublime" (260/143).

[3] It is here instructive to remember that in the reference Levinas implicitly makes to Kant's third critique, Kant's discussion is focused almost entirely on the way the mathematically sublime affects the rational faculties. Although the *felt* aspect of the effect of the mathematically sublime is discussed, it is a felt aspect of the interplay of reason's faculties that is crucial for Kant's account. Levinas is talking about the felt aspect of a feeling before the possibility of the distinction between the "rational" and the "emotional" or "felt," in what Levinas terms "sensibility." Levinas, *Otherwise Than Being*, 50-55. Levinas continues: "For the Kantian 'I think' - which is capable of reuniting and embracing the most heterogeneous and disparate givens into order and meaning under its a priori forms—it is as if suffering were not only a *given* refractory to synthesis [it cannot be brought under the transcendental unity of apperception such that to every experience one can prefix "I think that"], [it is not just this] but the *way* in which the refusal opposed to the

Suffering marks a limit of reason, not in the simple sense of "you can go no farther—you have to head back," but in the sense of aporia: no way out at all. I would argue that Levinas' sense of suffering is not simply one of aporia, but aporetic aporia—not a limit or inability to find one's way, but a limit to knowing the limit, an inability to even mark the terrain by which one experiences.[1] Ariadne's thread is of no use here. As Levinas puts it, "it is the explosion and most profound articulation of absurdity" (157). Nietzsche gets close to this insight when he remarks, "what really arouses indignation against suffering is not suffering as such but the senselessness of suffering."[2] Yet, it is not just the senseless or absurd; it is the very explosion of the absurd.

It is only at *this* point, this very precise point in his phenomenology that Levinas writes, "the least one can say about suffering is that in its own phenomenality, intrinsically, it is useless, 'for nothing'" (158). This formulation is precise—he does not

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assembling of givens into a meaningful whole is opposed to it: suffering is at once what disturbs order and this disturbance itself" (156). A given not given and experienced *as* refusal. A givenness *of* refusal. This is, Levinas points out, "a quasi-contradictory structure, but a contradiction which is not formal like that of the dialectical tension between the affirmative and the negative which arises for the intellect; it is a contradiction by way of sensation: the plaintiveness of pain, hurt [*mal* - so also evil]" (157). This leads to Levinas' formulation of suffering as a passivity "more passive than receptivity...an ordeal more passive than experience [I imagine one should hear the Greek *pathein* here]," an original passivity "independent of its conceptual opposition to activity," for "in suffering sensibility is a vulnerability" (157). This is, if one will allow the spatial metaphor, a deeper passivity. He continues, "what counts in the non-freedom or the undergoing of suffering is the concreteness of the *not* looming as a hurt more negative than any apophantic *not*" (157). The apophantic not, the not which shows or displays something as false, as not the case, is a negativity that can only be thought in relation to a positivity. One says not-A only if A is logically thinkable, only if A functions as a discrete proposition within a logical system, and visa versa. A negativity that suffuses being thoroughly can no longer be thought in relation to positivity. In extreme suffering, *there is no comparison, no gradation, no anticipation or retrieval: there is only pain, which is always experienced as the pain of pain*, and it this doubling for which we usually reserve the term suffering even colloquially. This plaintiveness of pain has no time. It suffuses; it saturates. It cannot have reasons. This is why Levinas can say, "All evil [mal] refers to suffering. It is the *impasse* of life and being, their absurdity...the evil [mal] of pain, the harm [mal] itself" (157). Since it hard to use the word absurd without implicitly invoking Camus, Levinas' use is striking here. In *The Myth of Sisphyus,* Camus calls the absurd "sin without God…the absurd is essentially a divorce. It lies in neither of the elements compared; it is born of their confrontation." Albert Camus, *The Myth of Sisyphus and Other Essays*, trans. Justin O'Brien, 1st Vintage International ed. (New York: Vintage Books, 1991), 40, 30. Yet, this cannot be all that Levinas means, for a divorce still requires a binary, and Levinas is describing a phenomenon that occurs outside of a binary, outside of a confrontation—suffering as saturating consciousness.

[1] Camus also defines the absurd as "lucid reason noting its limits." , 49.

[2] Nietzsche, *On the Genealogy of Morals; Ecce Homo*, 68.

claim that suffering cannot be appropriated into human projects, that it cannot be excised from its own domain, and placed into services, such as, for example, Sartrean freedom.[1] Levinas claims, instead, that any such use or end is extrinsic to suffering itself; it is given as useless, which he links to its senselessness.

For the sufferer, however, while suffering is in and of itself useless, the other can open this self-enclosure. “For pure suffering,” Levinas claims, “which is intrinsically meaningless and condemned to itself without exit, a beyond takes shape in the inter-human...in the suffering of suffering, the [my] suffering for the useless suffering of the other person, the *just* suffering in me for the unjustifiable suffering of the Other…the ethical perspective of the inter-human” opens onto suffering” (158-59, my italics). It is “this attention to the Other which...can be affirmed as the very bond of human subjectivity, even to the point of being raised to a supreme ethical principle” (159). The only meaning suffering suffers is that of helping, of attending to the other. Is the consuming pain of suffering a bond of human subjectivity? Is constitutive or component pain not?

§2.5 Whose Pain?

> You come out of the whole thing bewildered. You no longer recognize yourself: but “recognize” no longer means anything. Very soon, you are just a wavering, a strangeness suspended between poorly identified states, between pains, between impotences, between failings. Relating to the self has become a problem, a difficulty or an opacity: it happens through evil or fear, no longer anything immediate—and the mediations are tiring. The empty identity of the “I” can no longer rely on its simple adequation (in its “I = I”) as enunciated: “I suffer” implicates two I’s, strangers to one another (but touching each other). The same holds for “I delight” (we could show how this is indicated by the pragmatics of either statement): in “I suffer,” however, the one I

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[1] Sarte writes, “We are free when the final term by which we make known to ourselves what we are is an end.” Sartre, 621. This is complicated by his later writings where “integral humanity” becomes a focus over solely individual “freedom.”

> rejects the other, while in "I delight" the one I exceeds the other. Two drops of water are doubtless no more, and no less, alike.
> —Jean-Luc Nancy *on the experience of a heart replacement*[1]

Recall that Scarry argues that pain is a subjective experience, that no one can have *my* pain. "When one speaks about 'one's own physical pain' and about 'another person's physical pain,' one might almost appear to be speaking about two wholly distinct order of events."[2] Toombs, who I discuss at length in chapter 4, argues similarly about illness. "Illness is, first and foremost, a subjective experience…there is an unshareability characteristic about illness which derives from its being an inner, rather than an outer, event."[3] The refrain that no one can have and thus understand my pain is almost as ubiquitous as the refrain that no one can die my death. These refrains, often taken as truisms, are then used to argue that pain, like dying, is a wholly or primarily individual experience. The problem with this argument is that it relies upon a spurious, implicit split between meaning and experience propped up by an individualistic ontology and a dismissal of vast empirical evidence to the contrary.

Take Scarry's argument as an example. First, she often reduces the interpretation or meaning of pain to its linguistic or discursive expression. Second, she understands the experience of pain to exceed the bounds of linguistic expression. Thanks to this, she can claim that while the meaning of my pain is necessarily shared insofar as language is shared, the experience of pain is not shared insofar as my experience is subjective and in excess of language. This only makes sense if one assumes an atomistic ontology of the self coupled with an expressivist theory of language. Given these two assumptions, if one asks whether "my" experience of pain equals "yours," it obviously doesn't. On such an

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[1] Jean-Luc Nancy, *Corpus*, trans. Richard A. Rand (New York: Fordham University Press, 2008), 169.

[2] Scarry, 4. This is a constant refrain. Cf. Woolf. Cf. Frank, 29.

[3] Toombs, *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient*, 23.

assumption about the natural of individuals and individual experience, we cannot experience a given phenomenon in the same way, and we surely cannot directly experience each other's experience. If one further asks whether I can "express" the experience of my pain, one obviously cannot. As atomistic selves who use language to outwardly express inward experience, inner experience outstrips its expression. Yet, does this understanding of the self and of language make sense?

In the section typically presented as Wittgenstein's argument against the possibility of Cartesian private objects, he writes,

> "Another person can't have my pains."—Which are *my* pains? What counts as a criterion of identity here? Consider what makes it possible in the case of physical objects to speak of "two exactly the same", for example, to say, "This chair is not the one you saw here yesterday, but is exactly the same as it".
>
> In so far as it makes *sense* [Soweit es *Sinn* hat] to say that my pain is the same as his, it is also possible for us both to have the same pain. (And it would also be imaginable [denkbar] that two people feel pain in the same—not just the corresponding—place [an der gleichen—nicht nur homologen—Stelle]. That might be the case with Siamese twins, for instance.)
>
> I have seen a person in a discussion on this subject strike himself on the breast and say: "But surely another person can't have THIS pain!"—The answer to this is that one does not define a criterion of identity by emphatic stressing of the word "this". Rather, what the emphasis does is to suggest the case in which we are conversant with such a criterion of identity, but have to be reminded of it.[1]

Wittgenstein understands pain as a primitive mental state, like joy or sadness, and he argues that the locution "I am in pain" *expresses* the experience of this primitive mental state.[2] When one expresses such a state, the expresser acts as a sovereign epistemic authority. By hitting one's chest, one refers to a case for investigation of our intuitions about such authority. Hitting one's chest exemplifies, not explains the issue. One's expression is *beyond doubt for one oneself*, and in a certain sense, it is not subject to

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[1] Wittgenstein, §253.

[2] Ibid., fn. (a) on pg. 50 and §154. ibid., §244-46. Especially: "So you are saying that the word 'pain' really means crying?"—On the contrary: the verbal expression of pain replaces crying and does not describe it. 245. For who can I go so far as to try to use language to get between pain and its expression?

epistemic assessment by others.[1] I might think you are lying, but I cannot definitively prove you are lying by directly referring to your mental state or putting you in an fMRI.

I understand Wittgenstein to be arguing that by relying on subjective emphasis ("Which are *my* pains?"), his imaginary interlocutor reveals he in fact doesn't understand the meaning of the phrase "I am in pain." To emphasize the "I," the mineness, in that phrase is semantically superfluous. The emphasis proves nothing about the subjectivity of experience, just as the non-emphatic version proves nothing—it merely *asserts* it. This assertion appears problematic at best, indefensible at worst, if one does not assume the chain of claims outlined above with respect to Scarry: subjects are atomistic and subjective experience is thus "inner," linguistic expression is a tool to "outwardly" express inner experience, and inner experience exceeds the tool of language.

If it is the case that subjective experience, the "I", is extended and relational, not atomistic and private, then the chain falls apart. Phenomenologically, pain is an exemplary phenomena to see how the identity of the "I" is "empty", to follow Nancy's phrasing. In pain, the "I" is at odds with itself. That is to say, one's *sense* of oneself, whatever it might be, is disrupted by pain. Unlike consuming pain, component and chronic pain is always distinguished from me. More strictly, it is neither me, nor not me: it is constitutive of my being without being identical to it. To conclude from this that it is "my" pain and to think this means it is only "in" my conscious field is to assume that my

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[1] "It can't be said of me at all (except perhaps as a joke) that I know I'm in pain. What is it supposed to mean except perhaps that I am in pain? Other people cannot be said to learn of my sensations only from my behavior—for I cannot be said to learn of them. I have them. This much is true: it makes sense to say about other people that they doubt whether I am in pain; but not to say it about myself." Ibid., §246. Cf. also "One also says 'I know that he is in pain'. The language-game is different every time, we are sure every time, and people will agree with us that we are in a position to know every time. And that is why the propositions of physics are found in textbooks for everyone. If someone says he knows something, it must be something that, by general consent, he is in a position to know." *On Certainty/Über Gewissheit*, English and German ed. (New York: Harper & Row, 1972), §555. See also §563.

conscious experience is my own. Yet that is exactly what pain so convincingly demonstrates as false. I *find myself* in pain. Pain overtakes me. What type of being must I be in order to experience something like pain? What type of being must I be such that the intensity or even existence of pain can be modulated by whether or not a friend is nearby…by whether or not the pain is part of a cultural or religious ritual? I must be constitutively *open* to the world and to myself in the world. Not inside, not individual—but outside and relational. I must be ecstatic.

To exist is to be thrown, to find oneself already on the way. My pain is not “my pain” anymore than sun’s warmth on my body is “my warmth.” I am conscious of my pain just as I am conscious of my warmth, but my consciousness *of* these phenomena is constituted by histories of which I am not author and materials of which I am not artisan. Imagine standing next to a friend at the beach on a sunny day, and they, hitting their chest, were to proclaim, “but surely another person can’t have THIS warmth!” Or say, while eating a meal with one’s family, pointing to the entrée, and proclaiming, “but surely another person can’t have THIS taste!” This example makes the *stakes* of theories of pain obvious. Pain, unlike warmth, is both implicitly and explicitly assumed to be a ground of normative claims, especially claims in the domain of liberal social justice projects. Warmth is not so associated even though being warm, like eating and having shelter, is a threshold for flourishing.

Even though the example of pain appears more obvious than that of warmth or taste, Wittgenstein makes the example of pain strange by asking: what is the criterion of identity that the “my” in “another person can’t have my pains” picks out? Although Wittgenstein does not explicitly state it, his analysis implies that this criterion of identity is one of a solipsistic ontology. To say that you cannot have my pain is to think one has demonstrated the individuality of experience when one has merely asserted it. To say that you cannot have my pain is to assume that ‘having a pain’ is for a person like what ‘having the color of red’ is for a painting. Following Merleau-Ponty, it is of course true that no two paintings have the exact same red, but we are not paintings and pain is not paint. We are not blank, isolated slates, but meaning-making creatures. And meaning-making is a social project all the way down. We use all sorts of histories and materials to tell stories that help us make sense of things, but these are never fashioned ex nihilo. Pain does not demonstrate there are meanings that are ours alone. Pain demonstrates that we, along with meaning, are porous. Pain reminds us that the ability to make and experience meaning occurs within social contexts and can only in the most extreme situations be taken away.[1]

§2.6 Conclusion

I earlier defined the ableist conflation as conflation of pain with suffering or, more specifically, the assumption that disability is a harm and thereby concomitant with pain and suffering. I then pivoted to an examination of pain because so many thinkers—from Levinas to Rorty, from Stoics to Rationalists—fail to analytically distinguish “pain” from “suffering,” and, *a fortiori*, distinguish between various types of each. No one, however, whether a political theorist or applied ethicist, is in the business of keeping people from the possibility of component pain. That is a condition for the possibility of any model of a flourishing life, as the stories of congenital pain insensitivity patients make evident. What

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[1] I cannot broach the topic here, but it would be worthwhile to place pain, conceived in terms of the various models described in chapter one, on a continuum with negative categories of social justice: oppression, domination, etc. I suspect that the line between harm and social harm is less abstract than one imagines.

ethicists and theorists are in the business of doing, however, is minimizing constitutive and consuming pain. It is now clear that *the ableist conflation understands the "pain" or "suffering" of the non-normative life in terms of constitutive pain*. The ableist conflation implicitly takes the distinction I have made between component and constitutive pain into account, for, as will become clear, it is precisely in terms of the horizon of an entire life that a person living with disability is assumed to be suffering.

Ableism assumes, in other words, that the very conditions of the possibility of living with a disability are fundamentally *constricted* possibilities and possibilities which one actively experiences *in that constriction*.[1] This is the logic of "I'd rather be dead than disabled." This is the logic of those who refuse to wear head-protection when motorcycling because the thought of paraplegia seems worse than death. Still, the other primary nominal component of the ableist conflation is "disability." While I have now explained and refined the type of pain at issue in the ableist conflation, the understanding of disability operative therein is still untouched. But what if that understanding is likewise imprecise, perhaps even entirely false? What if the ableist conflation is wrong not simply in its linking of disability with pain, but in its understanding of disability? What if this understanding flatly contradicts much of the first-person testimony from people with disabilities concerning their lived experience, even though it has and still is used as a justification for institutionalization, sterilization, and death?[2]

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[1] I.e., the ableist conflation assumes a person living with a disability to experience their possibilities *as* foreclosed and constitutively so.

[2] The infamous conclusion of the United State's 1927 *Buck v. Bell* case put this logic in crystal clear terms: "We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices…in order to prevent our being swamped with incompetence. It is better for all the world, if…society can prevent those who are manifestly unfit from continuing their kind…Three generations of imbeciles are enough." *Buck V. Bell (Carrie Buck V. James Hendren Bell, Superintendent of State Colony for Epileptics and Feeble Minded).*

I now turn in the second chapter to a phenomenology of disability through the figure of a person living with multiple sclerosis.

☙ DISABILITY ❧

3 THEORIES OF DISABILITY

Our aversion to the very idea of being disabled forestalls our
understanding the disabled from their perspective.
—Anita Silvers[1]

The concept of ‘disability’ is notoriously difficult to define. There is little, if any, widespread consensus among even otherwise like-minded disability theorists.[2] Nancy Eisland explains the difficulty as follows:

> The differences among persons with disabilities are often so profound that few areas of commonality exist. For instance, deafness, paralysis, multiple sclerosis, and mental retardation [sic] may produce the same social problems of stigma, marginality, and discrimination, but they generate vastly different functional difficulties. Further, people with the same disability may differ significantly in the extent of their impairment. The level of impairment for a person with dyslexia may be dramatically dissimilar to that of a person with severe mental retardation [sic], though they can both be identified as having learning [or intellectual] disabilities. Finally, disabilities can be either static or progressive, congenital or acquired. The social experience of a person who becomes disabled as an adult may differ significantly from that of a person with a congenital disability. These dissimilarities make a broad definition of people with disabilities difficult, if not impossible.[3]

Along the same lines, Fiona Campbell argues that ‘disability’ is a catachresis. For Campbell, disability is not catachrestic because it is denoting the *wrong* thing, as the

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[1] Anita Silvers, "Reconciling Equality to Difference: Caring (F)or Justice for People with Disabilities," *Hypatia* 10, no. 1 (1995): 37.

[2] One could go so far as to say that it is hard to find an explanation of various definitions or models of disability that does not begin with saying how hard or impossible it is to do so. See, e.g., Steven D. Edwards, *Disability: Definitions, Value and Identity* (Oxford: Radcliffe, 2005). To be clear, I would not recommend Edward’s work on disability. Although written in 2005, he does not engage the theoretical frameworks upon which disability studies has emerged over the last three to four decades. E.g., Edwards treats the “UPIAS” model as its own category instead of as one species of the social model, and, furthermore, his analysis does not engage a number of central figures working on disability in the 80s and 90s. To take another glaring example, he speaks of “deafness” as a lack, ignoring the substantial literature on Deaf culture. I am not alone in assessing Edwards’ research and expertise to be wanting. He himself begins a 2007 review of Shelley Tremain’s edited volume, *Foucault and the Government of Disability*, by admitting “I am relatively unfamiliar with the work of Foucault, and of disability theory.”

[3] Nancy L. Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville: Abingdon Press, 1994), 23-24.

prefix *kata* normally indicates, but because it simply has no denotational referent at all. Campbell further explains, “there is no literal referent for this concept. As soon as we discursively interrogate ‘disability’, its meaning loses fixity and generality, and ultimately collapses.”[1] This is not merely to say that disability is not a natural kind. It is that disability can upend the question of the “natural” itself. “One of the problems of operating within the duality of ‘abled’ and ‘disabled,’” she writes elsewhere, “is that the boundaries between both signifiers interpenetrate. For example, the rise of new perfecting technologies not only reinscribes ‘disability’ but also reinscribes ‘normalcy’—that which is species-typical.”[2] This is, in other words, not just a general point about the nominalism of the concept of disability. Campbell is gesturing towards the way in which ‘disability’ names anything that falls outside ableist norms. Does this mean that the concept of “disability” is either too incoherent, vague, or expansive to have analytic value?

It goes without saying that ableist norms change significantly across history and between cultures. But they are more than variable. From melanin levels to the tilt of a spine to the length of a femur to hemoglobin count to the pace and timber of pronunciation, ableist norms can range over *anything and everything*. The list is endless and endless in principle. As Lennard Davis puts it:

> It is hard if not impossible to make the case that the actual category of disability really has internal coherence. It includes, according to the Americans with Disabilities Act of 1990, conditions like obesity, attention deficit disorder, diabetes, back pain, carpal tunnel syndrome, severe facial scarring, chronic fatigue syndrome, skin conditions, and hundreds of other conditions. Further, the law specifies that if one is “regarded” as having these impairments, one is part of the protected class.[3]

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[1] Fiona Kumari Campbell, “Legislating Disability” in Tremain, 127, fn. 1. This argument is repeated in her earlier piece: Campbell, "Inciting Legal Fictions," 43, fn. 1.

[2] "Inciting Legal Fictions," 58.

[3] Lennard J. Davis, *The Disability Studies Reader*, 4th ed. (New York: Routledge, 2013), 271.

That act, even in its originating and more narrow 1990 form, gave rights to the US's *largest* minority.[1] Tellingly, one of the primary issues taken up in the ADA Amendments Act of 2008 was in fact a *broadening* of the legal definition of "disability."[2]

In large part, disability activists achieved this milestone by utilizing the social model of disability to change public perception of disability from a question of individual's bodies to a socially-oppressed minority group. They were able to achieve this *despite* the heterogeneity of forms and meanings of disability. They were able to achieve this despite the fact that with increasing technological capacities, the identity of this minority can shift (and has shifted) at an unparalleled pace and in a manner that, arguably, other minority identities do not.

Rosemarie Garland-Thomson illuminates the increasingly complicated techo-historical aspects of disability as follows:

> Our present moment of late modernity increasingly creates large populations of people with disabilities through institutions such as modern warfare, environmental degradation, consumerist reproduction, socioeconomic oppression, medical treatment, and social expectations which disable people in their fulfillment. (Just a few examples of disability growth areas are diagnostic categories such as carpal tunnel syndrome, depression, anxiety disorders, anorexia, cancers, attention deficit disorder, autoimmune disease, spinal cord injuries, autistic spectrum disability, and dementia.) Whole categories of disability and populations of disabled people have also vanished or diminished significantly in late modernity. All manner of the orthopedically and sensorily disabled populations along with consumptives, polios, those with the appearance impairments of a smallpox survivor, and increasingly, people with Down syndrome are waning populations.[3]

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[1] *Enabling Acts: The Hidden Story of How the Americans with Disabilities Act Gave the Largest Us Minority Its Rights* (Boston: Beacon Press, 2015).

[2] The Senate and House of Representatives of the United States and of America in Congress, "Ada Amendments Act of 2008," (http://www.eeoc.gov/laws/statutes/adaaa.cfm). It is important to keep in mind that the ADA came on the heels, historically speaking, of Section 504 of the Rehabilitation Act of 1973. The latter was not enforced until 1977, after widespread demonstrations on capital hill by people living with disabilities. See "The Power of 504 (open caption) part 1," https://www.youtube.com/watch?v=HMC5UuiIQkI. The lead-up to the enactment of the ADA was supported by massive demonstrations as well: see, e.g., "Capitol Crawl c PBS Independent Lens," https://www.youtube.com/watch?v=ueQ0TfVGxU4.

[3] Rosemarie Garland-Thomson, "Disability Gain", unpublished manuscript, 2013.

To borrow a term from Eduardo Mendieta, disability requires that we think the *technosomaticity* of history, the way technology and bodies mutually shape each other.[1] One cannot think "dis/ability" without technology, for one of the primary ends of modern technology is mastery over the body, or, more precisely, mastery over the art of altering the body. When technology changes, so do the experiences and categorizations of disability.

All this being said, I disagree that disability has "no literal referent." I would argue that "disability" indeed names a coherent set of phenomena: the experience(s) of being non-normate. Rosemarie Garland-Thompson defines the "normate" as the ideological figure carved out from the plethora of non-normative bodily variabilities, variabilities which it need not consider and yet which constitute it by providing, through relief, its shape.[2] As she puts it, the "normate" picks out

> The veiled subject position of the cultural self, the figure outlined by the array of deviant others whose marked bodies shore up the normate's boundaries. The term *normate* usefully designates the social figure through which people can represent themselves as definitive human beings. Normate, then, is the constructed identity of those who, by way of the bodily configurations and cultural capital they assume, can step into apposition of authority and wield the power it grants them.

If disability, as I am provisionally defining it here, means "the experience of being non-normate," then this includes the question of "regard" and the other's gaze noted by Davis, for social factors always contribute to the creation and maintenance of the normate in any given socio-historical context.

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[1] Eduardo Mendieta, "Mitchell, Andrew 2010 Heidegger among the Sculptors, Reviewed by Eduardo Mendieta," *Society and Space* (2012), http://societyandspace.com/reviews/reviews-archive/andrew-mitchell-heidegger-among-the-sculptors-reviewed-by-eduardo-mendieta/.

[2] Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997), 8.

The hesitancy to grant the ‘disability’ coherence stems from the fact that being normate or non-normate is constituted by a dazzling panoply of intersections: history, technology, religion, law, medicine, gender, race, sexuality, class, citizenship, politics, science, culture, policy, evolution, indigeneity, architecture, economics, etc.[1] Because, as I will argue at length in the concluding chapter, ‘disability’ is a function of ability expectations relative to any given domain, *disability intersects with everything*. That is to say, disability intersects with all forms of identity and meaning-making. Disability is constitutive of human life.

For the purposes at hand, however, I will not mount a defense of the realism or nominalism of ‘disability.’ Instead, I will focus on its use. I will do because even if one is convinced that the concept of ‘disability’ is either so complex or vague as to be without analytical value, this does not therefore mean one cannot learn something by analyzing its deployment in practices of knowledge building and dissemination. Accordingly, I will focus on the ways disability functions in each of its three overarching theories, which I group as the individual, social, and post-social theories of disability.[2]

By the end of this chapter, I will be in a position to argue that the function of conceptualizations of disability for the experience of living with disability are to exteriorize in individual theories, politicize in social theories, and problematize in post-

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[1] Each of these intersections in turn contain mediating interstices; it is precisely the difficulty of sufficiently handling such macro-, micro-, and meso- issues that all research dedicated to intersectionality faces. I speak to this question below when I discuss the following article: H. Y. Choo and M. M. Ferree, "Practicing Intersectionality in Sociological Research: A Critical Analysis of Inclusions, Interactions, and Institutions in the Study of Inequalities," *Sociol. Theor.* 28, no. 2 (2010).

[2] Various authors have provided overviews of models of disability, but none as I do here. See Barbara M. Altman, “Disability Definitions, Models, Classification Schemes, and Applications” in Gary L. Albrecht, Katherine D. Seelman, and Michael Bury, *Handbook of Disability Studies* (Thousand Oaks, Calif.: Sage Publications, 2001). That piece, due to Government support, is in the public domain. See also the piece by Gareth Williams that immediately follows it in the same volume, entitled “Theorizing Disability.” See also David; Wasserman et al., "Disability: Definitions, Models, Experience," *The Stanford Encyclopedia of Philosophy* (2013), http://plato.stanford.edu/archives/fall2013/entries/disability/>.

social theories. That is to say, I will look to the effect these concepts have on the bearing and comportment of a life. I will further argue that both individual and post-social theories of disability fail in offering allostatic regulation, in giving one back to oneself. Unlike theories of pain, the production of "disability" forged through non-social theories is leveling or scattering, not enhancing, to the projects of a life.[1] To be clear, this is not to say that individual and post-social theories are without merit—it is merely to note the limitations of such theories, especially relative to questions of praxis

Notably, the theories of disability I discuss below are more heterogeneous than the models of pain presented in the first chapter. As I mentioned above, this is largely due to the fact that disability has not only become a political issue, but a political *identity* in the late twentieth century. It has become so in a way that pain has not (yet) for people living in chronic pain or for people living with chronic illness.[2] This chapter lays the groundwork for the fourth chapter, where I provide a phenomenology of disability through a person living with multiple sclerosis.

§3.1 Individualist Theories

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[1] Except, to repeat a central point from chapter two, in the case of chronic pain. Whether or not people living in chronic pain desire to identify as disabled (and there are political, medical, social, et al., reasons why such persons would choose or not choose to do so), the social ramifications of chronic pain place one squarely in the position of disability as understood in social models. It is worth noting that chronic pain and illness creates issues for dominant theories of pain *and* dominant theories of disability. I think this has something to do with the inherent tensions involved in the normativity of pain experience, and I will return to this issue in the conclusion of the dissertation.

[2] As an example, many texts that have been definitive for disability studies in the UK claim that disability-related political activism in the UK tends to emphasize structural oppression and neglect impairment, e.g., Torn Shakespeare and Nicholas Watson, "The Social Model of Disability: An Outdated Ideology?," in *Exploring Theories and Expanding Methodologies: Where We Are and Where We Need to Go*, Research in Social Science and Disability (Emerald Group Publishing Limited). Contrarily, chronic pain support and advocacy groups (CPSAGs) in the US tend to emphasize impairment and neglect structural oppression. See, e.g., the American Pain Foundation, American Chronic Pain Association, International Association for the Study of Pain, and the Pain Connection. I owe many thanks to fruitful discussions with Florian Kiuppis on this topic.

In what follows, I use the common terminology of disability studies with respect to the language of the "medical model" and "social model(s)" of disability, but I will group these as versions of broader individual, social, and post-social *theories*. To repeat from the explanation given at the beginning of chapter one, my use of the term "theory" is captured well by Thomas Nail's discussion of a "theory" of the border. "The purpose of a theory or concept of [a phenomenon] is not to explain or predict every detail of empirical [phenomena of that sort]; a theory…aims to describe the conditions or sets of relations under which" those phenomena occur (11). To this I would only add for the present purposes, a theory aims to describes the conditions or sets of relations under which a given phenomenon is experienced as *meaningful* or ought to be so experienced. My aim is to understand how each of them might shed light on the errors of the ableist conflation. I will now turn to the first and most historically dominant individual theory of disability: the moral theory of disability.

§3.1.1 Moral

As I commented when discussing the religious model of pain in chapter one, because I am working within the Western philosophical tradition, I here treat what I am calling the "moral theory" only with respect to the Abrahamic traditions: Judaism, Christianity, and Islam. At the outset, it is important to flag a historical terminological issue: arguably, no language or culture in antiquity (Israelite, Greek, Egyptian, or what have you) contains what we today in English call "disability." Some historians would extend this claim to medieval and modern times as well. In these cultures—and, with respect to historiography and anthropology, these *time periods*—one finds only a number of distinct terms with no overarching concept: blindness, muteness, lameness, paralysis, etc.

In the same way that Foucault claims, “man is an invention of recent date,” disability historians argue that ‘disability’ is an invention of (even more) recent date.[1] It is recent thanks to, among other things, the emergence of the anatomo-clinical gaze and the myriad programs of eugenics and population metrics in the long 19th century.[2] I will follow the lead of disability historians and risk anachronism by keeping the term.[3]

The Jewish Tanakh/Christian Old Testament seems, in certain passages, to present no ambiguity concerning disability.[4] Take Exodus 4:11 as an example: “then the Lord said to him, ‘Who has made man's mouth? Who makes him mute [אִלֵּם], or deaf [חֵרֵשׁ], or seeing, or blind [עִוֵּר]? Is it not I, the Lord?’”[5] The logic here is simple: if God is creator, then *all creations* are purposive. While implicit in the latter verse, the idea that people who are “mute”, “deaf”, or “blind” are at a *disadvantage* is addressed explicitly in other passages. Leviticus 19:14 reads, “you shall not curse the deaf [חֵרֵשׁ] or put a stumbling block before the blind [עִוֵּר], but you shall fear your God: I am the Lord.” Deuteronomy 7:18 provides another example, “Cursed be anyone who misleads a blind

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[1] Michel Foucault, *The Order of Things: An Archaeology of the Human Sciences* (New York: Vintage Books, 1973), 387.

[2] *Birth of the Clinic*.

[3] Martha L. Rose, *The Staff of Oedipus: Transforming Disability in Ancient Greece* (Ann Arbor: University of Michigan Press, 2003); Irina Metzler, *A Social History of Disability in the Middle Ages: Cultural Considerations of Physical Impairment*, Routledge Studies in Cultural History (New York, NY: Routledge, Taylor & Francis Group, 2013).

[4] There is a substantial literature within and on the periphery of disability studies that argues for alternate understandings of disability with various theological frameworks. I leave to the side the theological openings scriptural texts may indeed offer through liberatory or other such approaches.

[5] Each of these terms is used in ancient Hebrew both literally and figuratively. Being without sight [עִוֵּר] is being without intelligence, as we also say in modern English. As an aside, it is worth asking whether or not Moses is presented as having a speech “disorder” in the previous verse, when he says to God, “I am slow of speech and slow of tongue.” His dysfluency is further contrasted with that of his brother Aarons’ a few verses later in 4:14. On the treatment of “speech disorders” and disability, see Christopher Eagle, *Literature, Speech Disorders, and Disability: Talking Normal*, Routledge Interdisciplinary Perspectives on Literature (New York: Routledge, 2014).

[עִוֵּר] man on the road." The purposiveness of creation is affirmed at the same time that the social disadvantage of certain forms of creation are protected against.

That is to say, the assumption that disability might lead people to treat others poorly is conjoined with the affirmation that disability is natural and purposeful. Indeed, the primary defense against the expected mistreatment of disability is an appeal to a theological teleology. While this balance between human discrimination or oppression and divine creation might seem understandable under this teleology, when questions of social hierarchy and privilege come into play, disability can become a marker of exclusion *by God's own standards*. Leviticus 21:17-23 reads:

> No one of your offspring throughout their generations who has a blemish [מום] may approach to offer the food of his God. For no one who has a blemish shall draw near, a man blind or lame, or one who has a mutilated face or a limb too long, or one who has a broken foot or a broken hand, or a hunchback, or a dwarf, or a man with a blemish in his eyes or an itching disease or scabs or crushed testicles. No descendant of Aaron the priest who has a blemish shall come near to offer the Lord's offerings by fire; since he has a blemish, he shall not come near to offer the food of his God. He may eat the food of his God, of the most holy as well as of the holy. But he shall not come near the curtain or approach the altar, because he has a blemish, that he may not profane my sanctuaries; for I am the Lord; I sanctify them.[1]

Here, disability allows one to partake in sustenance, in the maintenance of one's existence, but it categorically prevents one from some forms of connection with the divine. The Hebraic (pre-Israelite) treatment of disability appears mild in comparison to an Attic Greek context, in which disability commonly warrants infanticide or 'exposure' [ἐκτίθημι].[2] In either case, while God or the gods decide the ultimate 'fate' of the person born or living with a disability, that life is *outside* the established moral universe. That is to say, disability marks a life as normatively *exterior*. Exterior to the point that divinity, on the hand, intervenes with maxims in order to compensate for the expectation of

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[1] The meaning of blemish [מום] is understood as a stain, as a mark, that is either physical or moral. Strong.

[2] Rose. See also Mark Golden, "Demography and the Exposure of Girls at Athens," *Phoenix* 35, no. 4 (1981).

unethical treatment and, on the other hand, divinity sets up its own limits as to level of intimacy it is willing to truck with people with disabilities—to the point that they should not approach the altar.

In the Christian New Testament, there are some notable differences. After the reference to the ancient commonplace that disability was due to sin, John 9:2-3 recounts, Jesus' "disciples asked him, 'Rabbi, who sinned, this man or his parents, that he was born blind?' Jesus answered, 'It was not that this man sinned, or his parents, but that the works of God might be displayed in him." After this comment, however, Jesus takes actions that lead to the blind man's healing. Here, the display of God's "works" is presumably in the *making able* of the disabled man, even though Jesus decouples his sin from personal or generational congenital disability.[1] Jesus heals the man despite or regardless of the fact that no sin brought about his disability, and yet, Jesus' act of making him "able" is a sign of God's *power*.

This understanding is complicated, however, by the emphasis Jesus places on the "disenfranchised." Take as an example Luke 14:12-14: "He said also to the man who had invited him, 'When you give a dinner or a banquet, do not invite your friends or your brothers or your relatives or rich neighbors, lest they also invite you in return and you be repaid. But when you give a feast, invite the poor, the crippled, the lame, the blind [κάλει πτωχούς, ἀναπείρους, χωλούς, τυφλούς]."[2] The emphasis on such people is a mainstay of

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[1] David T. Mitchell & Sharon L. Snyder. "'Jesus Thrown Everything Off Balance:' Disability Studies and Contemporary Biblical Exegesis," in H. Avalos, S. Melcher, J. Schipper, S. Studies (eds.). *This Abled Body: Rethinking Disability and Biblical Studies.*Atlanta: Society of Biblical Literature, 2007: 173-183.

[2] The world for "poor" is *ptochos*, literally "bent over," and is typically used to refer to one completely lacking resources. "Crippled" renders *anapeirous*, with -ana intensifying *peros*, which means 'maimed' or "lame." This term can also be used figuratively (Aristotle speaks of those "*peperomenos pros areten*," those incapacitated or unable to reach virtue). "Lame" translates *cholos*, which is literally "halted," dating back to Homeric usage, and "blind" translates *tuphlos*, literally "without sight," but it has both a literal and figurative meaning as with the Hebrew. Strong. See also Mark 7:32-36: "And they brought to him a man

the reported accounts of Jesus, yet it is crucial to recognize that disability does not function in an analogous way to the other categories, e.g., groupings arranged around class or job function, such as sex workers (Lk. 7:36-50) or financial workers (Lk. 19:1-10). How, then, does it function?

Disability, by virtue of being outside of ableist norms, is taken up as a vehicle for displays of divine power. Jesus does not perform work via touch or speech on tax collectors or sex workers in the same manner as he does on those with disabilities. Disability alone holds the position of the category of creation Jesus *re*-creates.[1] Disability serves divine power solely through its *repair*, solely through becoming non-disability.

An even clearer example of the role disability plays in the gospels appears in Mark 2:1-12:

> When he returned to Capernaum after some days, it was reported that he was at home. So many gathered around that there was no longer room for them, not even in front of the door; and he was speaking the word to them. Then some people came, bringing to him a paralyzed man [παραλυτικός], carried by four of them. And when they could not bring him to Jesus because of the crowd, they removed the roof above him; and after having dug through it, they let down the mat on which the paralytic lay. When Jesus saw their faith, he said to the paralytic, "Son, your sins are forgiven." Now some of the scribes were sitting there, questioning in their hearts, "Why does this fellow speak in this way? It is blasphemy! Who can forgive sins but God alone?" At once Jesus perceived in his spirit that they were discussing these questions among themselves; and he said to them, "Why do you raise such questions in your hearts? Which is easier, to say to the paralytic, 'Your sins are forgiven,' or to say, 'Stand up and take your mat and walk'? But so that you may know that the Son of Man has authority on earth to forgive sins"—he said to the paralytic— "I say to you, stand up, take your mat and go to your home." And he stood

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who was deaf and had a speech impediment, and they begged him to lay his hand on him. And taking him aside from the crowd privately, he put his fingers into his ears, and after spitting touched his tongue. And looking up to heaven, he sighed and said to him, '*Ephphatha*,' that is, 'Be opened.' And his ears were opened, his tongue was released, and he spoke plainly. And Jesus charged them to tell no one. But the more he charged them, the more zealously they proclaimed it." Although a crucial point on many levels, the tension between the Jesus who is portrayed as seeking to loudly proclaim his powers in John and the Jesus who often wishes to hide those powers in Mark cannot be addressed here.

[1] Still, unlike the emphasis on purity in Leviticus (which has no normative content save for the priestly class), Jesus continues to split questions of purity from disability, amidst the fact that the "making able" of the disabled is nevertheless a show of power.

> up, and immediately took the mat and went out before all of them; so that they were all amazed and glorified God, saying, “We have never seen anything like this!”[1]

Jesus here leverages the play between disability-as-sin and disability-as-physicality. He mocks those for whom disability is understood as a price one pays for a wrong, as is the case for moral rationales of experiencing pain. His mockery of this idea is so intense that the physical-material *transformation* of the person with the disability is meant to be the punch-line of such an idea’s absurdity. It is as if he were to say, “You say this is a question of divine ‘sin’? Well, watch me overturn the presumed material manifestation of that with just a few words.”[2]

In many ways, the Koran treats disability similarly to the Jewish Tanakh and the Christian New Testament. Verse 80:1 reads

> He frowned and turned his back when the blind man [اسم مرفوع] came towards him. How could you tell? He might have sought to purify himself. He might have been forewarned, and might have profited from Our warnings. But to the wealthy man you were all attention: although the fault would not be yours if he remained uncleansed.[3]

The Prophet Muhammad turns his back on a blind man, and the text of the Koran calls the Prophet into question for this and asks how the Prophet could tell that turning his back would be justified. The assumption is that there *could be* a reason for which the prophet’s shunning of the blind man might be warranted. Instead, the text suggests that the Prophet could not know if this shunning was warranted *in the case that* the blind man

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[1] See Matthew 11:4-5 and 15:31.

[2] To be clear, the act of “healing” is not straightforward here. This could be read as a testament to the social model of disability: the “paralytic” is paralyzed by society, by the understanding that their paralysis is a product of their sin (or the sin of their family, etc.). When Jesus supports this person by disentangling the question of sin from their impairment, when Jesus makes their “disability” a question of societal norms and not intrinsic impairments, they are then able to walk. This narrative scene functions as a powerful metaphor of the way in which given social representations determines the *ability* of the people in that society, in that *polis*. To sufficiently address this, I would have to broach the connection of *logos* with power (*kratos*) and being (*ontos*) in the Christian New Testament, specifically in the gospel of John, a task impossible here.

[3] *The Koran*, 481. That disability would qualify as an exteriorizing category is also shown in verse 48:17, where while speaking of fighting for the cause of Allah, the “blind, the lame, and the sick” are allowed to stay behind.

might be saved, might be cleansed. The only reason to not shun the blind man is if one saves him in not doing so.[1]

It is important to note that in some religions, certain disabilities mark one as chosen or elected. For example, Suzanne Bost notes,

> In his study of Mesoamerican corporeal ideology, Alfredo Lopez Austin claims that "physical defects were considered signs identifying men as individuals with supernatural powers," because people who were chosen by the gods were often marked in some visible way. It was believed by the Aztecs and the Maya—and, to a degree, by many of their descendants today—that illness was a sign of disequilibrium between man and the elements of the universe.[2]

What ties together the contradictory pairs of disability as a marker of disfavor (due to sin) or as a marker of favor (due to selection) is that disability serves to demarcate the extremes of religious singularization—that by which one knows how one is related to the divine order. On the one hand, it marks the extreme of transgression, of a separation brought on by oneself or one's generational family that then takes a psycho-somal toll on the transgressor or the descendants of the transgressor. On the other hand, it marks the extreme of perfection, of a selection by the religious order that takes a psycho-somal toll on the selectee as a price for selection.

The primary disanalogy is clear: in one case, it is the fault of either the individual or the group for whom the individual is now a representative—one's family genealogy, one's past lives in reincarnational accounts, or actions in one's current life. In the other, although it can be due to actions of one's own, it can also be due to the capriciousness of

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[1] Maysaa S. Bazna and Tarek A. Hatab have argued that the Koran provides an understanding of disability that downplays individual impairments and instead valorizes "the degree with which" one seeks "the truth." Maysaa S. Bazna and Tarek A. Hatab, "Disability in the Qur'an," *Journal of Religion, Disability & Health* 9, no. 1 (2005): 13. They interpret the verse quoted above as communicating that "people with disabilities are to be treated with full regard to have the same subject-to-subject relations that are granted to the non-disabled." I simply cannot find any evidence in the text to support their claim.

[2] Cynthia Lewiecki-Wilson and Jen Cellio, *Disability and Mothering: Liminal Spaces of Embodied Knowledge*, 1st ed., Critical Perspectives on Disability (Syracuse, N.Y.: Syracuse University Press, 2011), 174.

the religious order, as with the case of Job. In the latter case, one does nothing negative to deserve one's selection, though that does not therefore mean that one is not responsible to act upon or even be thankful for that selection. In either case, it is a price one pays. In either case, disability functions to singularize an individual as at the limit or exterior to the dominant ontonormative order through either capricious or retributive divine power. Whether through sin or selection, it marks an ontonormative exteriorization of the individual. Whether ignored or fixed, whether defended as a purposeful creation or transformed into a new creation, the result of moral theory of disability is to stigmatize a life.

§3.1.2 Medical

The medical theory of disability is, arguably, the most prevalent theory of disability across the globe today.[1] This theory conceptualizes disability as an individual tragedy or misfortune due to genetic or environmental insult. Accordingly, disability is understood in the medical model as a pathology in that term's etymological sense: it gives an account of an experienced suffering. In a 2015 article in National Geographic, entitled "Surgeon Reveals Head Transplant Plan, But Patient Steals the Show," reporter Erika Engelhaupt follows the most common, misinformed, and pathetic disability tropes supported by the medical model: Look at the poor disabled person who wishes to be abled-bodied. Technology can/will/should/could fix them.[2] Within just the first few sentences, we find out that Valery Spiridonov, the proposed patient for the first head

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[1] As will become crucial in the following section on the social theories of disability, the separation from the medical theory of disability was decisive for early sociological research on disability, especially in the 1940s-60s, including Irving Goffman's influential *Stigma*. One should also reference the extremely influential edited collection by Paul Hunt, *Stigma: The Experience of Disability* (London, Dublin etc.: G. Chapman, 1966).

[2] Erika Engelhaupt, "Surgeon Reveals Head Transplant Plan, but Patient Steals the Show," *National Geographic* (2015), http://phenomena.nationalgeographic.com/2015/06/12/surgeon-reveals-head-transplant-plan-but-patient-steals-the-show/.

transplant, is “impossibly small,” held to a “motorized wheelchair,” and that his feet “dangle.” None of which, incidentally, is ever described by Spiridonov himself as being relevant to his reported desire to undergo the surgery.

The surgeon who propositioned the plan for the first head transplant, Sergio Canavero, promoted the talk for months. When Canavero is peppered with skeptical questions, he deflects the potential harms of the surgery by appealing to its potential ameliorative effects. He asks Spiridonov directly, “don’t you agree that your [current] condition could drive you to madness?” Engelhaupt reports, “Spiridonov answered quietly in the affirmative.” Like Jesus's engagement with people with disabilities—where typically, as I argued above, a random person with a disability acts as a token and foil for the real show: God’s power—Spiridonov is displayed and exploited by Canavero as token of (potential) medical power to improve bodies, even if improvement means discarding one’s body almost entirely.

The article conceptualizes disability as a tragic, individual problem only "solved" by medicine and technology. There is no discussion of the support services in Russia or the politics of being disabled there. Are there curb cuts where Spiridonov lives, so that he can lead a social life? Does he have proper medical care and support, whether in-home or out of home? What level of stigmatization do people with disabilities such as his experience in the socio-cultural-political context in which he lives? Does he have enough money to flourish inside of a capitalistic labor economy that likely does not value people with disabilities? Is he paid the same as an able-bodied person or paid at all? How does the Russian government treat people with disabilities? Is his wheelchair the right one for his needs? What access does he have to novel technologies that will enrich his life, rather than solely rehabilitative ones designed to “fix” his body?

As reported in the article, the explanation of his condition is curiously vague: “His condition is grave: a degenerative motor neuron disease that is slowly killing him.” Globally and locally, there are names for such things, and the fact that the name of this “degenerative motor neuron disease” is omitted should already raise suspicion. MS is one such type of disease, and in most cases, it is simply false that MS will “slowly kill a person” even in its degenerative forms, even though people, including naïve and irresponsible reporters, routinely present it that way. As I discuss in chapter four below, S. Kay Toombs talks about this at length in her phenomenological work on MS. The MS society she visited after her diagnosis made it seem like she'd be dead in ten years—and they were supposed to be the “supportive” ones! She was diagnosed in 1973 and is today an emeritus professor at Baylor University.

Canavaro relies on a variation of the “I’d rather be dead than disabled” trope by implying that Spiridonov would rather be dead than “mad.” The question that Canavaro baitedly asks him, “Don’t you agree that your [current] condition could drive you to madness?” functions on precisely that assumption. Furthermore, while we are not given Spiridonov’s age, the actual conditions of his life such that his condition could reliably be thought to drive him to “madness” (whatever that means) is left without any support. Tellingly, there is no mention of even an attempt to interview Spiridonov. The first-person experiences of the issues at stake are completely ignored by the reporter or allowed to be co-opted by Canavaro.

We do get a quote from Spiridonov's hosts in Annapolis, who, we are told, are friends of a friend of the Spiridonov family (how and why they are his hosts is also not reported). "'He's brilliant, he's happy, he's funny,' said Briana Alessi. 'If this surgery were to go through and if it works, it's going to give him a life. It's life-changing. He'll be able to do the things he could only dream of.'" The quote is strangely contradictory, yet the reporter doesn't address the questions it raises at all. If he is happy, then why would he want such a surgery? In what way does he conceive that replacing his body will increase his happiness? How does this conception relate to the mutable social conditions of his life as opposed to the "intrinsic" characteristics of his impairment? How, if at all, have those around Spiridonov worked to mitigate those corporeally intrinsic issues? The ethical questions about a head-transplant procedure are enormous, and judgments concerning it are, on the whole, negative, even drawing the ire of bioethicists as influential as Art Caplan.[1]

If we already have trouble transplanting organs like livers and kidneys and have to put patients on massive amounts of immunosuppressants, why would anyone think a body-head transplant will be accepted by the human body's immune system? There is also the phenomenological/cognitive neuroscientific research on phantom limbs and body integrity identity disorder that suggests that when the brain has a body map that doesn't actually match the body, it indeed can drive people "mad": the very thing Canavaro is supposedly trying to avoid for Spiridonov's future. That is to say, it can do so to the point where they report an enormous amount of existential suffering.

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[1] See, e.g., Arthur Caplan's piece in Forbes, "Doctor Seeking To Perform Head Transplant Is Out Of His Mind," http://www.forbes.com/sites/arthurcaplan/2015/02/26/doctor-seeking-to-perform-head-transplant-is-out-of-his-mind/.

It takes little reflection to judge Canavaro's project as both medically and ethically asinine. Assuming it were to happen, counterfactual questions further clarify its misguidedness. How many people could be helped with basic needs or access to resources with all of the money slated to be spent on this? Wouldn't that money be more ethically spent on integrated, independent living communities for people with degenerative motor neuron diseases? Despite the vulgarity of the Canavaro example, I find that the philosophical issue lies primarily in the question of the *location* of disability: it is "in" Spiridonov's body. With respect to the medical theory of disability, disability is not simply locatable, but locatable in a body via signs or symptoms. Thus, I will turn to a discussion of symptomatology.

With the shift from the humoral theory of Hippocrates and Galen to germ theory with Louis Pasteur's discoveries in the 1860s, symptomatology took a decisive turn inwards. This led from explanatory schemas such as nutritional disease (disease is produced not by microbes, but a deficient nutrient) and autoimmune disease (disease is produced by the immune system attacking bodily tissue instead of infectious agents) to molecular genetic disease (disease is produced by the abnormal functioning of the patient's DNA) and Mendelian disease (disease is produced by the inheritance of a recessive mutated gene from both parents).[1] Amidst these revolutionary shifts in the understanding of the foundations of *pathologies* came not only the ability to explain various diseases in terms of scientific etiology, but any physio-psychognomic difference, for "disease" is itself a category that relies upon the distinction of "normal/abnormal."[2] Corporeal difference itself became subject to pathologization.

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[1] Paul Thagard, *How Scientists Explain Disease* (Princeton, N.J.: Princeton University Press, 1999), 20-36.

[2] Georges Canguilhem, *On the Normal and the Pathological*, Studies in the History of Modern Science

When I say "any physio-psychognomic difference," I mean any specific difference relative to an established norm in a human organism: from non-phenotypical limb formation to atypical speech patterns to atypical learning patterns. The *typos* is that by which a given difference is pathologized, and any difference is potentially subject to such pathologization because there is nothing the "anatomo-clinical gaze" cannot incorporate.[1] *In-corporate*: this should be read literally, for the medical model situates disability *inside* bodies.[2]

Yet, saying that corporeal difference itself became subject to pathologization in individual bodies is still too broad. The underlying logic of medical diagnosis as a form of knowledge production is based upon semiotics: symptoms are understood as *signs*, as *σημεῖον*, that refer to physical or psychological causes. Thus, diagnosis necessarily relies upon semiosis, that is, it relies upon the process whereby something functions as a sign or, in short, the action of signs.[3] Diagnostic pathology relies upon the semiotic structure of symptomatology, *the accounting for misfortunes in the service of correcting them*.

Eugen Baer notes in "The Medical Symptom" that one must "be taken beyond Hippocrates back to an era of mythical consciousness" to find the medical symptom in its first abode:

> In narrative systems of ontological equivalences and proportions which crossed the now separated realms of biology, sociology, and psychology. The symptom 'stood' for the whole order of world experience, it evoked the sum total of human relations, it individuated the universe and its religious depth in one concrete existential sign of the

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(Dordrecht, Holland; Boston: D. Reidel Pub. Co, 1978).

[1] Foucault, *Birth of the Clinic*.

[2] Both in holistic medicine and in areas such as epigenetics, the environmental aspects of pathology play a greater role. Yet, on the whole, clinical practice still understands disability to be located inside bodies, even if it in some cases it might understand the specific etiology of a given "disability" to have been constituted in part or even continually shaped by environmental factors.

[3] See "semiosis, n.", "semiotic, adj. and n.", and "sign, n."—whose oldest etymological roots trace back to the ancient Greek σῆμα, sign (see seme n.), and σημεῖον, sign—in OED.

> body: it was, in short, *the* concrete universal.[1]

In harmony with this pluridimensional understanding of the medical symptom, Baer defines the medical symptom as “any sign which coveys to a perceiver that something is fine or wrong with the sender’s existence…Because of its crisis-provoking character…the symptom is a privileged mode of human experience.”[2]

In other words, the symptom is a symbol (συμβάλλω—*symballo*: lit. “to throw-with”), a literal throwing together, of an encounter of an organism with its environing world. While one could conceivably have a positive symptom (warm appendages could be a “symptom” of proper circulation), this would be a modification on the original sense of symptom as the happening of a fall as a misfortune.[3] Taken in its original etymological sense, the symptom only throws together human and world in the event of misfortune.

Baer calls the medical symptom “*the* concrete universal” because it, more fundamentally than any other symbol, announces the situation and thus situatedness of a life. It is the “sign” par excellence because it is both a sign that occurs universally and a sign whose referent is necessarily concrete. Yet, leaving the symptom defined as a simple ‘misfortune’ is too indeterminate, for do we not respond to various misfortunes with a wide range of affective scripts, from pity to hostility to indifference to fear? How does the medical theory of disability function in situations that are not explicitly medical? The answer is already found in the understanding of a symptom in terms of misfortune: disability as *tragedy*.

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[1] Eugen Baer, “The Medical Symptom,” John N. Deely, Brooke Williams, and Felicia Kruse, *Frontiers in Semiotics*, Advances in Semiotics (Bloomington: Indiana University Press, 1986), 140-41. See also, Eugen Baer, *Medical Semiotics*, Sources in Semiotics (Lanham, MD: University Press of America, 1988).

[2] Deely, Williams, and Kruse, 143.

[3] σύν, ‘together’, combines with πίπτειν, ‘to fall’, which is related to πτῶμα as a ‘fall or misfortune’ and thereby to σύμπτωμα as a ‘chance, accident, mischance, or disease’OED.

The Supercrip: From Tragedy to Mastery

The moral and medical theories of disability could each be grouped as *tragic* theories of disability. In each case, disability names a misfortune, and typically a grave one, for an individual. The trope of the *supercrip* is a potent cultural artifact that arises from and displays the logic of the medico-tragic model. As Kelsey Borrowman explains,

> Disability tropes range from the eternally innocent (*Forrest Gump*) and the object of pity (Tiny Tim in *A Christmas Carol*) to the victim of life's inherent cruelty and violence (*The Ugly Duckling*) and the vengeful cripple (*Richard III*). Each trope offers a different emphasis on the presumptions surrounding disabled lives while simultaneously overlapping and invoking one another…*within each is the narrative of overcoming*…super-crip is the term for the disability stereotype that positions persons with disabilities as heroes, admired for their courage in the face of their obstacles. There are two distinguishable figures of the super-crip. More recently, we have seen the emergence of the Average Joe super-crip, who is special and inspirational simply for living a "normal" life despite having a disability, such as an autistic teenager who attended his high school prom.[1] The second…is the super-crip who achieves extra-ordinary things. Here, we have the image of the amputee athletes, such as paralympic long-jumper and single leg amputee Marlon Shirley and Olympic participant and double amputee Oscar Pistorius. The simultaneity of the two figures epitomizes the "paradoxical figure of the supercrip [as] products of either extremely low expectations (disability by definition means incompetence, so anything a disabled person does, no matter how mundane or banal, merits exaggerated praise) or extremely high expectations (disabled people must accomplish incredibly difficult, and therefore inspiring, tasks to be worthy of nondisabled attention)."[2] In the latter, more traditional and prolific sense, the super-crip stereotype forwards the link between disability and superior ability. That is, as a result of being "challenged" in one capacity, another capacity reaches beyond able-bodied abilities. This is the mythology…that a person who is blind has a superior capacity of hearing [such as Marvel Comics' Daredevil], where superior designates a more-than-normal—normal, again, meaning able-bodied."[3]

Insofar as disability is understood as a sign of something unfortunate in the medical theory, then in overcoming it, one is praised, revered. The supercrip is an inspiration. The

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[1] Borrowman's footnote: "Notably, this article valorizes the unbelievable gesture of kindness from the young girl, giving great focus to her rather than the teenage, who they infantilize, or even autism itself. They are quick to note the two are not romantically involved. 'In The Moment - Prom a Memorable Night for Teen with Autism - and His Parents.' Accessed January 5, 2014. http://www.jsonline.com/news/wisconsin/prom-a-memorable-night-for-teen-with-autism--and-his-parents-6p9psmq-206029261.html."

[2] Borrowman's footnote: Alison Kafer, *Feminist, Queer, Crip* (Bloomington, ID: Indiana University Press, 2013), 90.

[3] Kelsey Borrowman, "Nietzsche and Crip Theory," unpublished essay, 2014, my emphasis.

supercrip can then function as a form of “inspiration porn.”[1] On the flip side, in failing to overcome disability, one is looked upon with compassion and mercy, such as in Jerry Lewis’ MDA telethons. The supercrip is praised; the crip pitied. Precisely as a *misfortune*, the medical model of disability assumes that disability is located in an individual and experienced as tragic. It then goes one step further to find the cause of that misfortune in the hopes of rehabilitation, repair, cure, or, in some cases, palliation.

In conclusion, whether engendering pity towards the crip or praise towards the supercrip, the medical theory of disability conceptualizes disability as an individual tragedy or misfortune due to genetic or environmental insult. This misfortune always has an etiology that is in principle discoverable through symptomatology, whether via refined forms of diagnostic technologies, the careless gaze of a hurried PA, or the gawk of an insensitive stranger.[2] The result is that disability is marked as fundamentally and intrinsically unfortunate. On the medical model of disability, a person living with disabilities is fundamentally different from others by experiencing and being told to experience their embodiment as a problem. The function of the medical model, then, is to exteriorize the experiences of disability and posit medicine and medical technologies as the only hope to bring one back inside the “norm” of health, life, and flourishing.

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[1] Scott Jordan Harris, "Despicable Memes: How “Miracle” Jokes and Inspiration Porn Demean Disabled People.," *Slate*2014.

[2] “Rather, the overwhelming focus is on the disease process, on the manner in which the patient’s experience manifests itself in terms of ‘objective,’ quantitative clinical data.”[2] S. Kay Toombs, “Disability and the Self,” *Thomas M. Brinthaupt and Richard P. Lipka, Changing the Self: Philosophies, Techniques, and Experiences, Suny Series, Studying the Self (Albany: State University of New York Press, 1994), 349.* Toombs here cites Stetten, 1981: 458-460, and Rabin, 1982: 506-509. Alternatively, Arthur M. Kleinman, in the article “Medicine’s Symbolic Reality,” points to the socio-cultural-historical mediation *any* medicinal theory necessarily takes. “Comparative studies of medical systems,” he argues, “document that medicine, from an historical and cross-cultural perspective, is constituted as a cultural system in which symbolic meanings take an active part in disease formation, the classification and cognitive management of illness, and in therapy.” Arthur Kleinman, "Medicine's Symbolic Reality: On a Central Problem in the Philosophy of Medicine," *Inquiry* 16, no. 2 (1973): 206.

§3.2 Social Theories

> The marginalization of disabled people is due not to a lack of determination or hard work or courage but to pervasive and persistent economic, political, and social exclusions.
> —Alison Kafer[1]

Both with respect to its political and academic dimensions, the history of social theories of disability is complex and would require an analysis that far outstrips the aims of this chapter. Besides, significant research has already been done with this scope in mind.[2] As with the analysis of theories of pain, my aim here is ultimately meta-theoretic with the goal of seeing whether and how the assumptions of the ableist conflation obtain.

Paralleling, at least in some respects, the enormous practical and theoretical effects feminist theory achieved by demonstrating that gender is not reducible to sex and that gender inequality is a product of mutable social norms and histories of sexism, disability theory has made significant gains for people with disabilities by demonstrating that disability is not reducible to impairment and that (dis)ability inequality is by and large a product of mutable social norms and histories of ableism. The most obvious gain, in the context of the USA, is the landmark passage of the Americans with Disabilities Act in 1995, an act that created the largest legally-protected minority identity in the country's history. However, there is still much to be done. Indeed, the central claim of this dissertation is that the ableist conflation continues to undermine and actively work against the power of the social theory. Although I will be critical of aspects of the social theories of disability, I view those criticisms as building upon and expanding it. I will first discuss what is referred to as "*the* social model" of disability in terms of its political

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[1] Kafer, 93.

[2] E.g., see Tom Shakespeare, *Disability Rights and Wrongs Revisited*, Second edition. ed. (London; New York: Routledge, 2014).

roots before turning to its legal and academic ramifications. I then discuss Tom Shakespeare's interactionist version of the social model.

§3.2.1 The Social Model

> The marginalization of disabled people is due not to a lack of determination or hard work or courage but to pervasive and persistent economic, political, and social exclusions.
> —Alison Kafer[1]

The political/activist history of the social model of disability is typically said to begin with the activism of Union of the Physically Impaired Against Segregation (UPIAS) in the United Kingdom, established in 1972 by Paul Hunt. UPIAS's version of the social model is called as the "strong social model" by some in DS communities, both because of an almost ideological emphasis on the social conditions of disablement and also because of its ties to Marxism. I can broach neither that history, nor the notable variations of the social model in other countries, including the particular US transformation of the model into a "minority identity" modeled on the successes of the civil rights movements.[2]

I will argue that each instantiation of the social model shares a similar domain, function, power, and result. It is the unity of various social models that account for "*the* social model's" success. Each social model ultimately operates within the *domain* of nomology, of the establishment of laws, insofar as these models provide a theoretical foundation for litigation: social inequality is the *reason* people with disabilities experience unjust treatment and unequal access to social goods.

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[1] Kafer, 93.

[2] Part of this story would focus on the role of Ed Roberts at UC Berkeley, the first student to attend with "severe" physical disabilities and one of the pioneering leaders of the disability rights and the independent living movement in the United States of America. In 1972, Ed Roberts founded the first Center for Independent Living in the USA. Kim E. Nielsen, *A Disability History of the United States*, Revisioning American History (Boston: Beacon Press, 2012).

That is to say, by taking disability out of the medical model, a person with disabilities is understood as oppressed due primarily to social structures. Thereby, liberalist goals such as equality and justice apply to the rectification of that oppression. Each social model thus *functions* to politicize people with disabilities in the hope of social change against that oppression. The socio-legal model’s *power* is political: as a socially oppressed individual, the polis is taken to be the space in which one’s resistance against oppression is staged. In the end, the *result* of the social model is to valorize disability as a political identity.

Although implicit in Erving Goffman’s 1963 *Stimga,* one of the first influential academic formulations of the “social model” of disability is Saad Nagi’s 1965 paper, “Some Conceptual Issues in Disability and Rehabilitation.”[1] Nagi’s theory of disability distinguishes between **impairment** as a physiological process or processes, **functional limitation** as limitation with respect to the completion of tasks and the carrying out of obligations within social roles, and **disability**

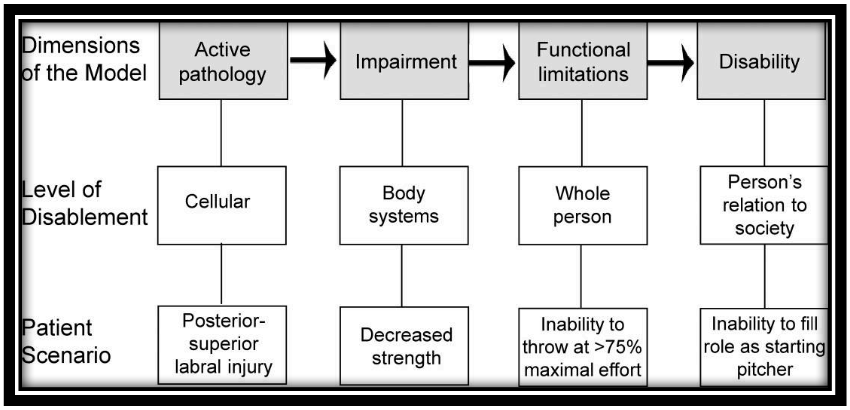

Figure 1: Nagi Disablement Theory

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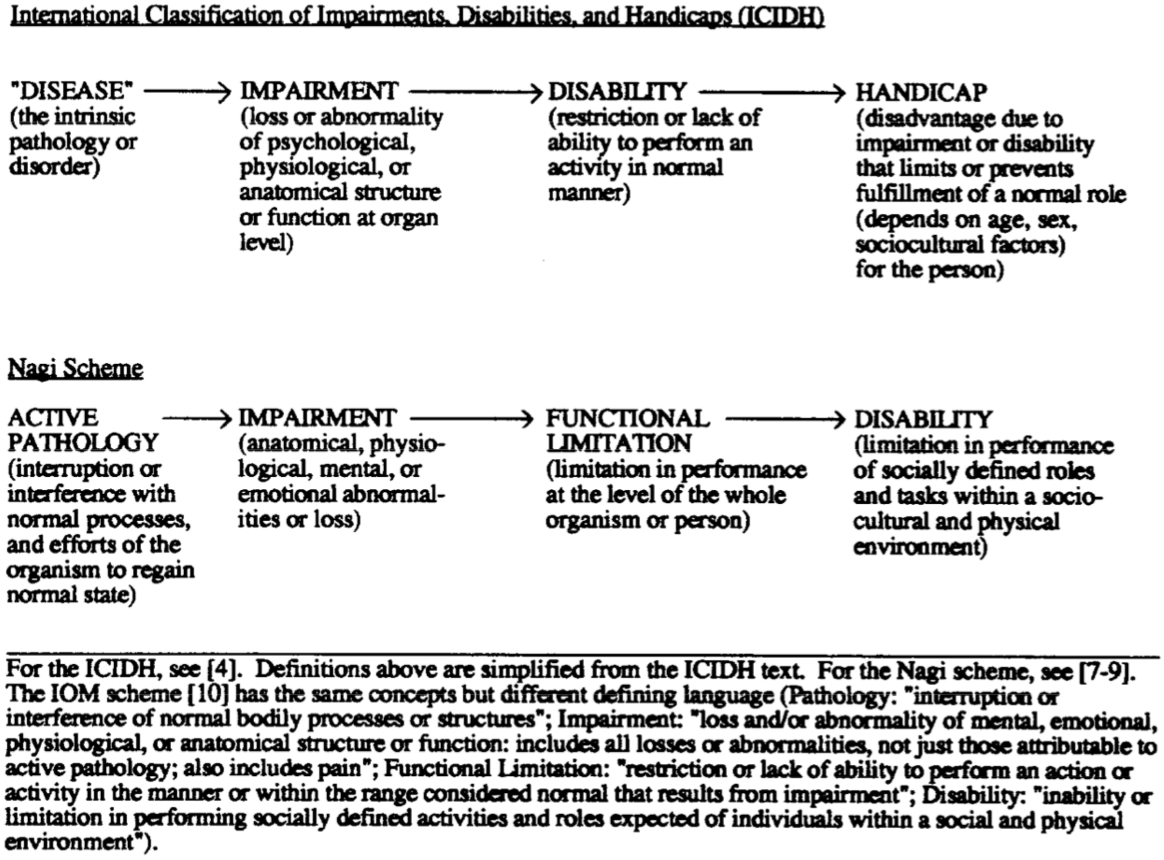
[1] Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity*, A Spectrum Book (Englewood Cliffs, N.J.: Prentice-Hall, 1963); Marvin B. Sussman, *Sociology and Rehabilitation*, ed. Marvin B. Sussman (Washington: Washington: American Sociological Assn., 1965), 100-13; Saad Zaghloul Nagi, *Disability and Rehabilitation: Legal, Clinical, and Self-Concepts and Measurements* (Columbus: Ohio State University Press, 1970).

as a long-term or continued impairment that is associated with functional limitation or limitations.[1] Nagi's model has had a continuing impact on *clinical* fields.[2]

In their 1994 article, "The Disablement Process," Lois Verrugge and Alan Jette contrast Nagi's model with the ICIDH's (International Classification of Impairments, Disabilities, and Handicaps).[3] As the Council of Europe's literature review on the ICIDH explains, "In 1980 the…ICIDH was published by the World Health Organization. It was indented to be complementary to the International Classification of Diseases (ICD).



For the ICIDH, see [4]. Definitions above are simplified from the ICIDH text. For the Nagi scheme, see [7-9]. The IOM scheme [10] has the same concepts but different defining language (Pathology: "interruption or interference of normal bodily processes or structures"; Impairment: "loss and/or abnormality of mental, emotional, physiological, or anatomical structure or function: includes all losses or abnormalities, not just those attributable to active pathology; also includes pain"; Functional Limitation: "restriction or lack of ability to perform an action or activity in the manner or within the range considered normal that results from impairment"; Disability: "inability or limitation in performing socially defined activities and roles expected of individuals within a social and physical environment").

Figure 2: ICIDH v Nagi Disablement Models

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[1] Sharon Barnartt, *Disability as a Fluid State*, vol. 5, Research in Social Science and Disability (Bradford: Emerald Group Publishing Limited, 2010).

[2] E.g., physical therapy journals still frequently refer to Nagi's model as a framework to assess clinical outcomes. Sharon Barnartt notes that while Nagi makes clear that "not every impairment results in a functional limitation (1965, p. 102)…he also suggests that disability is based on functional limitations (1965, p. 103)." A. R. Snyder et al., "Using Disablement Models and Clinical Outcomes Assessment to Enable Evidence-Based Athletic Training Practice, Part I: Disablement Models," *J Athl Train* 43, no. 4 (2008).

[3] L. M. Verbrugge and A. M. Jette, "The Disablement Process," *Social Science and Medicine* 38, no. 1 (1994).

The ICIDH was developed as a manual of classification relating to the 'consequences' of disease, whereas the ICD is a classification of diseases including disorders, congenital conditions and injuries."[1] Three of the largest differences of the ICIDH model are:

- The joining of impairment and functional limitation,
- The definition of "disability" relative to abilities performed "in normal manner," and
- The restriction of "sociocultural factors" to the disadvantage that *either* impairment or disability bring about.

However, the primary difference of these models is, on the whole, semantic. Whether or not one calls the ultimate social effects of an anatomo-psycho-physiological impairment a "disability" or a "handicap" matters not: the point is that the ultimate effect of such impairment for a person's life is *socially mediated.*[2] While there are notable intramural differences among the various types of social models, it is nevertheless the case that the social model, as Rannveig Traustadottir puts it, "has provided the knowledge base which has informed the international legal development aimed at full participation and human rights of disabled people."[3]

In summary, the social model of disability has marked the most significant shift in understandings of disability in history. In keeping with this momentous transformation in thought across Western and Eastern traditions in severing nurture from nature, necessity

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[1] C. Europe, *Literature Review of the Who International Classification of Impairments, Disabilities and Handicaps (Icidh) and Rehabilitation of People with Disabilities* (Council of Europe Pub., 1998). It now referred to as the ICF, short for ICFDH: International Classification of Functioning, Disability and Health.

[2] I discuss Carol Thompson and Donna Reeve's concept of "psycho-emotional disablism" in chapter four.

[3] Arnardóttir Oddný Mjöll and G. Quinn, *The Un Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, International Studies in Human Rights (Leiden; Boston: Martinus Nijhoff Publishers, 2009), 3-16. To repeat from above, what is typically referred to as the "social model" is in fact the British "strong social model," as I mentioned above: there are many social models. Tom Shakespeare, *Disability Rights And Wrongs Revisited*, Second edition. ed. (London; New York: Routledge, 2014), 12.

from contingency, the social model of disability is responsible, in large part, for the greatest shift in understanding concerning human embodiment to which history attests.

§3.2.2 Interactionist: Shakespeare, Wendell

Tom Shakespeare's seminal work in disability theory has had a wide impact on nearly every field that engages disability studies. One of his lasting contributions has been the development of what he calls a critical-material or critical-realist theory of disability, one which takes direct aim at what he holds to be the *untenable* distinction between disability and impairment in the social model

> The analogy with feminist debates about sex and gender highlights another problem: the crude distinction between impairment (medical) and disability (social). Any researcher who does qualitative research with disabled people immediately discovers that in everyday life it is very hard to distinguish clearly between the impact of impairment, and the impact of social barriers (see Watson, 2002; Sherry, 2002). In practice, it is the interaction of individual bodies and social environments which produces disability. For example, steps only become an obstacle if someone has a mobility impairment: each element is necessary but not sufficient for the individual to be disabled. If a person with multiple sclerosis is depressed, how easy is it to make a causal separation between the effect of the impairment itself; her reaction to having an impairment; her reaction to being oppressed and excluded on the basis of having an impairment; other, unrelated reasons for her to be depressed? In practice, social and individual aspects are almost inextricable in the complexity of the lived experience of disability.
>
> Moreover, feminists have now abandoned the sex/gender distinction, because it implies that sex is not a social concept. Judith Butler (1990) and others show that what we think of as sexual difference is always viewed through the lens of gender. Shelley Tremain (2002) has claimed similarly that the social model treats impairment as an unsocialized and universal concept, whereas, like sex, impairment is always already social.[1]

Instead of calling this, as he does, a "critical realist" approach to disability, I will use the term interactionist. I do so because (a) I find it most clearly indicates that the theoretical effort is aimed towards combining and integrated the social models demarcation between impairment and disability and (b) I wish to avoid the overburdened connotations "realism" bears within philosophical discourse. In a similar vein to the work of Susan Wendell,

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[1] Lennard J. Davis, *The Disability Studies Reader*, 2nd ed. (New York: Routledge, 2006).

Shakespeare has offered a crucial corrective to the indefensible bifurcation of material embodiment and social recognition and interaction held up by the social model of disability. What his work puts forward, however, is still a social theory of disability insofar as the social uptake of embodiment is held as a crucial component for how one interprets one's experience. Yes, neuropathic spinal pain cannot be fixed by better access to public transit, but one's identification as "disabled" cannot be thought outside of the historical stigmatization of one's embodiment. I thus understand interactionist theories of disability to function in accord with the politicizing aims of the social model.

§3.3 Post-Social Theories

Given the wave of anti-foundationalist, historicist, and other sorts of critical projects that took hold in the last half of the twentieth century, it is no surprise that these theoretical orientations would come to bear on disability theory. The social theories of disability, especially more rigid and underdeveloped forms of the "social model," have been subject to two primary critiques. To be clear, I mean the prefix in "post-social" to simply pick out that these are models that have been proposed after the uptake of the social model within disability studies. The first comes from Lennard J. Davis. As I explain below, he argues that the main effect of the social model of the disability was to create a political identity. Although this produced numerous positive effects, identity politics, he argues, is both outdated and theoretically inept, especially in light of an increasing awareness of the need for intersectionality for the success of any social justice project, not to mention one's self-understanding. The second comes from Shelly Tremain. Upon subjecting the concepts of the social model to a genealogical analysis, she argues that it is less radical than it might seem. The role of impairment, in particular, maintains a governmental-juridical constitution of a “disabled political subject” that is fraught on many levels. I will quickly sketch out each of their positions, before offering a concluding analysis of the individual, social, and post-social theories of disability as a whole.

§3.3.1 Post-Identitarian: Lennard J. Davis

When I opened this chapter on theories of disability by demonstrating the complexity of disability, I simultaneously foreshadowed the foundation of post-social theories. A clarification of this foundation can be found from its most prominent voice: Lennard Davis.

> We find ourselves in a morass in terms of identify politics and studies. There are various tactics one can take in the face of this conceptual dead end. One can object vehemently that X does indeed exist, that people have suffered for being X, and still do. Therefore, while there may be no basis in theory for being X, large numbers of people are nevertheless X and suffer even now for being so. Or one can claim that although no one has been able to prove the biological existence of X, they will be able to do so someday. In the gap between then and now, we should hold onto the idea of being X. Or one could say that despite the fact that there is no proof of the existence of X, one wants to hold to that identity because it is, after all, one’s identity. Finally, we can say that we know X isn’t really a biologically valid identity, but we should act strategically to keep the category so that we can pass laws to benefit groups who have been discriminated against because of the pseudo-existence of this category. All these positions have merit, but are probably indefensible rationally.[1]

If it is the case that identities are saturated by their social mediation—that is to say, although social mediation is not the only component in identity-formation, it is the most significant or determinate component—then the social category of ‘disability’ has no more absolute foundation than any other social phenomenon. A comparison between Davis’ post-social model of disability and Derrida’s understanding of justice is helpful here. Derrida famously claimed that justice is undeconstructible because justice is a

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[1] *The Disability Studies Reader*, 268-69. See the work of Mark Sherry, and his use of Lyotard’s concept of the “differend” as a way to think disability as a non-category.

possibility that functions by virtue of its impossibility.[1] That is to say, its power draws from the fact that it, as a theoretical goal, can never be reached in practice. In a parallel manner, Davis argues the power of the social model arises from the fact that the solidity of disability as an identity can never be reached. The hierarchies of disability *within* disability activism and studies (those with physical disabilities are, e.g., typically at the top of the "disability food chain") are one ramification of this. Strategic political solidarity? Yes. Ontological solidity? No.

Davis brings this set of problematics to a head by proclaiming:

> What we need now is a new ethics of the body [and] what I would like to propose is that this new ethics of the body begin with disability rather than end with it. To do so, I want to make clear that disability is itself an unstable category. I think it would be a major error for disability scholars and advocates to define the category in the by-now very problematic and depleted guise of one among many identities…[Disability] must not ignore the instability of its self-definitions but acknowledge that their instability allows disability to transcend the problems of identity politics. In setting up this model we must also acknowledge that not only is disability an unstable category but so is its doppelganger—impairment.[2]

In Davis' post-social, post-identitarian theory, disability functions to disorient *everyone* for whom the domain of disability is a possibility—which is to say, everyone.[3] Disability is a hermeneutic of *instability*. There is thus a way in which it is not a "model" or "theory" at all or at least not in the same sense as the others discussed in this chapter. Note, however, that the "new ethics of the body" for which Davis calls indeed operates

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[1] Drucilla Cornell, Michel Rosenfeld, and David Carlson, *Deconstruction and the Possibility of Justice* (New York: Routledge, 1992).

[2] Davis, *The Disability Studies Reader*, 271.

[3] I do not in this dissertation broach the topic of how human corporeal possibilities and organization relate to non-human corporeal possibilities and organization, and I do not do so here especially due to the history of offensively and problematically equating people living with disabilities with "animal" lives. Having said that, the formal similarity at issue here is simple: we fail at thinking lives different from extant norms so terribly, so unthinkingly, and so unethically, that we equate people living with disabilities with animals, instead of seeing the way in which differential corporeal variabilities can work to evaporate species-differences in the same way that they do ability-differences. Our failures at thinking and valuing lives lived with disability are demonstrated (*but not at all thereby identical*) in our failure at thinking and valuing lives lived in non-human animal forms.

from a principle of sorts: corporeal variability. But because it based upon a fundamentally unstable category, because based upon *variability*, such an ethics is without normativity in any traditional sense. So, how should one understand this?

If, as Judith Butler puts it, “the question of ethics is always a question of an ethical relation, that is, the question of what binds me to another,” then ethical truths can be insufficient even if they proffer insights.[1] To be worth their stakes, such truths must be *transformative*. It is in the turbulence of this question that one begins to understand the normative stakes of ‘disability.’ That is to say, stakes that turn in the ontological turbulence of ‘disability’ as a fundamental human variability. It may turn out that experiences of disability are normatively destabilizing.

§3.3.2 Foucauldian: Tremain, Hughes

Although Shelly Tremain is not alone in approaching questions of disability through a Foucauldian lens, she has produced the most scholarship in this vein and is the most well-known, especially for her seminal edited volume *Foucault and the Government of Disability*, now in its second edition.[2] Tremain’s understands a Foucauldian analysis to engage the analytical tools of archaeology and genealogy and the vast lexicon of Foucauldian concepts such as biopower and the anatomo-clinical gaze, et al. What most distinguishes Tremain’s theory of disability from Davis’ is the way in which the concept of impairment is undermined. There is no phenomenon to which a genealogical or historical analysis is not subject and thus what one might think of as “impairment.” Even

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[1] Judith Butler and Athena Athanasiou, *Dispossession: The Performative in the Political* (Malden, MA: Polity, 2013), 107.

[2] Shelley Tremain, *Foucault and the Government of Disability*, Enlarged and revised edition.. ed. (Ann Arbor: Ann Arbor: University of Michigan Press, 2015).

if defined very broadly as one's "embodied condition," impairment does not pick out a fact or truth about a body, but a historical product. As she explains it:

> Notice that if the foundational (i.e., necessary) premise of the social model—impairment—is combined with the preceding claims according to which modern governmental practices produce—that is, form and de‹ne—the subjects whom they subsequently come to represent by putting in place the limits of their possible conduct, then it becomes more evident that subjects are produced who "have" impairments because this identity meets certain requirements of contemporary social and political arrangements. Indeed, it would seem that the identity of the subject of the social model ("people with impairments") is actually formed in large measure by the political arrangements that the model was designed to contest.[1]

Tremain's overarching point is not simply that the concept of "impairment" is historically produced and contestable, but that it specifically came into being as a product of governmental and juridical practices to contain and interpellate certain populations. It actually functions to "legitimize the governmental practices that generated it in the first place."[2] The very logic of differentiation, whether between bodies or between states of heath, operates relative to a standard whose ultimate arbiter is governance, i.e., power relations acting upon and constituting productive subjects.

There is much more to be said about all that a Foucauldian analysis of disability might imply for understanding the ableist conflation. For the purposes at hand, I only wish to highlight the effect of such an understanding for the *lived experience* of one with disabilities. Although I find much merit in both Post-Identitarian and Foucauldian theories of disability, they are existentially deregulative. They do not help one gain or regain one's sense of self or assist in purposive action. As critical projects, this is not surprising and not part of their aims or concerns. Both post-social theories eschew what

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[1] *Foucault and the Government of Disability*.

[2] Ibid, 11. Tremain provides a helpful introduction to her own work in "This Is What a Historicist and Relativist Feminist Philosophy of Disability Looks Like," *Foucault Studies* 19 (2015).

could be called, following Spivak, the “strategic essentialism” of the social theories of disability.[1]

As I argued in the introduction, the ableist conflation undermines lived experiences of disability by conceptualizing disability in ways that function to flatten or hinder one’s sense of self and purposivity. Although post-social theories of disability are far more defensible than individualist theories, they also hinder or, at minimum, are neutral with respect to a life. I thus find that there is more work to be done sussing out the normative and theoretical implications of post-social theories of disability as they bear upon the lived experience of people with disabilities. This is not to say that these theories should be measured by their function or effect—it is only to say that such a limitation must be acknowledged and such theories should be recognized in their critical stance towards concrete projects of social justice. On this point, I imagine that both Davis and Tremain would agree.

§3.4 Conclusion: The Regulative Role of Disability

> Being a problem is a strange experience.
> —Dubois[2]

“Almost by definition,” Bill Huges writes, we “*assume disability to be ontologically problematic*, and many disabled people feel that many of the people with whom they interact in everyday situations treat them as if they are invisible, repulsive, or ‘not all there.’”[3] Why is it that disability is problematic? And why is that not the

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[1] Gayatri Chakravorty Spivak, *In Other Worlds: Essays in Cultural Politics* (New York: Routledge, Taylor & Francis Group, 2006).

[2] W. E. B. Du Bois, *The Souls of Black Folk*, 1st Vintage Books/Library of America ed. (New York: Vintage Books/Library of America, 1990), 7.

[3] B. Hughes, "Being Disabled: Towards a Critical Social Ontology for Disability Studies," *Disabil. Soc.* 22, no. 7 (2007): 673, my emphasis. It is worth quoting this passage in full: “In debates about disability questions of ontology are, it could be argued, never far from the surface. Formal, bureaucratic quality of life measures, almost by definition, assume disability to be ontologically problematic and many disabled

problem? Following Titchkosky and Michalko, perhaps one ought to respond, "that disability is conceptualized as a problem is what we take to be our problem in need of theorizing."[1] It is the unity of various social theories that account for its socio-political, legal, and academic successes.

Theories of Disability

Theory	**Individualist**	**Social**	**Post-Social**
Domain	Moral	Politico-Juridical	Diffusive
Function	Judgment	Adaptive	Heuristic
Power	Injunctive	Normative	Reflective
Effect	Exteriorize	Politicize	Problematize

I argued above that the function of conceptualizations of disability are to exteriorize in individual models, politicize in social models, and problematize in post-social models. The **theories** I name ultimately operate within the parameters of their respective **domains**. The individualist theories of disability operate within the parameters of morality, which is why distinctively moral concepts such as punishment and selection prove crucial for its understandings of disability. The **function** of names how the domain utilizes the phenomenon in question. For example, the social theories of disability operate with the domain of the politico-juridical, of laws and legally recognizable subjects.

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people feel that many of the people with whom they interact in everyday situations treat them as if they are invisible, repulsive or 'not all there'. Debates about selective abortion, pre-natal screening, euthanasia and physician-assisted death cannot be disentangled from sentiments that question disabled people's right to life (see, for example, Priestly, 2003, pp. 35–60 & 166–188). Medical literature on disability embodies an ontological subtext in which the distinction between the normal and the pathological suggests a hierarchical ontological dichotomy in which impairment/disability is associated with 'deficit' or a 'flawed' existence. There is a significant literature from a humanities/literary criticism perspective that focuses on corporealities and critiques the negative representation of disabled people in print and the visual media. This literature claims that the disabled figure is ubiquitously portrayed as a metaphor for embodied disruption and invariably represents the dependencies that a society based on the myth of the autonomous subject can only interpret as 'tragedy' (see, for example, Thomson, 1997; Deutsch & Nussbaum, 2000; Mitchell & Snyder, 2000). Furthermore, ontological arguments are implicit and sometimes explicit in the literature that describes the 'othering' of disabled people during the modern period (Shakespeare, 1994; Hughes, 1999, 2000) and the ways in which these processes invalidate disabled lives."

[1] Dan Goodley, Bill Hughes, and Lennard J. Davis, *Disability and Social Theory: New Developments and Directions* (Houndmills, Basingstoke, Hampshire; New York, NY: Palgrave Macmillan, 2012), 127. Titchkosky and Michalko further clarify this theoretical problem: "What is the meaning of human embodiment that grounds the unquestioned status of disability as a problem?"

Disability is used to account for *divergences* in such subjects. It thus has a normative function: it tells people how they ought or ought not to act relative to how they are interpellated in that domain.

Power names how the function in question is actually experienced in the meaning of disability determined by the model. The power of post-social theories of disability is reflective because the function of disability affords one the opportunity to self-examine the ways in which one's identity is constituted by extant norms. The effect deals with the intersubjective and cultural aspects that a model's understanding of a phenomenon effects. On social theories of disability, one understands oneself in a manner that affords one control over one's future and clarity over one's purposivity. On non-social theories of disability, one is ultimately exteriorized or disoriented. One is not given back to oneself. To summarize, the **effect** of the individualist theories of disability is to exteriorize the experiences of disability from normative realms; that of social theories of disability is to politicize experiences of disability; and that of post-social theories of disability is to problematize experiences of disability.

Note that in each case, the function of disability cannot be thought outside of both its normative and also its ontological dimensions. For example, the exteriorization in individual models places disability outside the understanding of what a body is and simultaneously indicates and delimits what a body should be.[1] Because disability is one side of the Janus-head of ability, it must be thought as both active and passive, as both

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[1] Historical connections between the monstrous and various forms of disability are telling here. Joshua Eyler, *Disability in the Middle Ages: Reconsiderations and Reverberations* (Farnham, Surrey; Burlington, VT: Ashgate, 2010); Metzler. The *body that should be* is constantly formed through the powers that determine what a body is, just as *the bodies that are* are constantly formed through the powers that determine how bodies should be. Desire, always formed through perceived possibilities, seeks to act upon the body it takes to be present, but that body is determined above all else in terms of ability expectations. The 'monstrous' offers the imaginary the hither side of ability expectations through the magnification of certain abilities along with the magnification of certain physical characteristics.

constituting and being constituted by the norms various ableist ideologies carve out. Disability is constituted *as* an outside only insofar as disability is constitutive *of* an outside. Disability is ontologically “other” than the able-bodied and the normate insofar as its meaning is *what a (normate) body is not* and *how a body should not be*. The ontological and normative dimensions of disability cannot easily be separated, if at all, and I will henceforth speak of its *ontonormative* dimensions.

Another clear example of disability’s ontonormativity is demonstrated when one analyzes differing attitudes towards restorative, reconstructive, and even cosmetic surgery as opposed to transabled surgery, surgery as a result of someone needing or desiring to “impair” themselves because they suffer their particular form of ablebodiedness. People of all ages with a host of “disabilities” are expected to both alter and also *desire to* alter themselves “back” to an ideal state—even if, in the case of congenital disability, they have never been in that ideal state.

On the whole, surgical procedures considered to “enhance” an otherwise “normal” body are supported, even if that “enhancement” is primarily for aesthetic reasons or if it runs counter to biological necessities such as aging. With respect to people who identity as transabled or those diagnosed with BIID (body integrity identity disorder), the need to go blind, amputate one’s arm, or become paraplegic is seen by the vast majority of health care professionals and society at large as only conceivable as a psychological disorder. If one points out the formal similarity between these cases, the real stakes of these differing attitudes unveils itself: with the case of disability, one is assumed to *not* enhance, *not* enable, *not* make more productive, and *not* fill-in-an-accepted-ableist-norm concerning one's life and body. I will return to the discussion of transability in the conclusion.

When in chapter two I said that pain functions as an allostatic regulation in each of its models presented above, I indicated that one misunderstands its function if one thinks it simply directs one towards norms such as "reconcile yourself with God" or "take solidarity with other humans." On the contrary, models of pain are actively responsive to the exemplar agents each model aims to empower. However circuitously, *each model of pain seeks to give one back to oneself*. On the other hand, the historically dominant individualist theories of disability do not give one back to oneself. Post-social theories also fail to give one back to oneself or afford greater purposivity. Only the social theories seek to give one back to oneself. I will now turn to contrast the theories of disability discussed above with a hermeneutic phenomenology of disability.

4 – A PHENOMENOLOGY OF MS

> The telescoping of our lives into simplistic categorizations of good and bad, pain and pleasure, denies that the lives of people with disabilities, like all ordinary lives, are shot through with unexpected grace, overwhelming joy, and love returned. *Life is simply a mixed blessing*.
> —Nancy Eiesland[1]

There are some who might find any attempt to provide a phenomenological account of "disability" misguided. Indeed, on the definition of disability I argued for in chapter three, disability as "non-normate embodiment," one might wonder whether a phenomenology of non-normate embodiment *as such* would be so broad as to pass over central structures of any given particular disability. I am sympathetic to such concerns and find the target phenomenon of "disability" problematically broad in analogous

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[1] Eiesland, 13, italics added.

manners to phenomenologies of "embodiment" that Merleau-Ponty, Michel Henry, and, in some respects, the early Judith Butler have attempted. I find it so especially because the meaning of disability, in any given case, is often centrally determined by more particular considerations.

For example, in at least some respects, I would argue that experiencing MS as a straight, white, upper-class, non-immigrant woman will be significantly, not peripherally, different from experiencing MS as a queer, black, lower-class, immigrant man. This is not to say that a phenomenology of MS, such as I develop below, is unfruitful, just as it is not to say that a broader phenomenology of embodiment or non-normate embodiment is unfruitful. It is to say that in proportion to the increasing generality of experiential structures (or defining features) at which one's analysis aims, one increasingly obscures the centrality of *comparatively* particular structures as well as the "downstream" norms that determine them.

I call this the *problem of ontonormative scope*: the more general the ontological analysis, the less apparent the particularity and contingency of the norms that afford such generality in the first place and prove determinate for one's lived experience.[1] By my lights, this is the problem at the heart of the infamous, near-total omission of the body in

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[1] It is not simply a question of a general-particular structure because that which is held to be general is always *held* to be so. For example, the level of generality at which Heidegger argues that ensnarement (*Verfallen),* existence (*Existenz*), facticity (*Faktizität*), and signification (*Bedeutsamkeit*) are existentials of Dasein, he cannot account, I would argue, for the way that racial or gender norms fundamentally alter the mode of these existentials. In other words, he obscures the fact that the *meaning* of the general structures relies less upon the fact of those structures and moreso on the way in which "downstream" norms and particularities afford them meaning. The norms determine the meaning of the structures just as much as the structures determine the possible forms and meaning of the norms. That, e.g., I might understand *the meaning of* being-thrown without attending to, say, race or sexuality is the worst sort of philosopheme. That being-thrown is a structure of existence (and I think it is) obscures the fact that it is always already a normative structure; it is value-laden all the way down.

Heidegger's work as well as the problematic omission of questions of gender and sexuality in Merleau-Ponty, among other examples. Furthermore, I take this to be a crucial and defining problem for emerging work in what is being called *crip phenomenology*, a problem arising not from a methodological flaw but from being beholden to the complexity of its phenomena. Allow me to explain what I mean through the work of Merleau-Ponty.

§4.1 Merleau-Ponty's Aveugle and Crip Phenomenology

Take Merleau-Ponty's famous example of the "blind man's cane" (*le bâton de l'aveugle*).[1]

> Without any explicit calculation, a woman maintains a safe distance between the feather in her hat and objects that might damage it; she senses where the feather is, just as we sense where our hand is. If I possess the habit of driving a car, then I enter into a lane and see that "I can pass" without comparing the width of the lane to that of the fender…the hat and the automobile have ceased to be objects whose size and volume would be determined through a comparison with other objects…the blind man's cane has ceased to be an object for him, it is no longer perceived for itself (*Le bâton de l'aveugle a cessé d'être un objet pour lui, il n'est plus perçu pour lui-même*); rather, the cane's furthest point is transformed into a sensitive zone, it increases the scope and the radius of the act of touching and has become analogous to a gaze. (144/178).

The cane is no longer an object *for* the "blind man," but is part *of* his being. Setting aside the ambiguity here with respect to congenital blindness (since it is not obvious at what developmental point the cane would be or cease to be an object), what does it mean for the white-cane to no longer be an object in this specific example? What does it mean that it is not just any cane, not a walking cane or fighting cane, etc. but a "blind man's cane"? And how can it become so in a manner *analogous* to a "woman's feather" and the habit of driving a car? Lastly, what—it is never asked—is actually meant by "blindness"? If

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[1] In the context of the USA, there are some in the blind community who prefer the terms "visually impaired" or "a person with a visual impairment." Because some in the blind community accept the term, I maintain the typical English rendering of Merleau-Ponty's phrasing.

one were congenitally blind or even in certain cases of non-congenital blindness, one might have learned how to use echolocation to "see." In such cases, one is not blind in the sense of not being able to "see" the world around one, as the term "blindness" is typically taken to mean.[1]

The object, we are told, must become inconspicuous to the point of being a part of one's being in and orientation to the world. Note that psycho-somal incorporation (*incorporation*) is at once intentional interiorization (*intériorisation*) in the description he provides: these objects become not just constitutive of one's sensing, but sense *(sens*) itself.

Yet, Merleau-Ponty's claims about the cane, as we will see below, are ultimately based in a *simulation* of blindness. Which leads one to ask: why would Merleau-Ponty assume this experience can be simulated? As people who are blind have argued, blindness *cannot* be simulated. Blindness is not a lack of sight, but a fundamental condition for the creation of a world. Many would say the same about Deafness. One cannot enter this world through a few minutes of "simulation" any more than one can enter the world of a different culture by spending a few minutes with its inhabitants.[2] John Hull, who experienced late-onset blindness, writes,

> First I believed that blindness was when you couldn't see because something had gone wrong with your eyes. Then I understood that blindness was a deprivation of knowledge for which alternative sources and kinds of knowledge would compensate. Gradually I came to see that blindness is a whole-body condition. It is not simply that your eyes have ceased to function; your whole body undergoes a profound transformation in its relationship to the world. *Finally, I came to believe that blindness is a world-creating*

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[1] Lore Thaler et al., "Neural Correlates of Natural Human Echolocation in Early and Late Blind Echolocation Experts," *PLoS ONE* 6, no. 5 (2011). Lore Thaler and Melvyn A. Goodale, "Echolocation in Humans: An Overview," *Wiley Interdisciplinary Reviews: Cognitive Science* 7, no. 6 (2016). See also "How To Become Batman," *NPR Invisibilia*, http://www.npr.org/programs/invisibilia/378577902/how-to-become-batman.

[2] See Georgina Kleege, *Sight Unseen* (New Haven, CT: Yale University Press, 1999).

> *condition.*[1]

Hull's description moves from an understanding of blindness cast in the logic of the ableist conflation—blindness as lack and suffering, as something "gone wrong"—all the way to a positive, generative, and rich form of life, however different from the "norm." Corporeal alteration does not entail corporeal degradation, although the transition to the new state may itself be quite difficult to experience. Hull had to not only *become* blind, but also shed the ableism with which he had experienced the world in order for him to account for blindness *as it appears from itself.*

As many disability activists and critical disability studies scholars have argued, simulation exercises not only fail to "simulate" the experience in question, they are actively harmful by *reinforcing* misguided ableist prejudices.[2] When an able-bodied person *pretends* to be blind, when they (attempt to) perform blindness, the cane, Merleau-Ponty argues, can still become incorporated "after time." Yet, it is not so clear that the cane enters into a process of incorporation in the case of the sighted person simulating blindness as much as it is an annexation, to translate the French more literally (*annexant*):

> In the exploration of objects, the length of the cane does not explicitly intervene nor act as a middle term: the blind man knows its length by the position of the objects, rather than the position of the objects through the cane's length…*If I want to become habituated to a cane, I try it out, I touch some objects and, after some time, I have it "in hand"* (« en main »)…Habit expresses the power (*le pouvoir*) we have of dilating our being in the world, or of altering our existence through incorporating (*annexant*) new instruments. (144-45/78-9).

The sighted person can surely annex a cane with some practice, but I am not persuaded that they could incorporate it. That would require blindness to be constitutive of one's

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[1] John Hull, *On Sight and Insight: A Journey into the World of Blindness* (London: Oneworld, 1997), xii, my italics.

[2] Multiple critical disability scholars have argued this point. See, e.g., Kafer, 4, 9.

world.[1] As John Jenkinson explains, “If visual feedback is being generated within the visual system, that’s going to be reflected in the underlying neural networks. So even if a sighted individual used a cane, that use, unless it became their primary mode of vision, would not rewire the brain because relevant feedback would still be generated by the optic system to maintain the neural networks it relies upon. However, absent such feedback, those brain regions typically used by the visual system could be more easily co-opted by other systems, especially if their use is similar (i.e. echolocation). So, sighted people can't really learn to see with other systems (like haptic feedback or echolocation) because that kind of plasticity is not available to them (those systems would be fighting against the tendency to strengthen vision-based wiring).”[2] This further suggests that blindness must not be thought as a modality of “normal,” “able-bodied” experience (albeit related), but as creating a unique world. And it certainly suggests that able-bodied habituation to sensory changes or incorporation of various objects will not be as instructive as one might think about experiences where those sensory experiences or object incorporation are constitutive of one’s world.

It is crucial to recognize that the “blind man’s cane” can only function as it does in Merleau-Ponty’s example when others do not treat him *as disabled.* When the “blind man” encounters another who speaks loudly (conflating deafness with certain visible

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[1] There are over seventy references to “blindness” (*aveuglement*) and just six to “disability” or being “disabled” (variations of *infirme*) in the *Phenomenology of Perception*: one at 84/111, four at 458/497, and one at 461/500. Nearly all uses are pejorative: blindness as not comprehending, etc. The quote above represents one of the few places where blindness is employed positively. In this positive case, the “disability” of blindness is described and reconstructed via a phenomenological reduction seeking to explain the relation of embodiment to existence. The incorporation of various prostheses becomes proof of the nature of our being, our finitude, and our corporeal ambiguity. Themes extant in posthumanist writings retroactively ring loudly, themes which have come under intense scrutiny in critical disability studies. See Donna Haraway, *A Cyborg Manifesto: Science, Technology, and Socialist-Feminism in the Late Twentieth Century* (New York, NY: New York, NY: Longman, 1998). For an extensive list of disability critiques and uptakes of Haraway, other post-humanist writers, and post-humanist figures such as the cyborg, see the notes to chapter 5, “The Cyborg and the Crip: Critical Encounters” in Kafer, 205-13.

[2] John Jenkinson, private correspondence, 2016.

disabilities, as is woefully common) or who refuses service to him, the smooth incorporation of his cane is disrupted.[1] The cane instead makes him *conspicuous*. When he cannot cross a street because of a lack of curb cuts or audible walk signals, that incorporation is disrupted as well. As the metonymy of "white-cane" for "blind person" demonstrates, let us not forget that the white-cane is taken as an obvious, extrinsic sign of blindness as a "disability."

If one wishes to attempt to experience blindness, one will fail by simply wearing a blind-fold while walking around with a cane or by imagining analogously how such an object would be incorporated if one simply "could not see." One will invariably fail by understanding blindness as an object—as a quality, *analytically separable*—of a subject. Though it would be an improvement, one will still fail to experience what we call "blindness" by donning non-transparent sunglasses, acquiring a white-cane, and then trying to arrange transportation from one's home to, say, a grocery store or perhaps an art gallery, all along the way discovering how others respond or fail to respond. One will also fail by then heading to a local disability services office to be processed as "disabled" in a legal sense by one of the many bureaucracies of our late capital economies. None of these will *suffice* to experience the type of world blindness creates *as* a world. To bring all this to its apex: the disanalogy between the white-cane, the feather, and the car is as important, if not more, than the similarities upon which Merleau-Ponty focuses.

When discussing disability, Merleau-Ponty assiduously avoids the Scylla of factical reduction and the Charybdis of aperspectival generalization. Whilst navigating these straights, however, he underemphasizes the role of the other's gaze, a gaze which

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[1] Gail Sullivan, "Uber Sued For Allegedly Refusing Rides To The Blind And Putting A Dog In The Trunk," *The Washington Post*, accessed September 10, 2014, http://www.washingtonpost.com/news/morning-mix/wp/2014/09/10/uber-sued-for-allegedly-refusing-rides-to-the-blind-and-putting-a-dog-in-the-trunk/.

cannot but carry normative weight, and he traffics in a host of ableist assumptions. I above outlined the *problem of ontonormative scope*: the more general the ontological analysis, the less apparent the particularity and contingency of the norms that afford such generality in the first place. Because Merleau-Ponty's aim in the quote above is primarily to glean insight about embodiment by looking to the proprioceptive incorporation of various objects, he misses a number of distinct and arguably central insights that blindness might have offered. He also failed to see the ways in which norms about sightedness allowed the analogy to function in the first place. Norms that, if assailed, might themselves provide insight about how sightedness informs (or fails to inform) proprioceptive incorporation or normate embodiment more generally. Indeed, I proffer that with a more sustained focus on the experience of blindness and with incorporation of writings by people who have experienced blindness firsthand, both congenital and non-congenital, *much more* would have been revealed phenomenologically, including the conditions and import of one's socio-historical context and the constitutive role ableism plays therein.

White-canes are *not* easily incorporated in a world made inaccessible in so many ways for so many bodies due to the structural and ideological stigmatization and exclusion of what is marked as "disability," which is to say, in a world made by normates. The way in which Merleau-Ponty's otherwise very astute analysis goes awry in its treatment of blindness demonstrates the need for crip phenomenologies. "Cripping" is here understood as a method of, first, exposing the able-bodied assumptions of a given conceptual terrain or methodology and, second, articulating a conceptual reconstruction of that terrain grounded in non-normate experience.[1] Given the aims of crip phenomenology, I do not understand what I will present below as a "phenomenology of disability." Instead, I understand it as a phenomenology of progressive degenerative multiple sclerosis (MS hereafter) that, where successful, proffers insights concerning a range of experiences of non-normate embodiment. I have chosen to focus on MS for five reasons.

First, as noted in chapter three, debates in disability studies over the theoretic value of the social model often center on concerns that the disability-impairment distinction both cedes epistemic authority over "impairment" to medicine and biology and also deemphasizes or even delegitimizes problems arising directly from impairments. The character and progression of multiple sclerosis forces one to attend to both sides of the social-impairment divide, thereby making it an ideal phenomenon by which to engage and enrich these debates. Second, because part of my goal is to analyze the ableist conflation's linking of disability with pain and suffering, it is more germane to pick an example of disability that clearly includes both phenomena.

Third, because multiple sclerosis occurs over multiple years and is a condition that typically affects previously able-bodied adults, it offers better insight into the effect of ability transitions on ability expectations than would a focus on a congenital disability. In the panoply of its ability transitions, MS captures a wide and often conflicting range of

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[1] I am amending a definition from Carrie Sandahl, "Queering the Crip or Cripping the Queer?," *GLQ: A Journal of Lesbian & Gay Studies* 9, no. 1/2 (2003). I became aware of this article from Alyson Patsavas, "Recovering a Cripistemology of Pain: Leaky Bodies, Connective Tissue, and Feeling Discourse," *Journal of Literary & Cultural Disability Studies* 8, no. 2 (2014). As McRuer puts it, "crip theory questions—or takes a sledgehammer to—that which has been concretized; it might, consequently, be comprehended as a curb cut into disability studies, and into critical theory more generally." Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability*, Cultural Front (New York: New York University Press, 2006), 35. There have been criticisms of the use of this term from multiple corners. A brief overview of this is provided in Margaret Price, "The Bodymind Problem and the Possibilities of Pain," *Hypatia* 30, no. 1 (2015).

ableist expectations and ableist assumptions harbored by both "able" and "dis-" abled bodies. That is to say, the progressive, non-congenital aspects of MS reveal *ability troubles* as they disrupt and transform not just to discrete activities or projects, but one's very sense of self. Ability troubles are revealed most clearly, I'll argue, when one's sense of what is possible itself is thrown into question. However variously I may experience myself across social landscapes (e.g., when I am in front of parents vs. peers or enemies vs. friends), when I experience a *fundamental* ability expectation as a loss—say the inability to speak or walk—the gravity of what I am calling "ability trouble" rears its head.

Fourth, multiple sclerosis itself involves multiple types of "disabilities," from paraplegia to blindness to incontinence. MS thus affords a type of intra- and inter-disability analysis. Fifth and finally, the effects of multiple sclerosis vary significantly over the duration of its progression. As I explain further below, the variability and diachronicity of MS put the phenomenologist in an exemplary position to confront the problem of ontonormative scope by the repeated disclosure of "new normals" on both micro and macro levels.

§4.2 Possibilities of Bodies

After learning of "my diagnosis," Havi Carel writes, "I had to overhaul all my plans, expectations, goals, projects and horizons. Most importantly, I had to rethink my idea of a good life."[1] Although speaking specifically of Lymphangioleiomyomatosis, Carel's words ring true for anyone receiving a life-altering diagnosis, that is to say, a diagnosis whose ability transitions result in a fundamental alteration of the majority of

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[1] Havi Carel, *Illness*, Revised ed. (UK: Acumen, 2013), 73.

one's abilities and ability expectations. If one follows Socrates in holding that "the most important thing is not life, but the good life (*to eu zoe*)," this should give one pause.[1] How could the state of one's body fundamentally change one's idea of a good life, perhaps goodness itself, or even life itself? Is the change Carel describes in fact a question of the "state" of her body, a state indicated by her diagnosis?

Or is it instead the body understood, to follow Beauvoir, as "a situation…[as] our grasp on the world and the outline for our projects"?[2] Over the course of this chapter, it will become apparent that, outside of the parameters of medical and scientific discourse, the 'body' functions more often than not as a synecdoche for a constitutively variable, yet bounded field of abilities and corresponding ability expectations. If the term 'body' functions in this manner, how do I employ it here? More specifically, how do I employ the concept of the body with respect to that of dis/ability?

While questioning the supposedly contingent role the body plays with respect to fundamental ontology, Michel Henry writes,

> We could, it is true, try to *base the contingency of the question on the contingency of its object*…rather, if the relationship *sui generis* of the body to consciousness instead proves to be the foundation of our idea of contingency, and more fundamentally, **of the very fact that such a contingency and even contingent facts in general are possible for us**, then does not this relationship truly constitute a *structure,* which is not only rooted in human nature, but which must further serve to define it? ….[3]

There are two claims of Henry's I wish to highlight here. First, it is the particular relationship of the body to consciousness that grounds the experience of possibility. Because it is neither the body, nor consciousness, but their relationship at issue, such a

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[1] Crito, 48b.
[2] Second Sex, 46.
[3] Michel Henry, *Philosophy and Phenomenology of the Body* (The Hague: Nijhoff, 1975), 2, 3, bold emphases are mine, italics are in the original.

formulation avoids strict forms of idealism or materialism. It is not simply that this relationship is a foundation or ground in the sense of determining the character of any given possibility or set of possibilities. Rather, the relationship of the body to consciousness makes the experience of possibility *itself* possible.

Second, although it is likely true of other beings, this relationship constitutes and defines the human. Carel reports that upon experiencing such a profound shift in ability expectations, she had to overhaul and rethink all her plans, expectations, goals, projects, and even her idea of a good life. It is perhaps more accurate to say that she was forced to rethink the very structure by which and out of which she *is* as a purposive being, as a being of both reflexive and projective possibility.

If Henry's claims are taken seriously, when one rethinks the relationship of the body to consciousness, one rethinks the ground of possibility itself. One rethinks *being human* itself. In investigating phenomena such as "disability," one is not investigating mere aberrations or divergences from the typical being of the human as bio-medical statistics or evolutionary phylogenetic cohorts might define it; one is instead investigating the conditions of the possibility *of possibilities* for such a being. This is not to say, for example, that the experiences subsumed under the name 'disability' reveal the conditions of possibility of the human full stop. It is to say that any particular possibility must be thought through the dialectics of the relationship between body and consciousness as the ground of contingency, one constitutive vector of which is disability.

At the close of this chapter, I argue that the phenomenology of MS provided here suggests that the corporeal variability of the human is such that the conditions of the possibility of possibilities must themselves be thought as variable. Put simply, fundamental and transcendental ontology assumes an idealized body, and when one examines the particular relations of non-ideal, non-normative bodies, the project of fundamental ontology is humbled as the role of the constitutive variability of human corporeality becomes clear. With this claim about the relation of contingency and bodies to the scope of phenomenological research in mind, I will now turn to develop a phenomenology of MS through the work of S. Kay Toombs.

§4.3 Sufficient Unto the Norm

S. Kay Toombs received her PhD in philosophy from Rice University in 1990. With regards to her personal and professional background, she writes

> I was diagnosed with multiple sclerosis in 1973. In my work I combine my philosophical training with my firsthand experience of chronic progressive debilitating disease in order to reflect on issues relating to the experience of illness and disability, the phenomenology of the body, the experience of disability, the care of the chronically and terminally ill, the challenges of incurable illness, the meaning of vulnerability, and the relationship between health care professionals and patients.[1]

I will focus on Toombs' work in part because she is, to my knowledge, the only person specifically trained in phenomenology, other than Havi Carel, whose body of work is written out of the experience of a degenerative disability. As I explained above, multiple sclerosis is a *complex* degenerative disease. Although research suggests that it involves both genetic and epigenetic factors, its precise cause is still unknown. Medical historian Colin Talley explains in more detail:

> Multiple sclerosis (MS) is a disease of the brain and spinal cord that usually strikes adults between the ages of twenty and fifty and affects women more than men by a ratio of two to one. In the United States, estimates of the number of people with MS range from 266,000 to 400,000. Some argue that it may be even higher, but it is hard to know because of the difficulty in diagnosis, lack of access to health care for many, and unavailability of neurological expertise for some. The International Multiple Sclerosis Federation estimates that there are over 2.5 million cases of the disease worldwide. It has

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[1] Toombs. CV.

> been established that there is a genetic predisposition for the disease. At some point there is an environmental assault which allows immune system cells to make it past the blood-brain barrier. The immune system then attacks cells in the central nervous system as if they were invading pathogens…As the body tries to repair the damaged tissues, there is an overgrowth of glial or connective tissue between neurons…Depending on where the damage occurs in the central nervous system, neural transmission and communication are disrupted, and various symptoms varying widely in form, pattern, and intensity are expresses…the disease process is a continual one; it is only the symptoms that often remit and relapse over the course of many years and decades.[1]

In one of Toombs' chief essays on the phenomenology of multiple sclerosis, "Sufficient Unto the Day," it is telling that she begins with a page-long, small print definition of the diagnosis of MS taken from a clinical neurology textbook.[2] The first words of the essay are neither in her own voice, nor based in her own experience. A medicalized third-person perspective announces dryly: "disseminated or multiple sclerosis is one of the commonest nervous diseases."[3] The first information we discover about MS in this textbook is statistical prevalence: it is "common." The authority of modern medicine, which is always the authority of various empirical sciences combined with that of population-level biometric statistics, gets the first word, and it says: common. Far from ceding authority to medicine, Toombs begins in this manner in order to expose that authority and the singularity covered over in *the statistical common*.

The first words in Toombs' own voice ring out decisively on the next page, "every multiple sclerosis patient can remember the moment of diagnosis."[4] It is a universal feature of narrative and phenomenological accounts of life-altering conditions that *upon receiving the diagnosis*, a total existential disequilibrium results. Toombs reports that, upon receiving the diagnosis, "the future disappeared." She no longer felt "in

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[1] Colin Lee Talley, *A History of Multiple Sclerosis*, Healing Society--Disease, Medicine, and History (Westport, Conn.: Praeger, 2008), xiii.
[2] "Sufficient Unto the Day" in S. Kay Toombs, David Barnard, and Ronald A. Carson, *Chronic Illness: From Experience to Policy*, Medical Ethics Series (Bloomington: Indiana University Press, 1995).
[3] "Sufficient Unto the Day" in ibid., 3.
[4] Ibid., 4.

control" of her life. The body that once provided a ground for all that was conceived as possible transformed into "a threat." Both the speed and scope of this transformation is remarkable. How could a constitutive, constructive condition of one's future become a deconstituting, deconstructive condition?[1] Recalling the quote from Michel Henry above, how could the human body suddenly transform from that which provides a ground for the possible to that which destabilizes possibility and, in death, extinguishes it? Does this possibility of such variability and transformation not mean, as Henry claims, that the body is ground of contingency itself? If that is the case, then dis-ability marks out the contours of human possibility and possibilizing itself.

Toombs writes that one effect of receiving her MS diagnosis stood out above all others: "there was the overwhelming realization that, from that point on, I would live every day with uncertainty, never knowing (from one day to the next) what the extent of my physical capacities would be"[2] This uncertainty did not simply throw her projects into question. It rendered unstable the conditions of the possibility of purposive action. Receiving a life-altering diagnosis destabilizes not simply particular possibilities, but the very ground of possibility.

The experience of diagnosis is especially difficult to analyze because it involves the construction, categorization, and social dissemination of disease states. It is thus simultaneously a question of access to medical knowledge, the state of scientific-medical research, the political and capital drivers guiding and shaping that research, and the uptake of medical information in various media outlets. Toombs notes that in the early days of her diagnosis, she entertained many false ideas about what MS would mean for

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[1] This problem is addressed directly, I would argue, by Heidegger in his meditation on Hölderlin's line: "where the danger is, the saving power also grows."

[2] Toombs, Barnard, and Carson, 4.

her.[1] Some of these were due to the medical definition of that diagnosis. There are a host of symptoms. There are states of remission with respect to certain symptoms, but those states cannot be predicted. Nor can the speed and specific character of the overall progression.

Toombs points out that aside from the medical definition's ambiguity and negative forecasting, her expectation of life with MS was framed by horrifying videos from the MS Society. These videos effectively conveyed that she would have no choice but to watch her life disastrously fall apart. That is to say, these videos suggested that her future would not simply alter, but disintegrate and *compress*: possibilities she once had were presented as impossibilities and multiple negative outcomes were presented as inevitabilities. "The reality of my illness in the early days would have been other than it was if the initial 'message' had been portrayed differently."[2] The message needlessly intensified the scope of disruption MS would cause.

> It is hard to express what that movie did to me, as it seared its way into my consciousness. I was still trying to understand what the diagnosis might mean of for my life…I yearned desperately for something—some evidence, some information about research, some positive example of a person living productively with MS—that would diminish the terror and give me a reason for hope. But, in large measure I lost my capacity for hope that night—not entirely, nor permanently, but for many months to come…the only question that now remained in my mind [after seeing the video] was how rapid my destruction would be.[3]

Even though Toombs interpreted her diagnosis as deeply negative and threatening, there is a clear divide here between the global anxiety or concern in the experience of receiving a medical diagnosis and that of recognizing the concrete, particular effects it will have on

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[1] I have discussed this at greater length in Joel Michael Reynolds, "Feeding Upon Death: Pain, Possibility, and Transformation in S. Kay Toombs and Kafka's the Vulture," *Jahrbuch Literatur und Medizin* 6 (2014).

[2] Toombs, "The Lived Experience of Disability," 19. Reprinted as "Reflections on Bodily Change: The Lived Experience of Disability" in *Handbook of Phenomenology and Medicine*, Philosophy and Medicine (Boston: Kluwer Academic, 2001).

[3] Toombs, Barnard, and Carson, 5.

one's life. That is to say, it is one thing to feel general existential disequilibrium; it is another to think that one will inevitably become divorced, financially destitute, and alone. The cultural imaginary about acquiring some form of "disability" is stark enough—why would a group designed as a support system for those with a specific disability create an informational video that in fact erroneously inflamed its negative aspects?

If those running the MS society still experienced themselves in terms of *before diagnosis* vs. *after diagnosis*, if prior to their diagnosis they assumed that, e.g., using a wheelchair meant being wheelchair *bound* as opposed to wheelchair *able*, if the horizon of interpretation of their lived experience was, in short, thoroughly ableist—then it is no wonder the video exacerbated rather than palliated. If those hypotheticals hold, the only cure and only positive outcome is a return to the state before MS and the only relevant prognoses concerning MS are negative and world destroying. If ableism and the ableist forms one's hermeneutic field, disability is invariably a form of demise and deprivation.

§4.3.1 Ability Trouble

But are the disruptions and transformations of MS in and of themselves deprivations? Does corporeal alteration entail degradation? Toombs writes, "multiple sclerosis, like every other illness, is experienced not just as the breakdown of the body, but as the disruption of *the life that is lived in that body*."[1] The shift from acute attacks to progressive degeneration brought this to light more than anything: "there began a slow but relentless, gradual progression of disability, in the course of which I have (among other things) permanently lost the full use of my legs, a good deal of upper body strength, my sense of balance, and normal voluntary control of my bowels and bladder."[2] But life

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[1] Ibid., 4.
[2] Ibid., 6.

is not merely lived in the body, and diagnosis is not prognosis. Anticipation and expectation alter the character and meaning of present experience. “In seeking a cure, the patient anticipates a perfect restoration of health, a return to the way things were before he or she became ill. In asking for a prognosis,” Toombs writes, “the patient expects a prediction of what is going to happen to him/her personally.”[1] The desire for cure and for prognosis each serves to combat the perception that one’s possibilities will be compressed, but insofar as they are held, they foreclose the possibility of desiring or achieving an equilibrium in one’s current state.

Both the diagnosis and the video indeed present MS as a “compression” of possibilities and as a “gradual progression of disability.” Yet, this assumes that the referent for Toombs’ *experience* of her body through the progression of MS will always be to a well-defined, able-bodied static “before.” Some of Toombs’ own analyses indeed operate along the lines of a dichotomy between life before diagnosis and life after. But it is *phenomenologically* inaccurate to simply say that Toombs, at point X, no longer had physical abilities she once possessed. This is inaccurate for at least two reasons.

First, the entire horizon upon which the meaning of her pre-diagnosis world relied became fundamentally altered in the purposive and, later, experiential incorporation of anticipated post-diagnosis ramifications. In this alteration of horizon, she came to experience new normals. Yet, the idea that she experienced the pure loss of a given ability does not square with the experience of new horizons and new normals. As I argue in more detail below, however inaccurate one’s anticipations might be upon receiving a diagnosis, even the experience of supposedly universal categories such as space and time

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[1] Toombs, *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient*, 18.

are altered in the experience of disabilities such as MS. In short, upon receiving the diagnosis and, *a fortiori*, after experiencing the condition that diagnosis describes, Toombs experienced *a different world*. As an example:

> Loss of mobility (be it prolonged or temporary) transforms the character of surrounding space…what was formerly regarded as 'near' is now experienced as 'far'…The answer to the question 'is it too far?' no longer bears any relation to objective measurement of distance. It depends, rather on what is *between* 'here' and 'there.' Are there obstacles that prevent the use of my scooter? Is the terrain suitable for a wheelchair? (It may also depend upon my level of fatigue).[1]

Space is experienced in its *inconsistency*—it is a domain relative to *this* body in *this* place in *this* time in *this*...one could continue multiplying such designations. Both the domain of space and one's movement through it are destabilized.[2] In summary, the first reason why it is *phenomenologically* inaccurate to simply say that Toombs, at point X, no longer had physical abilities she once possessed is because the very conditions by which one experiences an "ability" are thrown into question by a disability such as MS. The parameters by which one would speak of a "before" or "after" are themselves thrown into question.

The second reason why it is phenomenologically inaccurate to simply say that Toombs, at point X, no longer had physical abilities she once possessed is because this assumes what I call the naïve concept of ability. It assumes abilities inhere or otherwise attach to discrete subjects, when even a cursory analysis of the concept of ability proves such a thought false. "I can breathe" is no more descriptive of myself than it is of the

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[1] Toombs, Barnard, and Carson, 12, my italics.

[2] The change is both in terms of the kinetic abilities by and through which one perceives space as well as the parameters that define space ("here," "there," etc.). This connection between movement and possibility or potentiality goes back at least to Aristotle's *Physics* and *Metaphysics* with respect to the distinction between *kinēsis* and *dunamis*. E.g., Aristotle argues that "the being-towards-an-end of potentiality qua potentiality: that is motion [ἡ τοῦ δυνατοῦ, ᾗ δυνατόν, ἐντελέχεια φανερὸν ὅτι κίνησίς ἐστιν]." Aristotle, *The Physics*, trans. Philip Henry Wicksteed and Francis Macdonald Cornford, 2 vols., The Loeb Classical Library Greek Authors (London: W. Heinemann, G.P. Putnam's Sons, 1929), 201a11-12, my translation.

environment in which I breathe. A slight change to the proportions of oxygen and nitrogen in the air proves this swiftly and decisively. This is not to say that my lung capacity is not a relevant factor—it is merely to say the conditions of the possibility of a given ability are never isolated in a subject. Abilities are thoroughly relational.[1]

§4.3.2 'Disability' Trouble

Toombs' analysis hones in on quite specific bodily and social responses (fatigue, disequilibrium, depression, stigmatization, etc.). These are always presented *in terms of* their relational interactions with the beings, havings, and doings of her life. It is, however, in contrast to this attention to specificity and relationality that she employs the concept of "disability." In the article under discussion, Toombs seems to use it first as a synonym for dependency. She writes that after her divorce, "for the first time I wondered if I would be able to manage on my own. The fear that I might become disabled intensified my anxiety about the future. I had always been very independent" (10). In the following paragraphs, she describes the progressive stage of her MS as a "gradual progression of disability," but then switches back to speaking of illness thereafter (10-11). Toombs employs the term "disability" in the context of the medical model even though that use and understanding of the term is not borne out by her phenomenology.

Indeed, even if, instead of the medical model, one simply takes "disability" in its primary denotational sense of "lack of ability," that too is contradicted insofar as Toombs presses over and over again how her self-perception of lacking a given ability was always in a dialectical relation with her socially and medically pre- and post-diagnosis ability expectations. Disability, like ability, is not a quality that attaches like a predicate to a subject. Disability, like ability, is constituted by historically variable processes of

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[1] I spend the fifth and final chapter of the dissertation working to understand the meaning of ability.

interpretation and naming as these interact with material conditions both built and given. Ordinary language is telling on this point. We do not call an aging person disabled if they tire often. We do when they use a wheelchair, though we might not if they only use a wheelchair part of the time—"part of the time" being undefined. Both tiring often and using a wheelchair will create disruptive ability transitions. Both might fundamentally alter one's projects. Both involve diagnosable material factors. Still, these similarities fail to produce consistent description. The social imaginary concerning disability or, more accurately, the *disability imaginary*, does not actually follow the contours of experience. Why is this so?

What is today, arguably, the most recognizable symbol of disability? A wheelchair. Perhaps it is not coincidental that the *first* thing Toombs names in the litany of her "slow but relentless, gradual progression of disability," is the permanent loss of the full use of her legs. Although it is not explicit, one wonders if she imagines the dependency she so fears just two paragraphs earlier as primarily brought on by being in a wheelchair. The wheelchair forcibly shifts her into a new social category in a way that her disequilibrium or fatigue does not (at least not as automatically and not unavoidably visibly). The wheelchair makes the relative dependency brought about by the progression of her MS undeniably explicit, and this dependency is conceived as a constitutive suffering. "I would be unable to manage on my own" rings out with severity and solemnity.

While one of Toombs' own goals is to balance out the authority of medical, third-person knowledge with that of first person experience, her use of the term "disability" and her explicit conflation of disability with dependency are rooted in medical *epistemes*, not that of phenomenological reflection. As I argued in my analysis of models of disability in the previous chapter, the medical model of disability proves incommensurate with experiences of disability. So far from attesting to "disability," Toombs' analysis (despite some of her explicit statements suggesting otherwise) deconstructs the very concept of disability, despite her own deployment of the term.

Tellingly, at no point in her phenomenology would it make sense to say, "she is here speaking of disability." She describes the way ability transitions lead to sometimes minor, sometimes grave negotiations of personal ability expectations along with those of specific others such as her first husband and society more generally. She describes stigmatization. She describes the specific effects of specific conditions in specific scenarios or chronologies. She describes her expectations altering multiple times. She describes successes, such as getting her PhD, that would be judged as successes without qualification, successes that fly in the face of the "no future" to which the MS society's prophesy's condemned her.

It bears repeating at this juncture the epigraph above from Nancy Eislan: "the telescoping of our lives into simplistic categorizations of good and bad, pain and pleasure, denies that the lives of people with disabilities, like all ordinary lives, are shot through with unexpected grace, overwhelming joy, and love returned. *Life is simply a mixed blessing*."[1] Part of the larger philosophical point I wish to highlight here is that abilities are constitutively variable. That we attach enormous weight to some and not to others is, on the whole, often less a function of facts about bodies and more a function of societal and personal expectations. It is with this critical comment in mind that I now turn to the formal structures in Toombs' phenomenology of MS.

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[1] Eiesland, 13, italics added.

§4.4 – The Structure of MS

“Much of what befalls us remains to be interpreted.”
—Lysaker[1]

When I said above that Toombs now experienced a different world, I immediately pivoted to a discussion of space and time. The transformation of space and time should already suggest the ultimate stakes of changes to one’s abilities and ability expectations. One cannot attend to changes in abilities without simultaneously looking to the supports and structures in which those abilities simultaneously *are* and *can become* abilities in the first place. And one must look to the hermeneutic strategies we have developed in order to explain those abilities to ourselves. Alison Kafer notes,

> "Chronic" fatigue, "intermittent" symptoms, and "constant" pain are each ways of defining illness and disability in and through time; they describe disability in terms of duration. "Frequency," "incidence," "occurrence," "relapse," "remission": these, too, are the time frames of symptoms, illness, and disease. "Prognosis" and "diagnosis" project futures of illness, disability and recovery. Or take terms such as "acquired," "congenital," and "developmental," each of which is used to demarcate the time or onset of impairment. "Developmental" does double duty, referring both to lifelong conditions, including those that develop or manifest in childhood and adolescence, but also implying a "delay" in development, a detour from the timelines of normative progress.[2]

The semantic heavy-lifting of disability is adjectival and, given the arguments of chapter three, this should not be surprising. With the stunning breadth of such terms and the experiences to which they relate in mind, I will argue that Toombs’ phenomenology of MS suggests three general structures or features: attentional, personal-social, and horizonal reconfiguration.

§4.4.1 Attentional Reconfiguration

One of the more salient features of Toombs’ description is the role of *salience* itself or, more specifically, how the salience of any given thing is in principle subject to

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[1] John Lysaker, "Being Equal to the Moment: Form as Historical Praxis," *Philosophy and Literature* 38, no. 2 (2014): 405.

[2] Kafer, 25.

alteration in the experience of MS. I term this "attentional reconfiguration." To take one example, the scope of subjective attention is widened as one moves from focusing on the possibilities of a particular part of one's body (e.g., "I can't move my leg") to the incorporation of this experienced restriction as a *fact* of the world. Once incorporated, one now focuses on the possibilities of an entire field (e.g., "Is there access for a wheelchair here?"). This *in-corporation* is crucial, for salience is constituted by corporeal structures above all else.

To be clear, attentional reconfiguration is not a question of physiognomy or pathology: it is a question of the frame in which and by which one's world is structured. When Toombs, upon becoming a wheelchair user, cannot access location X because that location only has steps, a fundamental reconfiguration of sense has occurred. Yet, that reconfiguration alters not simply the way in which the world is understood (as if this were merely a question of epistemology), but the way in which the world is experienced: "I can't go there" means "that space is not designed for me." It is also a question of ontology, of the way "what is" responds or opens itself to "what I am."

The supposed "objectivity" of space always turns out to be framed by "fit." The purposivity or teleology of things informs one's place in the world—and in many experiences of disability quite literally. One can experience "I don't belong here" in non-built environments as well. A hurricane strikes. Or, less dramatically, one encounters a locale with predatory or territorially defensive organisms. In those cases, the salience of the *fluidity* of one's abilities will come to the fore quite explicitly. If one is ambulatory but, say, not able to run for whatever reason, that inability will be primary for one's survival. If one is allergic to the flora in the area, and this temporarily makes one "unable" to run, *that* inability will become primary. If one is entirely "normal," yet the organism hunting one is faster, then that species-level "inability" will become primary. Or, perhaps environmental factors come to the fore: the wind is strong or the ground is sticky. In each case, subjective, objective, *and*/*or* absolute abilities prove determinate.

Attentional reconfiguration occurs most obviously when the subjective salience of a corporeal engagement shifts to being an objective factor about the world. "I can't walk" becomes "Is there access for a wheelchair here?" "Design," whether human or evolutionarily based is key here. E.g., wheelchair users, especially prior to legal interventions, were *left out* by design in the built environment. Human organisms, on the whole, are left out by "*design*" (the quotation marks are important) with respect to well over 99% of universe.[1] In other words, when access is the frame for one's interpretation of corporeal difference and variability instead of impairment or accommodation, one begins to see the depths of built and "natural" inequality. Both physical limitations (e.g., the physical *inability* to walk) and the social determinates (lack of elevators) are determinate factors, and, as interactionist theories of disability argue, these can rarely be neatly separated.

Attentional reconfiguration always occurs in tandem with spatio-temporal transformation. That is to say, crip time and crip space are distinct from normate time and space. The time to get from place A to B, the way in which space is configured in that temporality—which is at once a spacialization—these are conditions or backgrounds against which one's attention is configured. One no longer simply sees "sidewalks," one sees sidewalks with or without curb cuts. Or, one "sees" nothing at all, and either hears

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[1] By using the term "design" in an evolutionary context, I in no way mean to indicate that there was an individual or group designer. I mean "design" in an analogous manner to Foucault's use of power. It names a force that exerts itself upon a number of phenomenon without a central, intentional "agent" or "cause."

the updated stop-walks that announce the timing of pedestrian traffic or is forced to deal with crossing paths with cars without such sonic markers. Attention is altered in light of the ability expectations from which one lives and is altered by how those ability expectations interact with various environments—built, social or what have you. In non-congenital disability, the shift from previous ability expectations to new ones is, as Toombs account suggests, the hardest factor with which one must deal.

§4.4.2 Personal-Social Reconfiguration

MS suggests a profound reconfiguration of one's sense of self and the way in which one is viewed socially. A shift occurs in the relative "unity" of the self as the injury or disease moves from "out there" ("my leg is damaged") to being constitutive of the self in at least some respect ("I *am* a wheelchair user"). Insofar as one's condition is variable—e.g., if one is unsure of how much pain one will be in—all of one's projects are thrown into doubt. One's identity, insofar as it is tied to one's abilities, becomes fundamentally *uncertain* or, at the very least, open to revision upon complications.

Recalling the discussion above of the import of the white cane vis-à-vis Merleau-Ponty, the gaze of the other (whether doctor, family, or stranger) co-constitutes the way in which these shifts occurs as well as their specific ramifications. Whether the people around the sufferer figure these changes as a "struggle" or an "enemy" against which one must "fight" or whether they figure them as "opportunities" for "growth" is not an arbitrary designation.[1] The disability imaginary of able-bodied people runs wild when

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[1] See Toombs, *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient*. See also: "Articulating the Hard Choices: A Practical Role for Philosophy in the Clinical Context," *Human Studies* 21, no. 1 (1998). Carol Thomas first coined the term "psycho-emotional disablism" to describe the way in which the stigma-related effects of disability determine one's experience of disability, and Donna Reeve has further developed this concept. Carol Thomas, *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology* (New York: Palgrave Macmillan, 2007). "'Psycho-emotional disablism: The missing link?' in Nick Watson, Alan Roulstone, and Carol

encountering a person with a disability with which they are either unfamiliar or about which they have insufficient disability education. Take as an example Toombs' experience of able-bodied disability conflation:

> Whenever I am accompanied by an upright person, in my presence strangers invariably address themselves to my companion and refer to me in the third person. "Can *SHE* transfer from her wheelchair to a seat?" Would *SHE* like to sit at this table?" What would *SHE* like us to do?" This almost always happens at airports. The person at the security barrier looks directly at me, then turns to my husband and says, "Can *SHE* walk at all?" We now have a standard reply. My husband says, "No, but *SHE can* talk!" (When I am unaccompanied people often act as if my inability to walk has affected not only my intelligence but also my hearing. When forced to address me directly they articulate their words in an abnormally slow and unusually loud fashion—in the manner that one might use to address a profoundly deaf person who was in the process of learning to lip read.)[1]

This type of situation, one attested by numerous wheelchair users as well as people with disabilities of other sorts, is preposterous. It exemplifies the ableist imaginary gone wild: "You're not like me. You're *disabled*. You **can't do anything**." It exemplifies a hyperinflation of the ableist conflation wherein disability is not simply a harm, but a global harm. One can neither speak, nor think, nor ____, just by the sheer fact that one utilizes a chair for mobility. Imagine how that must feel to anyone in such a situation.

§4.4.3 Existential Reconfiguration

At the outset of this dissertation, I asked, "How are we to hear the words, 'You are disabled'?" I also asked that with respect to pain and chronic pain. The most salient aspect of the phenomenological description of MS provided by Toombs is that MS effected an existential reconfiguration of sense. The conditions for the possibility of all of *her* possibilities was transformed. Precisely insofar as one's horizon, one's person, and one's social field are constricted relative to a prior configuration, *novel* transformations are also generated. For example, Toombs notes how physical abilities she once took no

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Thomas, *Routledge Handbook of Disability Studies* (New York: Routledge, 2012).

[1] Toombs, "The Lived Experience of Disability," 17.

notice of were, upon their impossibility for her, now *wondrous*.[1] Their phenomenality changed, and new sublimities arose. So, yes, in the existential transformation of non-congenital disability, certain aspects of the world can indeed recede or compress. Yet, certain aspects can be opened, generated, *enriched*. The quality of one's relationships may take on a new urgency or depth. The understanding of architectural and social space may be amplified and transmogrified in light of new interests and new problematics. More pedantically, the walking cane or some other assistive device, things which for many are but a helpful object from time to time, these might become beings through which and by which one lives—oftentimes literally. Such objects are no longer just things, no longer encountered as at-hand. They take on new meanings. Values change. Novel transformations emerge. *Alteration does not entail degradation.*

The ableist conflation gains traction at precisely this juncture: it only sees a life constricted relative to *normative* ability expectations, so it sees constitutive suffering.[2] But this assumption is profoundly misguided. In cases of *congenital* disability, such a thought is humorously mistaken. Anecdotally, when an "able-bodied" person expresses pity to someone who, e.g., was born without a phenotypical limb, and says, "You poor thing, it must be so hard without that!" the response is nearly always something like, "Uh, no, I was born this way, and I get along just fine." Whatever sufferings congenital disability can accurately be said to bring about, these are often not due to degradation, but to the structures and strictures of social spacialization and temporalization. One diagnosed with autism, e.g., is disciplined or cordoned off from other students. One who

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[1] Toombs, Barnard, and Carson, 13. Cf. Nancy Eisland makes a comment along these lines when describing the experience Nancy Mairs had of MS: "She gained an awareness of her body that she had never had before." Eiesland, 43..

[2] This is the case whether these ability expectations are constructed by reference to one's past, to societal norms or what have you.

utilizes a wheelchair cannot access certain areas because architects or other building professionals have assumed that wheelchair users need not be considered or that they would rather take the chance of a lawsuit by means of the ADA. None of this is necessitated by physical impairments. Although there are certainly limiting conditions, these are all primarily and for the most part effects of material and immaterial *constructions*.

§4.4 Conclusion: Disability as Deregulation

> We live in a world of norms. Each of us endeavors to be normal or else deliberately tries to avoid that state. We consider what the average person does, thinks, earns, or consumes. We rank our intelligence, our cholesterol level, our weight, height, sex drive, bodily dimensions along some conceptual line from subnormal to above-average. We consume a minimum daily balance of vitamins and nutrients based on what an average human should consume. Our children are ranked in school and tested to determine where they fit into a normal curve of learning, of intelligence. Doctors measure and weigh them to see if they are above or below average on the height and weight curves. There is probably no area of contemporary life in which some idea of a norm, mean, or average has not been calculated.
> — Lennard J. Davis[1]

Different ways of being in the world are not *by virtue of* being different worse. End-states whose transition is profoundly difficult are not intrinsically negative states *by virtue of* the difficulty of their transition. Although I do not wish to deny that a phenomenology of illness is impossible, I disagree with Toombs that "illness may be understood as a particular way of being in the world – a way of being that exhibits certain typical characteristics."[2] Illnesses are diffuse. The way in which they interact with common categories of "disability" even more so.

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[1] Davis, *The Disability Studies Reader*, 2.

[2] Toombs, *The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician and Patient*, xvi.

An initial implication of the phenomenology above is that in order to understand the "disabled" body, one must return to the concept of the norm, more specifically, to the concept of the normal body. The problem is that norms are are tenuous, ephemeral, and slippery. Eva Kittay, speaking of her intellectually disabled daughter, speaks powerfully of this relation: "that which we believed we valued, what we—I—thought was at the center of humanity, the capacity for thought, for reason, was not it, not it at all."[1]

Through corporeal variability, through myriad experiences of disability, and through the intimate intricacy of relations of care, the body reveals its infinity, the unending transformation the *whole* of which marks the terrain of that ambiguous phenomenon we call "life." The very texture, in other words, of *all* that is experienceable as both possible and actual can be made anew.[2] It is not like comparing this to that, before to after, but like comparing bounded infinities…one can compare them, but only by bounding two in principle limitless and thus two in principle incomparable phenomenon, only by treating them *as if* they were wholes. When the infinities to which we submit this subjunctive quantization are people, the ensuing deleteriousness is palpable. The ableist conflation performs precisely such a move and, in doing so, reveals itself as the most pernicious kind of conceptual subterfuge: in feigning epistemic obviousness, it provides a refuge for ignorance and prejudice.

It is here where the transversal position[3] of people with disabilities reveals the distinction between the able-body and the disabled body in its absurdity. Absurd—unless

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[1] Eva Feder Kittay, *Love's Labor*, 150.

[2] It is precisely out of a shared set of meanings and references that one can determine things "quantitatively" or "qualitatively" in the first place, which is why, to repeat, the latter designations cannot but fall short of capturing what occurs for a person living with chronic pain.

[3] The ease with which the "able-body" can become the "dis-abled-body" is indeed astonishing, but that transformation, if one takes it to mark a dynamism between two discrete positions, is false. The newly "dis-abled-body" becomes the new "able-body"—it becomes the referent, the hegemon, from which abilities are

it is understood relative to a fluid range of valenced possibilities. That one cannot access location X with a wheelchair or that one is treated differently by educational systems due to a diagnosis on the autistic spectrum are less factors about physiognomy or neurology or pathology or a number of other -ologies and more factors about *ability expectations*.[1] Those who do not fit the ability expectations of a given domain are the ones who experience that domain in its thetic authority and thus have the access to formulate its criticisms. It is at this juncture that it becomes clear that a remaining stronghold of the ableist conflation is not just its conceptions of pain or disability, but its conception of ability. It is to that topic that I will now turn in the fifth and final chapter.

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now judged. It is here where the social, architectural, historical, technological—one could go on and on—it is here where these appear in their malleability.

[1] That the suffix "-ology" has in the last three centuries come to mean empirical "study of" is of no coincidence on this point. See Foucault, *Birth of the Clinic*.

☙ ABILITY ❧

5 ABILITY TROUBLE

> "We must do more than simply extend the scope of morality."
> —Shildrick[1]

> "In vain we force the living into this or that one of our molds. All the molds crack. They are too narrow, too rigid, and too unyielding. Our reasoning, so sure of itself among things inert, feels ill at ease on this new ground."
> —Bergson[2]

I began this dissertation by asking how concepts of ability and disability bear upon ethics, upon the range of practices and thinking we deem "ethical." I then argued that across the history of philosophy, conceptions of what we today call "disability" are commonly informed by the ableist conflation: the assumption that disability is harm and thus coextensive with pain and suffering. From the triage unit to court bench, from common courtesy to principled thought, today this conflation ultimately functions as a mechanism of power to control, govern, and oppress bodies marked as "disabled." I then examined the two primary components of the conflation: "pain/suffering" and "disability." Through a critical analysis of theoretical models coupled with a phenomenology of each primary component, I contended that the ableist conflation is untenable. It misunderstands, mischaracterizes, and overgeneralizes the nature and history of both pain and disability as well as their relations.

However, one might counter: while I have offered explanations of various conceptions of pain and disability, I have not addressed why the two phenomena would

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[1] Margrit Shildrick, *Leaky Bodies and Boundaries : Feminism, Postmodernism and (Bio)Ethics* (London ; New York: Routledge, 1997), 2.
[2] Henri Bergson, *Creative Evolution*, trans. Arthur Mitchell (New York: The Modern Library, 1944), xi.

have become so linked in the first place. What installed this powerful, deceptively simple, and deeply fraught habit of thought into such a vast range of minds and practices and traditions? Put otherwise, the question of the origin of the ableist conflation remains unanswered. I do not mean its historical origin, but its origin in the sense that term bears when thought as a *principium*: an origin that is at once a ground or foundation, that out of which and by which it could first of all make a claim on thought and practice.

I will argue that the principle of the ableist conflation lies not in its understanding of pain or disability, but in its *conception of ability*. That is to say, the problem of the ableist conflation is grounded in and originates from the implicit concept of ability operative across its various forms. This conception is one wherein ability is understood as a function anchored in and wielded by an individual to control relevant outcomes within a possible future. Put simply, ability is understood as control over one's possibilities. Such possibilities become salient and vary in relevance relative to the manner in which they enter into matters of concern. Ability, thought in this way, is a function of one's perception of personal control. I will henceforth term this *ability as personal power*.[1] It is this concept, I'll argue, that gets the ableist conflation off the ground and sustains its historical prevalence.[2]

I then develop an alternative understanding of ability: *ability as access*. It will quickly become clear that part of the difficulty in approaching the question of the meaning of ability is in assessing the relevance and range of its determinations in a given

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[1] It is the range and specificity of one's concerns, which are socially mediated, that determines which abilities "count" as value-conferring, neutral, or value-detracting.

[2] Whatever problems one might raise relative to such an understanding of ability, one is hard-pressed to deny that the ethical *subject* of canonical normative theories is assumed to be an individual and one for whom abilities are typically thought as matters of individual or personal power (even if Aristotle does not believe in modern senses of autonomy or individualism, the *Nicomachean Ethics* is still a project to educate and shape the will of a given individual). At the outset, if not the end, virtue, duty, and utility are assumed to be oriented by, if not ultimately questions of, individual praxis.

domain and, *a fortiori*, a given case. Working through a number of examples ranging from playing chess to sexual activity, I present a model for thinking of ability in this manner that I call the *charmed pendulum of ability*. This model serves as a heuristic for thinking the wide range of normative, epistemic, and ontological, et al., variations that the term "ability" picks out in a given context and serves as a heuristic for thinking how it is that abilities ultimately articulate avenues of access.

§5.1 Ability as Personal Power

If one looks to the ableist imaginary, at least as it operates in the United States today, the putative apex of conceptions of ability is found in the multiplicity of representations of the "perfect" body.[1] This is the (multiply) idealized body that confronts one relentlessly in advertising, fashion, and a host of vehicles through which consumerism engorges itself. As more than one commentator has noted, the relation of the desire for a perfect body (which is a way of indicating a perfect set of abilities) is not disconnected from the desire for a perfect text.[2] So far from a generalized and in some respects erudite point about the history of philosophy, this desire today organizes a wide swath of biomedical research and commands billions of dollars in funding nationally and internationally. With such stakes in mind, Lennard J. Davis writes:

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[1] For the purposes at hand, I am going to here gloss over a number of issues related to the term "perfect." Perfect relative to the discourses of health and medicine, the world of high fashion, Hollywood, or what? Perfect relative to what historical time period or culture? These are not the same, obviously, and I consciously use the term here without qualification to allow for this range of ambiguity, a range that is notably different not only across the globe today, but different across all manner of times and places. I mean it here as a placeholder for whatever ideals of the body hold sway in a given situation or context. Were I not wishing to leverage this ambiguity, I would begin by employing and further refining Davis' distinction between the ideal and normal body. See Lennard J. Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (London; New York: Verso, 1995).

[2] It thus resonates with a long a history, one which echoes, to follow Derrida, an obsession with and result of what he calls the metaphysics of presence. I am thinking here particularly of the essay, "Ousia and Gramme," in Jacques Derrida, *Margins of Philosophy*, trans. Alan Bass (Chicago: The Chicago Univ. Press, 1982).

> Somewhere, in some empyrean there exists the platonic human genome. This genome is a book or text made up of letters sequenced in the right order without 'mistakes.' As such, it is in fact a sacred text…errors of transcription have ruined the primal perfection for the text. The problem is related to exegesis and amanuensis. Thus, people with genetic diseases have 'birth defects' and are 'defective.'[1]

As I argued in the introduction to the dissertation, one of the central components of ableism, besides the assumption of a standard body, is the assumption of its perfectibility. This can take the form of valuing the standard body as if it were a perfect body (implicit in the joy underwriting the locution, "the baby is normal!") or the thought that the standard body is the only base from which a perfect body can exist (the Paralympic athlete, no matter their efforts, is not a pinnacle of human athleticism under such auspices). Ableism gains part of its affective and evaluative power through this *psycho-somal perfectionism*, to which the capital-fueled, medical establishment is, on the whole, beholden. Such perfectionism actively derides the sides of the infamous bell curve. Driven by lust after its fictional apex, a vast range of human activity lurches towards this reified and rarified air in which the very conditions for its own maintenance are, woefully and ironically, unsustainable.

This desire for a plenitude of ability, for having *all* the abilities one could imagine or desire and even certain abilities to the point of excess, is often displayed through how we narrate the human condition. *Why* do so many disregard or downplay the fact that we are not simply "disabled" in infancy and through aging, but that our "abilities" are themselves evidence of our constitutive "disabilities" and vice versa? As illness makes profoundly clear, that which we perceive as our "abilities" are not and never could be

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[1] DSR 4, (269).

things we possess. Abilities are at all times and in all places supported by the conditions of the vast range of possibilities of what we unthinkingly categorize as “disabilities,” of the constitutive variability that *it is* to be human. That I am able to run a 5k moderately well is conceivable as an “ability” only insofar as I am “disabled” without oxygen. That one uses a chair for mobility is conceivable as a “disability” only insofar as humans are “able” to be with or without upright ambulation. Any and every ability we take ourselves to have is a product of thoroughgoing dependence and support by others, by myriad and constitutively variable states of our body, and by our environment, which is itself considerably variable. Yet, at least as it functions in the ableist imaginary, the idea that abilities are individual, are properties of a subject, relies upon *an illusion of non-support.* Individual ability is the ideology of non-support. It is possible for me to do X, on such an account, solely due to what I can control on my own.

Whether one frames philosophical arguments over the nature of what is, of being, as having the poles of the one and many, intellectualism and empiricism, or transcendence and immanence, the deciding factor turns on how one conceives the relation between ideality and facticity or, in yet another philosophic idiom, between spirit/mind and matter. Yet, the conception of that relation is invariably determined by how one understands one’s relationship to the body and the role one grants or denies it. Is not our relationship to our own and to other bodies a, if not the, touchstone from which we conceive of and *live* possibility?[1] What does it mean to understand the body as a touchstone of existence? To understand the body as the anchor and ground of possibility?

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[1] By my lights, this question has been raised by everyone from Maurice Merleau-Ponty and Michel Henry in the phenomenological tradition, Judith Butler and Gayle Rubin in gender and sexuality studies, Charles Mills and Linda Alcoff in critical race theory, and Rosemarie Garland-Thomson and Lennard Davis in critical disability studies.

On the one hand, the body shapes the horizon of experience—it centrally and fundamentally determines what can and cannot appear, what can and cannot be disclosed to and for one as one finds oneself in the world. As Bryce Huebner succinctly puts it, "Even if we begin from shared assumptions, embodied trajectories through socially structured space will impact what we think and what we see as a possibility."[1] On the other, less ontological hand, the body has its own ways of being and ways of knowing which often never (and perhaps in some cases cannot) rise to the level of conscious awareness, whether first- or second-order. It is in virtue of these quasi-proprietary beings, knowings, and doings of the body that it sediments judgments in its very comportment and its complex matrices of response. It can do so often in spite of conscious efforts, as phenomena like implicit bias evidence well. To the extent that bodies are both sites and agents of doings, beings, and knowings, the articulation of the abilities of an embodied being is simultaneously ontological and normative.[2] This means that abilities are determined by a variable range of possibilities—from the necessary (the ability to breathe oxygen) to the contingent (the ability to touch one's nose with one's tongue)—that bears on and is structured by both what is and also by determinations of what should be.[3] Abilities are always determined by a range of *bionormative conditions* variable with

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[1] Byrce Hueber, review of Steven Horst's *Cognitive Pluralism*, *Notre Dame Philosophical Reviews*, September 3, 2016.

[2] With respect to sentient beings, this is always an articulation of the abilities of one's bodymind. I here use the term "bodymind" as suggested by Margaret Price as a simple, if unelegant, way to speak of the body and mind non-dualistically. Price. Qualifications such as bodymind, sentience, and even embodiment will be imprecise or problematic for some, especially given discussions of extended cognition. I cannot take up those debates here, and I will thus take an agnostic stance concerning the extent to which my claims here apply more broadly.

[3] I leave the determinations in question entirely open on purpose. The ablest conflation functions in part by embracing such ambiguity: whatsoever range of experiences is considered to exteriorize a person in a manner analogous to that captured by the English term "disability," that range of experiences causes or is coextensive with the range of experiences we in English call "pain" or "suffering."

regard to mode (necessity/possibility) and value (positive/neutral/negative). Put more acerbically, abilities articulate how, why, and, in certain cases, whether a being is at all.

What do I mean by this? Given its import, one's conception of ability informs how one understands "perception," "consciousness," "gender, "sex," "race," "dis/ability," et al., and, by extension, even "being." If I think that the sexual category "male" is the only sexual category coextensive with the "ability" to "reason," I will think that women do not have that ability.[1] If I, like Peter Singer, think there is an ability category called "cognitive ability" that is necessary for moral worth and also that certain humans are born without it, I will think that certain humans have no moral worth at all.[2] Such thinking removes those humans from existence in the moral universe entirely, and that is a prime example of my claim that in certain cases abilities articulate whether a being is at all. There are numerous other cases where abilities determine whether a being is at all: if I define as existent that which is reproducible under modern scientific constraints of experimentation, all manner of beings (and modes of being) are rendered non-existent. It is, for scientific thinking, the ability to appear under such constraints that determines whether something *is*. Does this not mean that one's understanding of ability determines one's understanding of being? And the reverse? How is one to think this linkage?

To be sure, the examples above suggest at minimum that concepts of ability are mutually reciprocal in determining how one understands and defines gender/sexuality and, *mutatis mutandis*, other such concepts that demarcate central ways of being in the world. But, more broadly, does this not mean that thinking ability is always an

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[1] To be clear, I am not here defending a particular view concerning the categories in question. I am using various assumptions about them to explore what inferences follow or do not follow and what premises are or are not implicit with respect to abilities and ability expectations.

[2] Eva Feder Kittay and Licia Carlson, *Cognitive Disability and Its Challenge to Moral Philosophy*, Metaphilosophy Series in Philosophy (West Sussex; MA: Wiley-Blackwell, 2010).

ontological undertaking? Is it not, at least in part, through abilities that a phenomenon is always and necessarily bounded? Furthermore, do not the possibilities and expectations those abilities pick out fundamentally determine the type, specificity, and in some cases singularity of a given being? And how, as I suggested above, do questions of normativity not simply factor into, but fundamentally determine these topoi?

Let me repeat some of the steps taken so far. With respect to the appearance and meaning of phenomena, ability expectations form a central, if not primary, nexus around which and through which various mediations congeal. Phenomena enter into intelligibility though dialectical processes, which is to say, through mediated processes. We have many names for many types of mediation: language, culture, evolution, history, etc. Ability is, on my account, an ultimate and undertheorized term for the power when subject and object meet. Once one reflects upon the concept of ability, the normativity of ability should be unsurprising given all the mediations out of which any given "ability" will appear. For an ability to "count" as a genuine ability, as opposed to what I'll call below a trifling ability, it will not designate a pure function of interrelations between an organism and environment; it will instead pick out a function that is held to be contextually valuable. What I can and cannot do is a vector of my situated worth. Abilities are invariably *evaluative*.

I suggested in the introduction to this chapter that ability, as implicitly conceived in the ableist conflation, is a function of perceived control over one's concerns. A constant and predominant criticism of modern liberalism lambasts its pervasive individualism. If one takes the concept of the individual as a starting point, it requires little to then assume abilities are a "power" of that individual, to assume that the abilities about which canonical ethical theories are concerned are personal abilities. Similar to the logic of the copula, "can" and "able" connect subject and object through a logic of identity. Under such auspices, "I can speak" means, "I am able, on my own, without help or interference from others, to speak!"[1] The "I can" is always already a condition and articulation of the "I am." To a philosophic ear so attuned, "I can speak" just means "I am a speaking being." That is to say, non-trifling abilities do not simply pick out accidental aspects of a being; they tell us something fundamental about a being. On this view, abilities *articulate* individual beings. They say what, how, and why one is. Who I am does not tell me what I can do as much as what I can do tells me who I am. Abilities determine and identify subjects. Yet, this identitarian logic of ability only functions when predicated on a specific concept of the individual, namely, the individual as autonomous.[2]

In *The Autonomy Myth*, Martha Fineman argues that individual autonomy is still today one of the core myths underwriting the cultural-political landscape in the USA. She lists all the ways in which autonomy is definitive:

> Autonomy is the term we use when describing the relationship between the individual and the state…we think of an economically self-sufficient individual as autonomous in relation to society [more broadly] and its institutions...the autonomy of the family…is expressed in the idea that it…is a 'private' institution…[and] there is…the autonomy of individuals within the family, for which feminists have fought by exposing domestic violence and child abuse.[3]

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[1] The idea that one must be *able* to do certain things without others in order to be considered as an individual is most obvious in law. I address this at length in an article currently in progress, "Ableist Saturation: The Case of Anna Stubblefield and the Intelligibility of Disability."

[2] See Appendix 1.

[3] Martha Fineman, *The Autonomy Myth: A Theory of Dependency* (New York: New Press, 2004), 21. Fineman then incisively asks: "What does a resort to the rhetoric of autonomy mask? Whose interests are served when it is invoked?"

Individual autonomy is a way of explaining what an individual *should* be able to do: it is a prescriptive framework for ability expectations that applies in principle to everyone. Yet, this is not just a matter of political or societal imaginaries. As Eva Kittay notes in *Love's Labor*, "a person who would do dependency work [Kittay's term for "caregiving"] … was viewed by Aristotle as the same person whose soul was defective in ways characteristic of a slave or a woman. Only the free male was thought morally capable of controlling the resources in the family economy and only he was granted the possibility of being a fully realized moral agent."[1] Certain types of dependent or caring relations were assumed to *restrain* the abilities of the politico-philosophical subject. The language of "defect" and "defectiveness," which Davis assailed above, is one way of marking out this putative inability. Yet, to mark such conditions as "defective" is to mark as defective what in many cases are inevitable and biologically "normal" aspects of the course of a human life. Insofar as the language of "defectiveness" relies upon a concept of the "natural" or "normal" whilst simultaneously hiding some of its conclusion, it reveals a fundamental mischaracterization and misunderstanding of the human. It marks a fundamental and damning, not incidental, failure of thinking what it means to be human.

In a related manner, Kant argues that autonomy, a concept that relies upon an understanding of ability as personal power, is the characteristic that grants humans dignity. As I gestured at above, the ethical ramifications of the logic of ability as personal power, a logic that links abilities to individual identity, should now be clear: significant abilities define the worth of an individual. On Kant's account, many people with

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[1] Eva Feder Kittay, *Love's Labor: Essays on Women, Equality, and Dependency*, Thinking Gender (New York: Routledge, 1999), 45. For more feminist critiques of autonomy, see Marilyn Friedman, "Beyond Caring: The De-Moralization of Gender," *Canadian Journal of Philosophy* (1987).

intellectual disabilities are not granted moral standing.[1] This is not simply a question of inclusion. Kittay points out that Kant's position "fosters a fiction that the incapacity to function as a fully cooperating societal member is an exception in human life, not a normal variation; that the dependency is normally too brief and episodic to concern political life, rather than [as is actually the case] constituted by periodic, and often prolonged, phases of our lives whose costs and burdens ought to be justly shared."[2] To suppose that autonomy, both in Kant's narrower sense and a more general sense, is necessary for moral worth is not only theoretically, but also empirically misguided. It's not ultimately a question of inclusion, but ontology; not norms, but the nature of being human. In short, understanding ability as personal power—which is implicit, yet foundational for Kant's account—assumes such a misunderstanding of the conditions of human life.

On its own, founding, and capable, the individual presupposed by an understanding of ability as personal power is one whose abilities are possessions. Ability as personal power assumes ability in terms of a thick concept of onto-normative perfectionism. This understanding reflects the stem of the Latin root for "possession" which relates to both *posse* and *potis*, "to be able" and "to have power."[3] Ability as personal power, then, draws upon the etymological link between ability and power, a link reflected in the Greek δύναμις as well.[4] On this view, what I can do tells me who I am because it is through the power relations *I wield* that I make myself known to myself and

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[1] There are some who argue a Kantian account can still grant moral worth to those without intellectual disability. Patrick Kain, "Kant's Defense of Human Moral Status," *Journal of the History of Philosophy* 47, no. 1 (2009).

[2] Kittay, 92.

[3] See "possess, v." and "posse, n.1" in OED.

[4] See "δύναμις, εως, ἡ" in Graecae.

others. But, as I'll argue below, even a simple distinction between human, social, and personal abilities demonstrates how ability understood as personal power is reductionist. Opposed to ability understood as personal power, I'll now provide a model for thinking about abilities that, by my lights, overcomes or at least improves upon its errors.

§5.2 The Charmed Pendulum of Ability

The person with exceptional, non-trifling abilities often receives praise because such abilities evoke awe. The very same abilities can, alternatively, evoke resentment and jealousy. The perception of exceptional *in*ability often receives pity because—if inability is equated with disability as understood through the ableist conflation—such inabilities evoke fear. That pity and fear can, alternatively, be expressed in hostility and anger. While the Jerry Lewis MDA Labor Day Telethon makes significant money by evoking pity for people with visible physical disabilities, hate crimes against people with disabilities increases after the ADA.[1] The Leadership Conference, a civil and human rights coalition, reports that "in one of the few disability-bias cases successfully prosecuted [since the ADA], in 1999, Eric Krochmaluk, a man with cognitive disabilities from Middletown, N.J., was kidnapped, choked, beaten, burned with cigarettes, taped to a chair, his eyebrows shaved, and ultimately abandoned in a forest. Eight people were subsequently indicted for this hate crime—making this one of the first prosecutions of a disability-based hate crime in America."[2] While the self-professed Good Samaritan might give the disabled vet a dollar, they might also vote against the expansion of Medicare or Medicaid and resent those "on disability." How is one to understand the asymmetry

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[1] Sherry; Longmore.

[2] "Hate Crimes Against People With Disabilities." The Leadership Conference. Accessed Aug. 25, 2016.

between these fundamental affective responses to varying types of abilities—praise or resentment due to awe and hostility or pity due to fear?

Following Gayle Rubin's "Charmed Circle of Sexuality," Bethany Stevens has crafted a Charmed Circle of Ability (Figure 1 below).[1] What Stevens' circle depicts so well is the way in which norms fundamentally determine ability. Depending on the strength of a given norm in a given situation, the overall existential impact will change accordingly. For example, what counts as "cognitive impairment" will vary—and vary wildly—across historical epochs and various norms of intelligence. Modes of identification, chosen or applied, co-determine not only how any given norm interacts, but the very meaning of each of the terms at issue. Disability might be experienced as feminine by a male raised under patriarchal ideology or, on the other hand, being good at sports might be experienced as masculine by a female raised under similar ideologies. Alternatively, being bad at sports, regardless of one's sexual identity, might be experienced as an inability due to the way that certain sports racialize ability (the stereotype of the young, black male being exceptionally good at sports is a prime example here). Coming

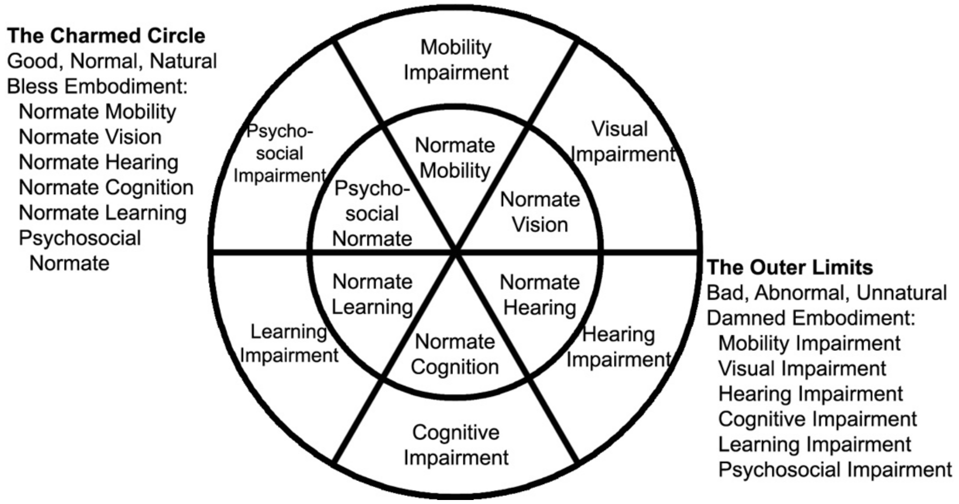

Fig. 1: The Ability Hierarchy - The Charmed Circle v. The Outer Limits

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[1] Bethany Stevens, "Interrogating Transability: A Catalyst to View Disability as Body Art," *Disability Studies Quarterly* 31, no. 4 (2011).

out as bi or gay or transgender or genderqueer might be experienced as, on the one hand, taking control over one's identity or, on the other hand, as an opening oneself up to potential pain and thus a loss of control in a different aspect. The extent to which one experiences pain will be affected by a wide range of ethnic or cultural ideals about self-control and gender roles in such cases and also more generally—just think of the refrain "boys don't cry." Malnutrition might be experienced as normal due to free trade agreements that destroy developing countries' economic self-sufficiency in the context of global capitalism and which offer no international, citizen-based rights. Self-control might be a minor experience in certain cultures, including some indigenous communities in North America, where control is not understood as individual and the fear of death is mitigated in a number of scenarios, such as warfare, or more generally, with respect to a Weltanschauung that emphasizes the non-material values and meaning of material life.

In each of these cases, one encounters a complex, variable organism striving to live in a complex, variable environment with a host of normative determinations that bound the parameters of its self-interpretation and self-determination. That organism, by virtue of existing in relation to a complex environment, is taken to "have" certain abilities. It will only "have" these depending on how we determine the bionormative limits of that organism in differentiation to others in a given context. To repeat from above, no being "has" any abilities as a property of their being. Abilities are reifications of patterns of fluid relations.

It is for this reason that I put forth the model of what I call the *charmed pendulum of ability*.[1] It is my hope that this model does better job than that of the circle to

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[1] By using this phrasing, I mean to invoke Gayle Rubin's Charmed Circle of Sexuality. Gayle Rubin, *Deviations: A Gayle Rubin Reader* (Durham, NC: Duke University Press, 2012). As will become obvious,

understand the macro- and micro-variabilities of any given ability as well as the blurred lines between any given normate vs. non-normate distinction. For example, the line between "normate vision" and "visual impairment" is profoundly difficult to distinguish, as the normalization of the prosthetic devices we refer to as "glasses" makes clear. That we even consider "blindness" to be a lack is itself philosophically problematic.[1]

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the structure of my arguments are indebted to theorists critical of deviance studies—from Canguilhem to Butler.

[1] See Reynolds, Joel Michael, "On Being Outside The (Normate) Body: Merleau-Ponty's *Aveugle* and Crip Phenomenology," *Chiasmi International*, forthcoming.

First, a word about the physics of pendulums is in order. A pendulum decelerates up to a positive peak and then accelerates from that peak back to the neutral line where it reaches maximum velocity. Its movement repeats this process until it has expended all its energy. Since, from a Newtonian perspective, a pendulum in the absence of any friction would maintain its energy and swing forever, this expenditure is a product of friction from air or other such particles. Assuming such conditions of resistance, the motion of a pendulum and its continual expenditure of energy is best understood as having four phases. "A pendulum swings to and fro. According to the more accurate definition of a vibration what we consider as one vibration is really two vibrations which are mirror images of each other. On the right side is the Negative phase with the Positive phase on the left. When swinging to the left the action is expanding to the Positive. So the motion is a Positive-Positive one. After reaching the full extent of its swing it begins to collapse back to the Neutral line. This is a negative motion (to the center) so it is a Positive-Negative phase. Just the opposite occurs on the right and Negative phase side. The conventional two phases of a vibration are in actuality four phases."[1] That is to say, one must think in terms of vectors: directions with magnitude. The force of the pendulum

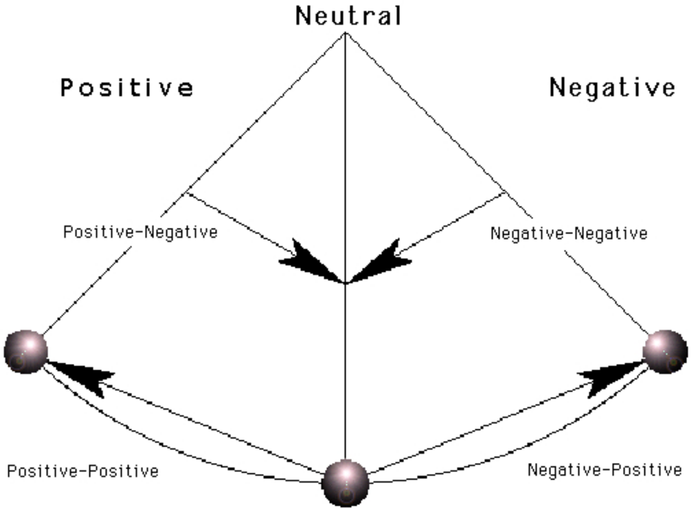

Fig. 2: Physics of Vibration as a Pendulum

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[1] Taken from "Vibration as Pendulum Swing," http://www.svpvril.com/Fig_3.1.html. Accessed November 2014.

must always be understood in terms of its relationship not only to the center, but the direction of its origin point and which of the four possible phases its motion represents. As a model for thinking of bivalent experiences, pendulums are inherently relational and dynamic.

Before I explain the three primary vectors of the charmed pendulum of ability, I want to repeat and re-emphasize the constitutive variability and contextuality of any given ability. I argued above that implicit and varying concepts of ability are always at work in our understanding of ourselves. At the level of ordinary language and "common sense," we think of abilities as things we possess; they are conceived as individual, stable powers. When one cannot do something one *expects* oneself to be able to do, that potentiality is rendered an "inability" and the outcomes to which it relates as failures. Note, of course, that if the "ability" in question does not enter into meaningful relations, it will never be considered an "inability." I can't tap dance while drawing a perfect circle. I can't skydive while building a house. The former is plausible, but unimportant. The latter is simply impossible. Some abilities, whether due to the parameters of our environment or our corporeal form, cannot overlap spatially, temporally, or both.

To take an autoethnographic example, as opposed to the ability to tap dance while drawing a perfect circle, the ability to write (bracketing for a moment the extremely wide range that verb captures) is not only central for both my self-understanding and also the regard of others, but I also take myself to be—hopefully slightly—*better* at it than a person not trained to do so. Well…at least with respect to philosophy. Note, yet again, that the moment one begins to define a given ability, one is forced to confront the normative dimensions by which its specific characteristics and general range is defined and rendered relevant in a given context. Having said this, any given "normal" ability will always be interpreted in relation to a perceived lack and perceived intensification of it. One cannot determine a particular ability *as such* without simultaneously thinking the germane hyperability and inability to which it is related and defined. To experience or think an ability is thus always a function of *valenced* possible experiences and valenced conceptions by virtue of which it is defined.

§5.2.1 The Pendulum of Health

One central, contemporary component through which we experience and understand the pendulum of ability is through the concept of health. Today, when you woke up, what were you thinking about? Probably what you need to accomplish: you focused on your projects. But let's say you get a cold. Now you are forced to focus on your body: your nose runs, and you get tissue for it. You feel lethargic, and you lay down to rest, etc. You may still focus on your projects and plans, but they are altered or suspended in light of the illness. At the opposite end of such experiences, when one is supremely healthy—having, say, the remarkable energy of a child or the heart and lung capacity of many professional athletes—this is often registered as being beyond "normal" health, a state I'll call *hyperhealth*. Note that relative to a human life of even just thirty years, we all experience varying levels of this pendulum swing. *Health is never simply maintained*.

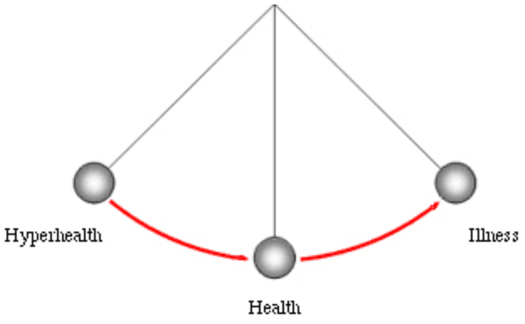

Fig. 3: The Pendulum of Health

Health thus refers to that state in which we both are and also perceive ourselves to be in organismic homeostasis. It involves proprio- and interoceptive regulation, embodied and habituated ease of being in the world, and a host of self-relations that are always already socially co-determined. This is one reason why understanding health in terms of a pendulum, as opposed to something a static model such as a circle, is important and instructive. Note, however, that the meaning of the right side of the pendulum is not symmetrical with the left. Because we tend to start with the negative to help us define the point of equilibrium, hyperhealth is not understood as ‘not being healthy’, but as being healthy in an extreme or intensified way. The vector of the pendulum of health starts from the right side, from the “negative” side in the depiction of figure 3 above.[1] I’ll return to this point again, for it will prove crucial in understanding the phenomenon of health and how it interacts with understandings of ability.

If an illness comes with discrete pain—say, a migraine headache or severe aches—one is forced to focus even more on one’s body. Perhaps one can no longer open one’s eyes in light or get out of bed. Now, one likely isn’t paying attention to one’s projects any longer; they perhaps move all the way from attentional foreground to background to virtual disappearance. But, to return to a point from chapter four, what should one conclude from the fact that one’s projects *are capable of* receding to the point of evaporation—capable even if they are primary life projects around which one has shaped and oriented one’s entire life? What type of being is the human in order for such a thing to be possible? It is helpful here, as earlier, to look at how we talk about such cases. An ordinary language analysis reveals that we speak in terms of inability. “I cannot get

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[1] I put negative in quotation marks because one must stipulate the valence of the “sides” of a pendulum model. One could imagine health instead being defined in terms of the “positive” side (and, though it seems to me to not be the norm, people sometimes talk this way).

out of bed; I am not able to." "I have given up on being a pilot; I can't do the job." The "I can" and "I cannot" form the primary language of such transitions, of such movements with respect to one's relationship to one's body as a touchstone of existence, as that through and by which we experience things as possible or not. This language reveals an implicit understanding of health as tracking ability, as a fundamental vector in and through which we experience and interpret our being in the world.

Note, however, that in all of the concrete cases I've mentioned, we register our health as in terms of "feeling good" or "feeling bad" along the lines of pleasure and pain. These are taken as two opposing poles of what could be called a neutral affective state.[1] The pendulum of health swings in tandem, then, with a pendulum of affect. Illness is not just about pathology and diagnoses, as we might think when we use the term in a medical context. Illness is not *merely* "not being healthy"—it is also about being in a negative affective state, which we often phrase and interpret as "being in pain." Here again, the two poles are asymmetrical. "Neutral affect" is not commonly thought as "not having pleasure" but as "not in pain."

To repeat a point from earlier, *the negative component is more determinate than the positive for the conception of the central, neutral, anchoring term*. This means that the meaning and possibilities of phenomena linked to the negative term will be assumed to be far more foreclosed than those linked to the positive. Evidence to the contrary, of which there is much and about which I have detailed at length, has an uphill battle against such experience. At risk of belaboring the point, this is one reason why the linking of disability with "pain," "suffering," "illness," and even "death," is a normative guillotine.

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[1] I'm not confident humans are ever in a state of "neutral affect," but whether or not that is the case is not relevant here; the term "neutral" is here entirely relative to the model as a whole.

It doesn't simply shut down reflection; it actively evokes affective and intuitive responses of fear and repulsion.

As I noted in the chapters above on pain, whenever one opposes pleasure from pain, one must explain how putatively painful experiences are described by some as pleasuring or the reverse. It's not just that pleasure and pain are on a continuum; it's that there is good empirical evidence to suggest that in some cases, those terms fail to track what we take to be the same phenomenon as instanced across individuals, cultures, and historical epochs, and so on. This is not a problem for the model under discussion because the terms are relative to the model as a whole. When the model is applied concretely to person X, their life experience might be such that hanging from hooks is neutral or on the left. They report to experience pleasure as a form of health or hyperhealth precisely *whilst* feeling the pain of such hooks. This means that they while they surely feel pain, they do not interpret their experience as being *in pain* due to them, to use a distinction from chapter two. Waterboarding, on the other hand, might still be on the right for person X. The socio-cultural, historical, and ultimately singular context of the person as well as their personal life-history will fundamentally determine in a given situation how a particular phenomenon is experienced and judged relative to the pendulum. The point is that the pendulum will, in any given case, describe the movement and contextualized range of a given experience with respect to the poles of pleasure and pain. The meaning of health (and the affects that both precede and follow it) is the meaning ascribed to a particular way of interpreting the experience of ability and the promise of relevant ability expectations. Health is a central vector of perceived ability.

§5.2.2 The Pendulum of Regard

How does the pendulum of health affect judgment? How does it inform whether and how we offer praise or blame to others? When we experience the pendulum as either neutral or positive, we experience our relationship to our body lithely. It is not that effort is never required, but that one experiences one's body as working with and for one vis-à-vis one's projects. Depending upon what one's projects are, the fluidity of one's relationship to one's body and the relevant abilities may or may not stand out. The conspicuousness of abilities and, correlatively, inabilities is often the primary frame through which the body is rendered conspicuous and thereby an object of judgment. Because the term "judgment" has an illustrious and disjointed career in the history of philosophy, I will instead use the term "regard." This term better encompasses both cognitive appraisal and the feeling or concern for a thing that can easily outstrip conscious awareness.

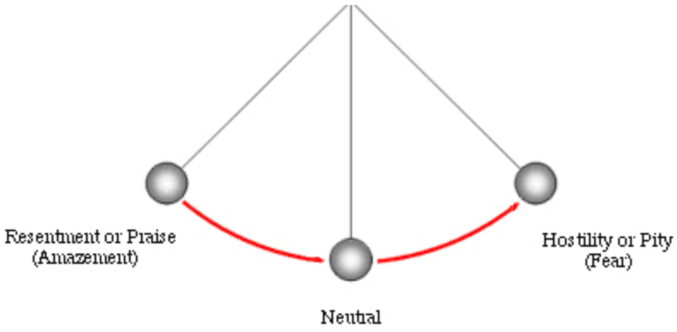

Fig. 4: The Pendulum of Regard

As I explained at the beginning of this section, we praise people with "extreme" health, which is itself an indication of a certain set of "extreme" abilities. This can also easily lead us to resent them when we interpret such people relative to ourselves and our comparative lack. In some cases, the hyperability itself produces social exclusion—think of the 'reclusive' or 'socially awkward' genius. When widespread fame comes along with a hyperability, that also surely affects the judgments under consideration.

Regard cuts two ways on the right side of the pendulum (Figure 4 above). If someone falls ill or if someone is perceived to be disabled, we might pity them (assuming the logic of the ableist conflation to be at work). We may, on the other hand, respond to them with hostility. The almost ubiquitous bullying of elementary, middle, and high school children with disabilities is one example of this; the social exclusion of people who are significantly ill or the logics which place blame for illness on wrongs done by that person or their family are other examples. Tellingly, after reading Havi Carel's experience of the lung disease Lymphangioleiomyomatosis, my students typically—and, I find, expectedly—report one of two gut reactions: pity or hostility. "Oh my, such an illness would be terrible" or "Yeah, shit happens." This is expected to me because pity and hostility are modifications of *fear*.

In each case, either pity or hostility, one first exteriorizes the other: one perceives them to be in a state that one is not and, even if for that reason alone, as *other* than oneself. One then imagines oneself in that state.[1] Pity is typically thought to occur through deploying the imagination—bracketing the many issues that term raises—to put oneself in the other's situation and then further imagining what one would want if one were in it.[2] This is, by my lights, the normative logic, the exhortation, of the golden rule. Counterintuitively, hostility occurs through the same first step—imagining oneself in the same situation—but then it takes a very different turn: one fears that situation.

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[1] Note, of course, that one is not, in that dialectical moment, focusing on the other. I address this in more length in my forthcoming article in the APA Newsletter on Philosophy and Medicine entitled, "Ableism, Affect, and the Transabled Body."

[2] An implicit assumption is that one would act beneficently if one imagines oneself in the other's situation. Also, the whole logic assumes individuality. If one genuinely begins from a "we"—such that one's language or concepts (to invoke the Sapir-Whorf hypothesis or Robert Levy;s thesis of hypocognition) cannot perhaps even say I—how would empathy look? In some indigenous languages, one cannot easily say "I," and I assume that my analysis would alter significantly under such circumstances.

What do we do when we are fearful? We seek to mitigate the control wielded over us by the fearful object or objects. Running away is one option. Attack is another. Fear, understood as a lack of control, can be expressed as hostility to the point of violence as a way to counter the perceived power of the fearful object. Pity, however, can also act to reassert control over a fearful object. One way of doing so is by overly narrowing and diminishing the import of the object such that one can forget about it. Pity lets people forget: you give a homeless person a few bucks and go on with your day.[1] That that person is, at least given conditions in most places in the USA, constitutively open to the possibility of being without shelter and to extreme social isolation is left to the side.

Our judgments towards those who are thought to be experiencing pleasure and pain are also dual. Those who are perceived to have extreme amounts of pleasure (think Great Gatsby, Wolf of Wall Street, or Donald J. Trump) can end up praised, even revered. If one, however, interprets that pleasure through one's own comparative lack of pleasure, that awe is instead expressed as and transformed into resentment and envy. With responses to those in pain, a similar pattern emerges. On the one hand, we might pity a person in great pain. On the other hand, one might respond with hostility, whether that is though ignoring their pain, delegitimizing it, or taking their pain as an affront to oneself. As strange as this might sound when put abstractly, simply think about certain responses to the #BlackLivesMatter (BLM) movement. The #AllLivesMatter response is predicated upon understanding BLM as an incursion on the worth of other, non-black lives; it interprets BLM as *hostile* and, often without any information actually suggesting

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[1] Empathetic and sympathetic responses are likely different. Whereas hostility and pity are characteristic of distant relationships—strangers, acquaintances—empathy and caring are characteristic of caregiving relationships. I sadly cannot further broach this topic here. Suffice it to say, in this range of possible responses (of which they are surely more), a key, if not prime, determinant is the extent to which control is integral for one's relation to oneself. I will return to the role of one's self-relation to control in a moment.

so, putting an "only" or "just" prior to its defining slogan. To interpret it as hostile, however, one must at minimum hold the pain and injustices to which BLM is a response as either insignificant or illegitimate.

Pain is the best and most deployed moral intuition pump in history. Despite the fact that pain functions as an obvious phenomenological negative—at least in its unfortunately typical reflective underdetermination—and despite the fact that it further thereby functions for most as reason worthy of eliciting response, being overtly hostile to the non-violent pain of another is unlikely. It is thus easier and more effective to ignore or delegitimize.[1] As helpful as this may be as a first step to understand the variance between disability telethons and disability hate crimes, the range of responses from awe to fear cannot be understood outside of their relation to one's sense of control.[2]

§5.2.3 The Pendulum of Control

Because each of the terms discussed so far—health and regard—are centrally determined by one's relation to oneself (and one's perception of that relation), when one perceives oneself to be outside of the point of equilibrium, one's sense of self is altered. In what ways? Well, why do people want to be healthy? Why do people want to be able to do "what they want"?[3] Well, how do we imagine 'being able to do something'? We imagine the things we want to do or have as under our control. Control: that is the key,

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[1] This is one reason why one might want to judge the failure to learn about others' pain as morally blameworthy. It's also a reason why any attempt to minimize the reported pain of another should be looked upon with great and immediate suspicion—the burden of proof should be on the person minimizing another's pain, not the reverse.

[2] One might counter that awe is a modality of fear (or the reverse). I don't deny this, and I'm open to entertain the idea that they are each modalities of a more fundamental response, at varying levels, to something unexpected. Whatever unique insights might arise from an analysis of such responses in general, that analysis is too broad for the purposes at hand.

[3] On this point, see Reynolds, Joel Michael, "Infinite Responsibility in the Bedpan: Response Ethic, Care Ethics, and the Phenomenology of Dependency Work," *Hypatia*, forthcoming.

the legend, to each of these pendulums. When at equilibrium or accelerating towards a "positive" apex, *we perceive ourselves to be in control.*

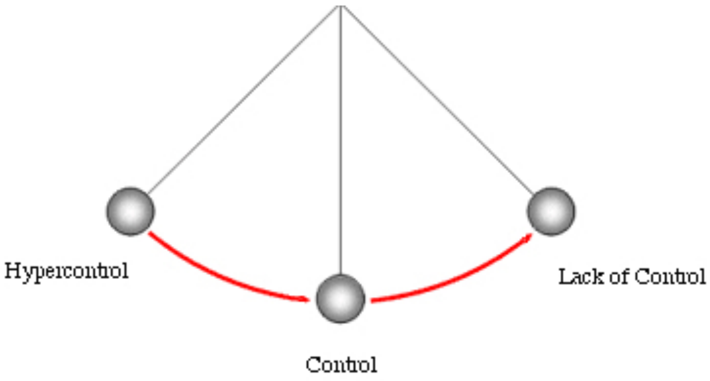

Fig. 5: Pendulum of Control

With respect to our relation to our self-relation, equilibrium and positive acceleration give us to ourselves—that is their bionormative function. In such times, we sense ourselves moving through the world easily and thus find an accord between our "selves" and the world. Control is a way of saying: homeostasis. On the whole, things go our way or get out of our way as we reasonably expect. This is what gives us the enticing illusion of individual, personal control. Although I above assailed that illusion as philosophically untenable, I have now provided an explanatory schema for why that illusion grips intuition as it dos, for why so-called common-sense understandings of ability are as they are.

Of course, when one takes into account socio-cultural factors—for example, varying levels of emphasis on individuality or on communality—the background against which the pendulums are interpreted will be rendered differently, as I argued above. One may understand one's self-relation to control as relying in part or whole upon the grace of God or the help of others, including past generations. Or, in the other direction, as due to solely one's own efforts: Horatio-Alger style boot-strapping and so on. But regardless of the socio-cultural factors, phenomenologically, *sudden jolts out of personal equilibrium* *will be experienced as a loss of control*.[1] While I have now discussed the pendulums of health, regard, and control, I have yet to sufficiently explain how they operate together—how they mutually determine each other as fundamental manners in which one finds oneself in the world. How does the charmed pendulum of ability function as a whole? The unbelievable amount of money people spend on anti-aging products, the push for technologies to increase human ability, whether in the form of psychotropics or genetic manipulation—all of these things demonstrate the way in which hyperability functions in relation to an *active* mitigation of pain, illness, lack of control, and, inability. One might be tempted to construe these relations as, ultimately, functions of our relationship to death. I find, however, that this actually misses the forest for the trees. It is instead a question of the extent to which we perceive ourselves as able to attend to the things about which we care.[2] The value of abilities is not ultimately a function of our relationship to death. It is a function of our relationship to the range and content of our concrete, lived, and often idiosyncratic concerns. The charmed pendulum of ability (Figure 6) equilibrates according to control over one's concerns. A first, provisional definition of ability is now

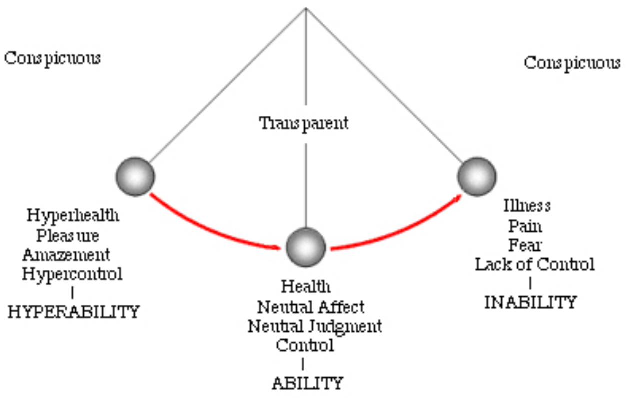

Fig. 6: The Charmed Pendulum of Ability

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[1] In superhero films, this is represented in the ubiquitous primary stage of lack of control over a newly acquired power, a stage which requires a *process* of mastery, typically taking up much of the first third of such films, that brings that "power" into the realm of background abilities.

[2] To flesh this out, a discussion of *Sorge* in *Being and Time* would be requisite, but I don't have space to deal with that here. Suffice it to say, I find *Sein-zum-Tode* to take on too strong of a role in that work.

possible*: the meaning of ability is a function of control over concerns.* Abilities articulate avenues of access that outline the perceived and actual differential relations of power between one's body and one's environment, including the host of dynamic, differential relations of power with other self-relational, reflexive beings.

§5.3 Ability as Access

The charmed pendulum of ability counters the coherence and applicability of the concept of ability as personal power. Abilities are neither simply individual, nor value-neutral. Recall a question I raised earlier: how can an ability, in one context, be a superpower and, in another context, a stigmatized disability? Another way to answer this is to note that the moment one analyzes concepts such as ability (analogously to the concepts of health and illness), one is not simply analyzing ontological realities, but simultaneously socio-political *imaginaries* and, as Ellen Samuels sagely puts it, *fantasies of (mis)identification*.[1] One is dealing with a vast complex of ideologico-philosophical background conditions that determine particular interpretations along the charmed pendulum of ability. Even if I am born with an entirely phenotypical corporeal structure—a structure that is considered "normal" under the Linnaean taxonomic category *homo sapiens*—the oppressions I suffer *may or may not* have anything to do with the determinate, normative structures of that category.

They may have to do with acute occurrences (acne); they may have to do with the way I dress (fashion); they may have to do with the money I or my family leverages (class); they may have to do with the meaning of the perceived color of my skin (race); they may have to do with where I am from or where I am trying to go (ethnicity,

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[1] Ellen Jean Samuels, *Fantasies of Identification: Disability, Gender, Race*, Cultural Front (New York: New York University Press, 2014).

nationality, indigeneity); or they may have to do with the makeup of my genitalia and my relationship to them (sex, gender identity), and so on. But the meaning of each of these phenomena is normatively inflected and forever relative to the constitutively variable set of abilities by which we judge a given life in a given context. In order to better understand the meaning of ability as access, I will turn to explore three examples of ability: playing chess, engaging in sexual activity, and breathing.

§5.3.1 Chess

For example, when we say, "she is good at chess," we may, depending on the circumstance, mean nothing more than that she can follow and anticipate serially predetermined, complex algorithms well. That one's abilities with respect to chess are only *contingently* trivial, however, is offset when one becomes a grandmaster or World Champion—when the ability becomes exceptional to the point of being so in relation not to some, but *all* others. For example, if you are Robert James "Bobby" Fischer, now your abilities might lead certain countries to go out of their way to help (or hurt) you. In the case of chess, a seemingly trivial ability expectation to which one would not think to tie substantial normative value becomes one to which immense value is tied once it becomes superlative in a given context. The point here is not to say that we shouldn't praise people who have exceptional abilities. The point is to demonstrate the *constitutive variability* and *context-dependence* of those abilities.

One might counter with the following question: surely there are neutral or meaningless ability expectations. For example, the ability to count backwards from a high number quickly and accurately. But what ability is that? The content of the ability in this example is misleading because its form is just one possibility brought about by the ability to manipulate the decimal notation of the Hindu-Arabic numeral system. That, to my knowledge, there are not situations in which that content (counting backwards) is held as meaningful in no way disproves my point. But to say that that content does not have value is *not to say* that the form of that ability is therefore value-neutral. That is to say, the form of the ability to count backwards could be held as valuable with respect to some possible world where that ability is in fact value laden, but that world is not today's.

The claim I wish to highlight here is that an ability must count as an ability, must be deemed as such, in order to *be* an ability: the normative component functions to judge *which* biological and ontological determinations prove relevant. If it doesn't count, that ability is, in situations of which I'm aware in this world, what I'll call *trifling*. The more provocative conclusion to draw is that any function could either count as an "ability" or be trifling in some possible world.[1] Put more flexibly, the concept of ability extends to range over any iterable outcome produced by a determinate set of relations: *abilities are iterable mediations of interrelations*.

Accordingly, the breadth of the range of such mediations is astounding. Moving one's forearm in the four cardinal directions; blinking a single eye in response to discrete patterns; photosynthesizing light; withstanding tons of pressure; speaking in quasi-patterns that are not recognizable as known languages…the examples could be multiplied ad infinitum. What abilities did I just name? The ability (in part) to conduct an orchestra, the ability (for some) to communicate while experiencing locked-in syndrome; the ability to maintain sustenance for some plants; the ability to exist as a deep-sea organism or as anything worth naming in some celestial environments; the ability to "speak in tongues."

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[1] I am here using the term "function" in its mathematical sense: denoting a relation between an input or set of inputs that produces and is directly related to an output or set of outputs.

Placed out of context, these “abilities” might seem trifling, strange, or absurd. But each name functions of interrelations between organisms and their environment that are or *could be* essential not only to that organism’s ability to survive or for its identity, but for what, how, why, and whether it is as a being at all.

As I noted above, one could imagine a different use of the Hindu-Arabic numeral system where the value of counting backwards from one hundred might be essential to all trade. Such a counterfactual supports the general point at issue here, which can now be expressed more clearly: abilities are constitutively variable with respect to their form, content, and value, and any determinate ability must be thought through the relevant and complex relations, histories, and contingencies into which it enters. Abilities are not reducible to the conditions of support requisite for a given ability; any given ability is, in a way, *supervenient* on a host of conditions. But any given world and any given context will render a vast range of abilities—like counting backwards or touching one’s tongue to one’s nose—mere triflings. On the other end of that spectrum, some abilities will be necessary to prohibit one’s death. Or its moral sanctioning. Or to reliably afford one’s very entry into the world.

§5.3.2 Sex

I above discussed chess, but there are perhaps better (and likely more interesting) examples. Take the activity of sex. There are historical and complex manuals about sex—the Kama Sutra, e.g. There are entire industries based upon selling (the idea of) suggestions concerning how to engage in such an activity (Cosmo, Playboy, etc.) There is a curiously wide range of understanding of what it means to engage in “sex”—not only with respect to the range of activities that might count as “sexual” but also their meaning, from those that are highly ritualized to those that are little more than pleasurable ways to pass time. However one conceives the meaning of such an activity, the abilities it involves are extremely complex. To be successful in the act, whatever that might mean in a given context, often involves an intricate (whether scripted or unscripted) play of responsivity and passivity. To demonstrate this point, note that depending upon the situation, the success of one's response may be measured by the sheer *lack of control* one has over oneself. Alternatively, it may be measured by masterful and calculated actions, however effortlessly they seem to by another to be performed, whether one's partner or partners.

Furthermore, what it means to "be a good lover" is not simply differential relative to unique individuals, but to the community in which one's sexuality interacts (communities or subject/sexual-positions that are by some variously termed as "heterosexual," "gay," "dyke," "bear/twink," "alpha/beta," and so on.) Given all of these factors, the meaning of the "ability" to have sex, much less to have sex *well*, is profoundly diffuse and singular. And the range of abilities that may or may not enter into judgment over one's ability (whether that judgment derives from self- or other-regard) is also almost overwhelmingly profuse. From the ability to lightly touch and tickle in singularly stimulating ways to sensing the rhythm of another's body amidst the full range of another's bodily movements, from the depth of a kiss or caress to sensing a desire for the increase in one's emotive or physical aggression because arousing to another—the level and breadth of response, if one is to be equal to the moment, is astonishingly complex and variable. Consensual, well-wrought sexual interaction is, perhaps, an exemplary model of the ambiguity, complexity, and intensity of intersubjective sensitivity and response. More pertinently, such interaction is an exemplary model of the ambiguity, complexity, and intensity of what it might mean in any given case to “have” an ability.[1]

Let me return one last time to the example of Bobby Fisher. The form of the ability expectation in question (“to follow and anticipate serially predetermined, complex algorithms well”) moves from irrelevance and inconspicuous when it takes on a very specific content (“the ability to play chess better than any human”). The value of this ability expectation is transformed due to the qualitative intensity of its specific content in a given socio-cultural context. That Bobby Fisher is held to be better than any human at chess becomes a reason to single him out as an exemplary object of praise or blame. That chess is held by many as an esteemed and elite game across the “globe” is another reason. But such facts, to repeat what is hopefully obvious at this point, are due to the contingency of social values placed on playing chess at a particular historical point across a certain swath of the global human population.

When I above defined the ability to play chess as “the ability to follow and anticipate serially predetermined, complex algorithms well,” did I not leave out a host of other factors? Does it not require an ability to physically manipulate objects, viz., the pieces on the table and the gameclock or some device utilized to manipulate the latter objects? Does it not require an ability to assess not only the moves of the other player (typically, though not necessarily, through sight), but also to anticipate their moves (though some form of a theory of mind)? The “ability to play chess” presupposes a host

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[1] Alternatively, think of massage therapy. LMTs (licensed massage therapists) are tasked with interactions of a kind, I would argue, with those of sex. There is, unlike in at least some sexual interactions, a certain reservation that is, perhaps paradoxically, definitive of the otherwise erotic encounter. The extent of tactile, habituated knowledge combined with reflective, learned assessment is immense.

of bodily conditions: psycho-somal conditions relating to focus, higher-order cognitive tasks, theory of mind, core corporeal manipulation of objects or commands to do so, etc. Any given ability, whether at the level of form or content, will involve a set or *complex* of abilities, which will each, on their own, have varying normative determinations. Given this level of complexity, is the concept of ability not too broad or too variable, such that it is indefensibly vague and thereby vacuous?

I think not. With respect to both chess and sex, the larger point here is that bionormative assumptions form determinate moments in the dialectical process by which, in any given historical epoch, we identify and grant varying levels of value and meaning to a life based upon its perceived abilities.[1] All human abilities require the presence of oxygen, which in turn require the presence of an organ or organs by with to breathe, which in turn requires the existence of carbon, which in turn requires the biosphere of the planet earth and the known universe, etc. By virtue of the formal problem of infinity upon which Zeno's paradoxes trades, when one seeks to quantify a relation, the process of quantification (i.e., the process of formal division) never ends in principle. This means that any thinking of ability will be reductive if it neglects to sufficiently interrogate the full range of *relevant* ways in which its form, content, and specific value are interpreted through social, cultural, historical, and, in short, normative spheres. Accordingly, hitting

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[1] The 2001 Supreme Court case between Casey Martin and the PGA Tour further demonstrates the ambiguity of determining which abilities are "proper" or "essential" relative to a given domain, in this case whether or not walking during the last third of the qualifying tournament was an essential part of the ability to play golf. PGA Tour, Inc. v. Martin 532 U.S. 661 (2001). James L. Cherney, "Sport, (Dis)Ability, and Public Controversy: Ableist Rhetoric and Casey Martin V. Pga Tour, Inc.," in *Case Studies in Sport Communication*, ed. James L. Cherney, et al. (Westport, CT: Praeger, 2015); C.M. Parent, "Casey Martin's Four-Year Struggle with the Pga Tour," *Sport Lawyers Journal* 9 (2002); W. Kent Davis, "Why Is the Pga Teed Off at Casey Martin? An Example of How the Americans with Disabilities Act (Ada) Has Changed Sports Law," *Marquette Sports Law Journal* 9, no. 1 (1998).

the mark in understanding any given ability, much less the concept itself, proves to be a difficult, laborious endeavor.

Abilities are not only irrelevant as value-granting mechanisms when they are trifling, but also when they are sufficiently strange. For example, the ability to be a contortionist, to manipulate one's body in ways that do not conform to phenotypical joint and ligament formation (whether due to hypermobility or training) is a unique form of ability and ability expectations. Relative to the politics of the Cold War, however, the person named the "best contortionist" in the world was afforded less value than that of the eleventh World Chess Champion. There are certainly situations in which the set of abilities of best contortionist would afford value, but the putative cultural "strangeness" of contortionism (historically tied, one should note, to the exhibitionism of freak shows and other such historical analogues) renders it less value than playing chess—at least in the context discussed here. Because the very concept of the "strange" is fundamentally normative and, upon even minimal reflection, obviously so, this supports my claim about the normativity of ability. To call an ability strange *or* trifling is to say that it does not enter into meaningful social relations as determined by extant, contextualized norms.

The examples discussed above suggest that where an ability form has substantive value, it is typically because that form is both assumed to apply to the "standard body" and also because that form corresponds to an activity or form of life held to have value. The importance of the content and its valuation will thus vary accordingly with respect to that of its form. It will also vary with respect to the futures an ability is *thought* to afford, hence my addition of the phrase "ability *expectations*" at various points.

§5.3.3 Breathing

In the vast majority of instances, the ability to breath oxygen affords nothing meaningful in terms of social standing. It is often only when one requires a machine to breathe in place of one's lungs that we give significant meaning to that ability. That meaning is sometimes considered so momentous that a life lived without technological assistance to breath is often preemptively judged to be not worth living.

The equilibrium of the charmed pendulum of ability is that in which living is experienced most easily, a life where the reach of one's control is, at minimum, stable. It is the pendulum in which we perceive things to get out of our way or go our way when we want. For example, I argued above that the charmed pendulum of health ultimately tracks the ease with which one experiences charmed pendulum of control, but, as every student of public health now knows, social structures are the prime drivers and determinates of that ease. Today, in America and elsewhere, the most charmed is typically a white, heterosexual, cisgendered, monogamous, able-bodied, employed, upper middle class, university-educated, debtless or low-debted, monotheistically religious, developed-nation born, capitalism-supporting male. That this charmed figure is ultimately in control is, of course, an illusion, for that charming requires enormous supports (besides the fact that it is also a historical product of everything from colonialism to patriarchy to…etc., the moral culpability of which I will here leave open).

Yet, we don't *see* successful supports when those supports facilitate our habits and desires. Successful supports are invisible. Yet, someone might retort: a body born without an arm…is that not a body that calls attention to itself? Is it not a body literally unable to do what "we" desire and want it to do? Is not such a body unable to produce and work *as well* as the "normal" body? Is not such a body analogous to the "ill" body, the body to which we are beholden despite our will—the "ill" body that not only alters our sense of agency but, in some cases, makes our agency nearly irrelevant? When we ask these questions rhetorically, we take ableist assumptions—assumptions that predetermine both what one *should* be able to do and also the empirical conditions of all human doings, beings, and knowings—to tell us that a given way of being in the world is bad. We confuse different ways of being with *worse* ways of being, and we thereby deem them "sufferings"—the quickest, commonest, and most imprecise way to name "bad" ways of being in the world.

A crucial fact about disability that is especially hard for the able-bodied to swallow is that while any social stigma can become disabling in the mere sense of constriction, 'disability' names social stigmas explicitly related to the normative conditions of *conceptions* concerning what we call "ability."[1] Ability is, unavoidably, hegemonic. Analogously to whiteness with respect to race, the obligation to interrogate and undermine its power lies more so on those who benefit from its privilege than those who do not. But, as I've argued, we—the able-bodied majority of philosophers today and historically—haven't thought much about the meaning of "ability," much less about "disability." The culpability in question stretches wide and far. Do we mean that the latter term is a "limitation" of what we would otherwise do? Otherwise relative to what? To our imagination? To what other people can do? To what people should be able to do? Should relative to what? To what one would like to do but currently and contingently can't? Contingently or currently how? And in what respect? What concept of "ability" informs

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[1] This is the power (and weakness) of the social model: once disability is separated from the bio-physiological, that which "disables" socially is, in principle, made wide-open.

the confidence of our assertions about the human? What ontology informs such a concept and what miasma of unexamined or underexamined assumptions hide behind it? I hope to have now demonstrated that "ability" is one of the more complicated and prejudged concepts by which we understand and go about the world. I hope to have shown the ways in which ability is an ultimate and undertheorized term for when subject and object meet. It is with these complications and the hesitancy they should evoke that I have here discussed what "ability" might mean.

§5.4 The Scope of Ability: Human, Social, and Personal

Despite this difficulty, at least one categorical claim is warranted at this point: the ontology of ability is misunderstood if construed as merely a property of an individual. Abilities are always in constitutive and fundamental relation to structural, environmental, and intersubjective supports, et al. One cannot attend to the meaning of ability without looking to the constitutive supports and structures in which abilities *are* and historically *can become* abilities in the first place. If one wishes to fully grapple with the difficulty of this claim, one must grapple with the role of *range* in determining what is possible. I mean possibility not merely as an abstract category in which logicians trade and deal, but as a determination of praxis, of the conduct, values, and comportment of a life. Let me explain, then, what I mean by the question of range in thinking the meaning of ability.

If all the oxygen on earth were to disappear, every human organism (and numerous other organisms) would die. The ability to do anything for any given human would suddenly shift to an inability due to the lack of an (assumed to be constant) structural support. This too would mark a "change in one's abilities"—the change being that one's ability to primarily breathe oxygen would abruptly and fatally become an inability to survive. Because we have an almost intractable tendency to think of ability as located in an individual, we often don't see the way in which environments fundamentally determine changes in "one's ability" just as much and *typically more so* than changes in one's ability in a strictly (abstractly) individualized sense; the effects of structural poverty are a powerful example of this.

For example, gluten allergies are typically represented as an individual "issue," whilst the near ubiquity of gluten in American food options, e.g., is due in large part to cost-cutting practices ultimately rooted in the logic of late capitalist industrialism. Still, one could imagine the following response: "there were no changes in one's personal abilities when the oxygen went out of the room: the only thing that changed were the conditions that *enable* human life." If one assumes that the ability to breathe oxygen stops at the skin, as it were, one will think that the "ability to breath" is solely a question of an individual. Analogous to the error made in medico-individual models of disability, such an understanding of ability misses the forest for the trees (actually, only a few trees). In order to better understand why I find in such a view misguided, perhaps it is helpful to heuristically distinguish between human, social, and personal abilities. This distinction will further illuminate the parameters of the charmed pendulum of ability discussed above.

Human abilities are abilities without which no human could survive. In this sense, they can be called necessary. One can continue living even if a machine breathes instead of one's lungs, but no human organism can survive without any oxygen whatsoever, at least given technology and the evolution of the human species up to this point. The ability to physically incorporate oxygen is, in this sense, absolute. The same goes for the ability to drink water, to eat a minimally nutritious diet, to have location-specific shelter, and to have dependency workers provide for one in infancy, in times of some forms of illness, and in many conditions pertaining to old age, etc.

Social abilities are abilities that we take to reside in societal or political configurations. Person X, Y, and Z's *ability* to transport themselves in expected amounts of time in modern societies is made possible above all else, thanks to taxation or other such monetary remuneration for the building and maintenance of roads, a host of economic considerations related to the building of various vehicles for transportation, road controls (stop signs, lights, etc.), and other such things. Or, to take a different example, Person X, Y, or Z's ability to interact in the vast majority of modern social exchanges is supported, above all else, in the continued creation and maintenance of fiscal mediums (money) and various types of fiscal policy (inflation control, interest regulation, markets of varying size, scope, and location, etc.).

Personal abilities are abilities that we take to reside in individuals. Person Y is better than Person X at math. We might then say that Person Y's personal ability to do math is greater than Person X. That ability is understood to be something like a predicate of the subject here named "Person Y." We understand an ability such as this to be supported, above all else, by Person Y's intellectual *ability*. If so, *salient* environmental or technological factors—anything taken to be an "enhancing" or "conditional" support—will modify such an understanding of subjective ability. If Person Y utilizes a calculator or was born with genetic enhancements or grew up with a mathematics professor as a guardian, the comparison with Person X will be downplayed or even nulled if such a view of ability is operative.

Having laid out these heuristics, let me now return to the oxygen example. While breathing oxygen is indeed a human ability, both the social and personal ability to do so is socially mediated. If a construction worker is exposed to asbestos thanks to the negligence of management to test properly, and that exposure, unbeknownst to the worker, leads to lung cancer, now the construction worker has a “personal inability” to breathe well. Unlike the chess player, with the case of asbestos we tell a history that excises personal responsibility for that personal (in)ability—we instead blame social factors, pertinent to their individual history.[1]

But what about cases that involve widespread pollution? A democratic government fails to pass clean air legislation and allows corporations to pollute with immunity, whether due to failures or absences of communication on the part of constituents or due to failures of whatever sort by their representatives. There is now a social inability to breath well. Who do we blame? Where do we situate the *ability* to breath in such a scenario? We resist blaming either the human ability or the person ability operative in such a situation: we tend to blame the conditions that brought about the social inability, though those conditions are diffuse across social and personal dimensions. We constantly grapple with the role of history when we wish to assign moral valence to the range of *abilities* salient for a given phenomenon.

Yet, as individualistic models of disability demonstrate painfully well, we tend to blame personal ability when someone is born with or, in many cases, acquires a disability that causes them to breath in non-phenotypical ways. It is thus not surprising that

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[1] I say “unlike the chess player” because a mixture of talent and hard work might have lead the worker into this particular profession. Also, to be clear, in a different set of circumstances the “inability” to breath oxygen well might lead an organism to survive. To repeat from above, when I refer to human abilities, I mean that in terms current evolutionary state of the human organism as well as its current locale (earth), and I am consciously limiting my examples to the human throughout.

conservative arguments against welfare focus upon acquired disabilities or inabilities through perceived personal negligence and then employ those examples to make sweeping arguments against welfare (or, for that matter, basic support for the conditions of existence) as a whole. To see how this logic is expanded, take the example of a person who wishes to vote against a raise in taxes to pay for curb cuts—what is the typical justification? "Why should I have to pay for struggles with which someone else deals?" The primary implicit assumption in such a thought is that those who are not *sufficiently* like one do not require one's concern and, by extension, one's money. Although clearly underdefined, the concept of personal ability, when coupled with a posited "norm," offers an easy and putatively "common sense" way out. "*Most people* are ambulatory: I can't spend my money helping that small percent of people that aren't…" The (what should be obvious) fact that curb cuts help people of all sorts in all sorts of situations and will help nearly everyone avoid injury or death of themselves or others at some point over the course of a life doesn't even arise in such a framework. The question I have am addressing in this chapter, a question that should be, in multiple ways, profoundly disturbing, is: what concept of ability has been operative such that, historically, ability rarely rose to the level of normative concern and has contributed so ubiquitously to the entrenchment of the ableist conflation?

Abilities are projections and repeated performances that assume massive levels of production and support. Abilities are mediations. Abilities are modalities of relation. Abilities are social. Abilities are shared. Abilities are fluid and unequally distributed. Abilities track systemic and particular privileges. Some abilities are world-creating; others are trifling. Some abilities form identity; others form nothing at all. Some abilities appear only in tandem; others are singular. Some abilities are primarily human; others social; and others yet personal. Abilities are strange kinds of things. Still, when all is said and done, to be able means to be supported to be able, to be *en*abled. Abilities articulate conditions of support. Abilities hold me together as the type of being I am and am taken to be. I am insofar as I am abled, which is always to say, *I am insofar as I am disabled*.

6 CONCLUSION: HARM & THE NON-NORMATE BODY

> Unless we can put ourselves in the place of another, unless we can enlarge our own perspective through an imaginative encounter with the experience of others, unless we can let our own values and ideals be called into question from various points of view, we cannot be morally sensitive.
> —Mark Johnson[1]

> When I judge the other, I simultaneously direct toward her that stream of negative affect that cuts off my feeling of kinship from her as a fellow living, suffering, joyful creature.
> —Teresa Brennan[2]

Let me retrace my steps. People with disabilities and people living in pain have historically been given remarkably short shrift by philosophers, specifically those working in the field of ethics or moral theory. If ethical theorists have {a} done a poor job of accounting for and being responsive to these phenomena, and {b} failed to incorporate their unique insights and problematics, then these two phenomena are well-suited to critique ethical theorizing. Why? Because ethical theories have constitutively failed with respect to these phenomena, phenomena which are *integral* to human life. While, as I noted at the outset, the well-documented and widely-assailed denigration of embodiment in the Western intellectual tradition is in part to blame, there are concrete socio-economic and politico-historical reasons for this as well: accessibility, representability, intelligibility, grievability, etc.

For example, numerous social-political philosophers of late have attempted to rectify the glaring insufficiency of historically dominant theories of justice for those who have been oppressed under their auspices. Normative ethical theories have historically emphasized their principles and rational grounding while deemphasizing their exemplars

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[1] Mark Johnson, *Moral Imagination: Implications of Cognitive Science for Ethics* (Chicago: University of Chicago Press, 1993), 199.
[2] Teresa Brennan, *The Transmission of Affect* (Ithaca: Cornell University Press, 2004), 119.

and material grounding; that is to say, whether framed as a question of virtue (Aristotle), duty (Kant), or utility (Mill), such theories have focused more on the grounds or axioms that determine the worth of ethical action and less on the type of people for whom such action is intended and meaningful in the first place.[1] This has not merely resulted in theoretical gaps, but also in pressing practical issues for everything from United Nations' mandates to legal interpretations of individual rights in the United States, such as in the Americans with Disabilities Act (1990, revised 2009).[2]

With respect to questions of disability, Martha Nussbaum has addressed this through the capabilities approach, a revision and expansion of Rawlsian political liberalism[3]; Eva Kittay by offering a relationally-based normative care ethics built off the work of Carol Gilligan and Nel Noddings[4]; and Anita Silvers by revising social contract theory into trust-based contractualism, building off of insights mined from Hume and Smith.[5] Relational autonomists such as Catriona Mackenzie and Natalie Stoljar have approached this issue through altering and expanding the notion of individual autonomy assumed by many of the theories under criticism.[6]

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[1] The touchstone(s) of these accounts has tended towards ideals and ideas, not materials and material bodies—towards questions of the good and justice, not questions focused upon the actual situations of the oppressed, victimized, or neglected. For Kantian deontology, the (primarily) intellectual recognition of the lawfulness of the categorical imperative is precisely that which grounds his ethics; for Millian utilitarianism, the assent to the greatest quantitative and qualitative happiness of the greatest number of people is likewise intellectual (I need not, e.g., care about the other qua other, nor ought I to care about those left on the losing side of a utilitarian calculus), and for Aristotelian virtue ethics, although he is arguably the most "materialist" of the three most historically dominant normative ethics of Western philosophy, the *phronimos* is still guided by the *ideal* of *eudaimonia*—for although "the Good" is not conceived like a Platonic form for Aristotle, the *paragon* of virtuous ethical agency is still, of course, a *philosopher*.

[2] See the United States Department of Justice Civil Rights Division webpage on the "Information and Technical Assistance on the Americans with Disabilities Act" at http://www.ada.gov/. Accessed March 2014.

[3] See Martha Nussbaum, *Women and Human Development: The Capabilities Approach*, The John Robert Seeley Lectures (Cambridge; New York: Cambridge University Press, 2000).

[4] See Kittay.

[5] See Anita Silvers and Leslie Pickering Francis, "Justice through Trust: Disability and the 'Outlier Problem' in Social Contract Theory," *Ethics* 116 (2005).

[6] See Catriona Mackenzie and Natalie Stoljar, *Relational Autonomy: Feminist Perspectives on Automony,*

The guiding frame of each of these thinkers has taken the form of the question: how does one conceive of justice such that *group X* is not excluded?[1] I find that framing the problem in this manner precludes a satisfactory solution from the outset. If Lennard J. Davis is right that "disability can be seen as *the* postmodern subject position"[2] and if Tobin Siebers is right that "all known theories of human rights, whether based on humanity, social contract theory, utilitarianism, or citizenship, exclude individuals from the rights-bearing community if they do not possess the specific abilities required for membership,"[3] then the meaning of disability *is at the core, not periphery of concepts of justice*. Ability and disability are not mere factors in normative theories. They constitute, in part, the very ground out of which a normative theory is first built.

As I claimed in the introduction, normative ethical theories have historically emphasized their principles while deemphasizing their exemplars.[4] In other words, whether framed as a question of virtue, duty, or utility, such theories focus more on the *ideals* that determine the worth of ethical action and less on the *people* for whom such action is intended to be praiseworthy in the first place.[5] This is not merely to say that

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Agency, and the Social Self (New York: Oxford University Press, 1999), esp. 3-31 and Lorraine Code's essay, "The Perversion of Autonomy and the Subjection of Women," 181-209.

[1] Rosemarie Garland-Thomson writes, "identifying and claiming status is perhaps the greatest anxiety in a theoretically egalitarian and volatile modern order." Garland-Thomson, *Extraordinary Bodies*, 64. The dilemma between recognition and oppression/domination/reduction is often presented as a maze, a problem with a potential solution relative to the problem's framework. Excluded groups seek recognition within existing orders (political, discursive, etc.), and yet the very conferral of such recognition levels that group to being the "same" as all other groups.

[2] Davis, *The Disability Studies Reader*, 233, my italics.

[3] Tobin Siebers, *Disability Theory*, Corporealities (Ann Arbor: University of Michigan Press, 2008), 178. One could respond: how could it be otherwise? I will return to this point below.

[4] Much of the material presented in the conclusion derives from a presentation given at the 2016 Society for Disability Studies and at the 2016 Eastern APA as part of a session for the Society for Philosophy of Disability. I am grateful to each audience for constructive and provocative feedback. Jennifer Scuro and Lauren Guilmette gave insightful and incisive feedback at every stage, and David Peña-Guzmán read over the penultimate form of this chapter, providing helpful comments both editorial and philosophical in nature.

[5] As I mention above, philosophers including Eva Kittay, Anita Silvers, Licia Carlson, Martha Nussbaum, and Shelley Tremain have each done significant work critiquing and/or amending such ideals.

Aristotle, Kant, and Mill, and often their followers, operate with insufficient or problematic accounts of subjectivity or assumptions about human nature—a claim scholars in feminist theory, critical race theory, and critical disability studies, among other fields, have argued at length for years. Following Gregor Wolbring, I find it illuminating to frame this more specifically as a neglect of the role *abilities* and *ability expectations* play in normative ethical theorizing.[1] Such neglect has led to wide-ranging oppression and discrimination, including and especially the historical, systematic exclusion of people living with disabilities from all canonical models of ethical flourishing.

I suggested in the previous chapter that ability is an ultimate and undertheorized term for when subject and object meet. That is to say, the abilities a normative theory implicitly assumes of its ethical exemplar (whether Aristotle's *phronimos*, Kant's good-willed rationalist, or Mill's sensing calculator) prove determinate for the content and form of the ideals to which the respective ethical subject is prescriptively beholden. Depending upon the historical epoch or author in question, these abilities might be demarcated as or at least assume specific forms of "rational" thought, ambulation, hearing, seeing, speaking, emotional regulation or any number of abilities afforded by class position, gender, sexuality, race, locale, and so on.

As a conclusion to the trajectory set out in this dissertation—from a decoupling of pain from disability to a thinking of ability, I will close by assailing the last primary component of the ableist conflation: harm. I do so by focusing on an experience that in many senses blurs the lines of ability and disability, however so defined: transability or

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[1] Gregor Wolbring, "Ethical Theories and Discourses through an Ability Expectations and Ableism Lens: The Case of Enhancement and Global Regulation," *Asian Bioethics Review* 4, no. 4 (2012); "Ability Privilege: A Needed Addition to Privilege Studies," *Journal for Critical Animal Studies* 12, no. 2 (2012).

BIID. It is an experience that unsettles intuitions concerning which abilities matter, how they matter, and why they matter at all. It is an experience that gets to the heart of how we think a body should be to be good and to do good. It is thus an experience that, by my lights, prompts a reevaluation of not only canonical ethical ideals and exemplars, but also the lived experience of being *subject to* the assumptions and prescriptions of normative theorizing.

While a significant literature in bioethics and other fields has arisen around BIID, only a small portion engages the breadth of work across critical disability studies and philosophy of disability, a tendency sadly and problematically still true of much bioethics literature more generally.[i] In this paper, I draw upon the latter fields to contribute to arguments for the support of surgeries for people with BIID. Because I find extant positive arguments persuasive, I here provide a negative account that critiques arguments based upon the principle of nonmaleficence *against* such surgery. I demonstrate how the action-relative concept of harm in such arguments relies upon suspect concepts of biological and statistical normality, and I contend that each fail to provide normative guidance. I then propose and outline a critical theory of harm defined by substantive engagement with both empirical and reflective inquiry across the sciences, social sciences, and humanities. I conclude by discussing implications of a critical theory of harm and, more generally, the dismantling of the ableist conflation, and broader implications of how this project might enirich ongoing debates about the relation of disability to harm and well-being in bioethics, philosophy of disability, and the health humanities more broadly.

By focusing on how arguments from harm have been deployed against therapeutic amputation for those with BIID, I will also have an opportunity to put the rethinking of ability outlined in chapter five to work, and I use the language developed there throughout. I conclude by discussing the broader implications of my analysis and critique of the ableist conflation and how this work bears upon ongoing debates in bioethics, philosophy of disability, feminist philosophy, phenomenology, and contemporary continental philosophy more broadly.

§6.1 Transability — BIID (Body Integrity Identity Disorder)

You wake up in a cold sweat. A hand lays dead upon your face. After a few hazy seconds of delirium, you realize it is your own. But it is also not your own. It is 'asleep', as one says, and while one knows perfectly well that it is one's own hand, 'it' feels unwelcome and alien. In this moment of derecognition of one's body, one perhaps approaches, however imperfectly, the experience of transability or BIID: body integrity identity disorder.[1]

BIID is a rare condition characterized by an intense desire or need to move from a given state of ability to one of relative impairment, most often through amputation.[2] As Sabine Müller puts it, "psychologists, psychiatrists, and neurologists offer quite different explanations for the amputation desire: they discuss whether it is a neurotic disorder, an obsessive-compulsion, disorder, an identity disorder like transsexuality, or a neurological

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[1] As I discuss below, "transabled" is a term some people who have been diagnosed with or experience what is categorized as BIID use to identify themselves. Transability, then, is not identical with BIID. The latter is a more recent medical diagnosis, one which is still being contested along with terms such as apotemnophilia and somatoparaphrenia, et al. "Transability," on the other hand, is a more politically-charged marker of identity and, depending upon one's situation, also community. Because it is currently the most accepted term in the literature of bioethics and philosophy of disability, I primarily use the term BIID throughout this paper.

[2] No sufficient statistical research has been carried out to determine the precise percentage of people living with BIID. Estimates, however, suggest that it is well below 1% of the population.

conflict between a person’s anatomy and body image, which could stem from damage to a part of the brain that constructs the body image in map-like form.”[1] That is to say, there is serious disagreement over the nature, definition, diagnosis, etiology, and prognosis of BIID. Since around 2008, cognitive neuroscientists have argued that, at least in some cases, it is a neurological, body-mapping problem caused by a failure to represent one or more limbs in the right superior parietal lobule.[2] It should be noted that the scientific

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[1] S. Muller, "Body Integrity Identity Disorder (Biid)-Is the Amputation of Healthy Limbs Ethically Justified?," *Am. J. Bioeth.* 9, no. 1 (2009).

[2] Research on BIID has exploded in recent years, including scholarship in fields ranging across sociology, psychology, cognitive neuroscience, critical disability studies (including, especially, English and literary theory), bioethics, philosophy of disability, feminist philosophy, queer theory, and trans* studies, among others. I thus take what I highlight here to be in no way exhaustive. After finishing the material presented here, I became aware of Christine Marie Wieseler’s June 2016 dissertation at the University of South Florida, entitled “A Feminist Contestation of Ableist Assumptions: Implications for Biomedical Ethics, Disability Theory, and Phenomenology.” The fifth and final chapter focuses on BIID, and besides being remarkably insightful, it is the most comprehensive analysis I have read on the subject. Needless to say, I highly recommend it. Her dissertation can be accessed at http://scholarcommons.usf.edu/cgi/viewcontent.cgi?article= 7629&context=etd. The first research, as far as I’m aware, on what is now called BIID is: John Money, Russell Jobaris, and Gregg Furth, "Apotemnophilia: Two Cases of Self-Demand Amputation as a Paraphilia," *The Journal of Sex Research* 13, no. 2 (1977). With respect to neurological literature, one of the first studies is D. David Brang, S. Paul McGeoch, and S. Vilayanur Ramachandran, "Apotemnophilia: A Neurological Disorder," *NeuroReport* 19, no. 13 (2008). The following article attempts to bring together the psychological and neurological findings: Michael B. First and Carl E. Fisher, "Body Integrity Identity Disorder: The Persistent Desire to Acquire a Physical Disability," *Psychopathology* 45, no. 1 (2012). For a critique of the epistemology of neurological etiologies with respect to such phenomena, see Carl Erik Fisher and Michael B. First, "Examining the “Neuro-” in Neurodiversity: Lessons from Body Integrity Identity Disorder," *AJOB Neuroscience* 2, no. 3 (2011). For key pieces in queer and trans* studies, see especially: Stryker, Susan, and Nikki Sullivan. 2009. ‘‘King’s Member, Queen’s Body: Transsexual Surgery, Self-Demand Amputation, and the Somatechnics of Sovereign Power.” in Nikki Sullivan and Samantha Murray, *Somatechnics: Queering the Technologisation of Bodies*, Queer Interventions (Farnham, Surrey; Burlington, VT: Ashgate, 2009); Alexandre Baril, "‘How Dare You Pretend to Be Disabled?’ the Discounting of Transabled People and Their Claims in Disability Movements and Studies," *Disability & Society* 30, no. 5 (2015); "Needing to Acquire a Physical Impairment/Disability: (Re)Thinking the Connections between Trans and Disability Studies through Transability," *Hypatia* (2014); Elisa A.G. Arfini, "Instructions for Becoming Disabled: A Narrative Analysis of the Project of the Transabled Body (Istruzioni Per Diventare Disabili: Un'analisi Narrativa Del Progetto Sul Corpo Transabile)," *Sutudi Culturali* 7, no. 3 (2010); "Transability," *TSQ* 1, no. 1-2 (2014). For work in critical disability studies, see Kate Noson, "From Superabilità to Transabilità: Towards an Italian Disability Studies," *Modern Italy* 19, no. 2 (2014); Stevens. In sociology, Jenny L. Davis has written insightfully and extensively on the topic: Jenny L. Davis, "Morality Work among the Transabled," *Deviant Behavior* 35, no. 6 (2014); "Narrative Construction of a Ruptured Self: Stories of Transability on Transabled.Org," *Sociological Perspectives* 55, no. 2 (2012); "Prosuming Identity: The Production and Consumption of Transableism on Transabled.Org," *American Behavioral Scientist* 56, no. 4 (2012). In legal studies, see Robin Mackenzie and Stephen Cox, "Transableism, Disability and Paternalism in Public Health Ethics: Taxonomies, Identity Disorders and Persistent Unexplained Physical Symptoms," *International Journal of Law in Context* 2, no. 4 (2006); Robin Mackenzie, "Somatechnics of Medico-

literature focuses far more often on limb amputation than other forms of transability (including blindness and deafness) and also that within the transabled community, well-known hierarchies of disability appear. For example, no one is reported to desire epilepsy, cystic fibrosis, or fibromyalgia. That is to say, no one is reported to desire an "invisible" disability or an "unhealthy" disability, to use Susan Wendell's distinction.[1] The question of the *desirability* of embodied condition X is thus front and center. There is disagreement whether those with BIID desire simply to be impaired in a specific manner; whether they desire to be socially disabled such that they are recognized to have a certain identity, the privileges and stigmas attendant with it, and afforded participation in the relevant communities; whether they simply desire their body to be "in alignment" with how they "feel" their body should be; whether and how this relates to erotic desire either of themselves or others as amputees; whether it is some combination of these; or whether the desire is something else entirely. Bioethics literature, however, by and large assumes this desire—whatever its explanation—to be pathological in nature.

Take the example of deafness by contrast. A number of decades ago, the desire to be deaf would likely have been pathologized across the normative board. Yet, with increased awareness of Deaf (with a capital D) culture, it is well documented that deafness is experienced by some as a positive and intrinsically valuable cultural identity, not as audiological lack or loss. To my knowledge, no commentators regarded as "pathological" the desires of the couple who in 2004 made international headlines for

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Legal Taxonomies: Elective Amputation and Transableism," *Medical Law Review* 16, no. 3 (2008).

[1] Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996); "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities," *Hypatia* 16, no. 4 (2001).

wanting to select for a child with deafness for an IVF procedure.[1] The debates revolved largely around the ethics of that desire relative to the ableist world in which we live. Yet, if a congenitally-hearing person desired or needed to alter their body such that they no longer hear, would this not be considered pathological and categorized as a form of BIID? But what if the desire to do so were expressed in terms of "deaf gain," i.e., gaining the ability to more fully participate in Deaf culture?[2]

Unsurprisingly, BIID raises a host of obdurate quandaries for ethicists. Take, for example, the questions BIID raises in relation to identity and desire. As public discussions surrounding Laverne Cox, Caitlyn Jenner, and Rachel Dolezal attest, our "Western" cultural imaginary can make at least some space for the desire to "transition" to another gender identity and even (though far less so) between racial identities. Unsurprisingly, people disagree over the nature, legitimacy, and appropriateness of that desire; but the desire itself is, on the whole, imaginable. There seems to be, on the contrary, no such space for the desire of disability.

One of the more famous spokespeople for BIID is Chloe-Jennings White. She has actively and for years sought a surgeon to sever her spinal cord so that she might become a paraplegic, and she has experienced the desire for paraplegia since she was a small child. For years, she has used a wheelchair because it feels "right" to her in a way that being upright and ambulating does not. While appearing as a guest on Anderson Cooper's CNN show, "360," at one point Cooper comments that White's desire to become paraplegic is "completely inappropriate" relative to those for whom paraplegia is not a

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[1] M. Spriggs, "Lesbian Couple Create a Child Who Is Deaf Like Them," *Journal of Medical Ethics* 28, no. 5 (2002).

[2] H. Dirksen L. Bauman, *Deaf Gain Raising the Stakes for Human Diversity*, ed. Joseph J. Murray, 孜晡讀楡 (Minneapolis: Minneapolis : University of Minnesota Press, 2014). I will return to the question of disability-gain or what Elizabeth Barnes calls "good-difference" views of disability below. Barnes.

choice.[1] The audience responds with applause. As disability studies scholar Fiona Kumari Campbell frames discussions over BIID, the desire for disability is (today) simply too transgressive.[2] It is not simply that in "choosing" to be "disabled" one is desiring an object that the able-bodied majority do not find desirable; it is that one is desiring that which is thought to limit and counter desire itself—that which from the perspective of ableism can only be experienced as a constraint, as an unsolicited and unwelcome restriction, and, for that reason, as something to be actively avoided, repulsed by, or even feared.

One might counter that Anderson Cooper, his audience, and all those who might applaud at the inappropriateness of White's desire are simply failing to be empathetic. One might counter that such persons should employ the golden rule: do onto others as you would have them do unto you. Bracketing whether or not health care practitioners (HCPs) should perform therapeutic amputation for people with BIID, if one were in White's situation, would one not want such a surgery? The golden rule appears in some form in nearly every religious tradition across history, and part of its power, I would contend, is in its implicit exhortation to *imagine* oneself in the other's situation.[3] It asks one to be morally sensitive in the way Mark Johnson outlines in the opening epigraph. When applied to BIID, however, the problem emerges quite clearly. If one cannot possibly imagine wanting to be disabled, one cannot determine how one would want to be treated if one experiences BIID. As Anita Silvers notes, "our aversion to the very idea

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[1] "Why Chloe Needlessly Spends Her Life in a Wheelchair," in *Anderson Cooper 360°* (CNN, 2012).

[2] Campbell, *Contours of Ableism*. Part of this relates to the question of the relationship of BIID to erotic desire. See Helena De Preester, "Merleau-Ponty's Sexual Schema and the Sexual Component of Body Integrity Identity Disorder," *Medicine, Health Care, and Philosophy* 16, no. 2 (2013).

[3] Harry J. Gensler, *Ethics and the Golden Rule* (New York: Routledge, 2013); Jeffrey Wattles, *The Golden Rule* (New York: Oxford University Press, 1996).

of being disabled forestalls our understanding the disabled from their perspective."[1] Indeed, it forestalls out understanding of human corporeal variation and experience *tout court*. The golden rule fails to have prescriptive force when one cannot imagine another's situation as the other attests experiencing it. I would proffer that implicit in Cooper's comment and the ensuing applause is not just disbelief in the veracity of White's claims about her own experience, but a more thoroughgoing incredulity regarding the very *possibility* of her desire.

That desiring disability is culturally unthinkable or unimaginable is demonstrated in part through the widespread and vitriolic stigmatization of surgery for BIID. In 2000, an article in the Atlantic was titled "A New Way to Be Mad."[2] In June 2015, an online article in the National Review ran the click-bait headline, "Bruce Jenner's Sex Change Is Self-Mutilation," for a piece entitled, "People Who Cut Off Their Own Limbs (and Their Enablers)," wherein the author used the example of "transabled" surgery to discount transgender surgery.[3] There is little difference between being unable to conceptualize a desire *as an authentic desire* and being able to imagine that desire only if pathologized. One can hide intolerance plainly in sight through the bastion of pathologization. Put otherwise, if another's desire for X is judged by one as possible only if something is "wrong" with that person, one's judgment of that person and their desire is shifted outside the auspices of social acceptability and typical constraints on moral praxis, specifically constraints which pertain to individual differences, choices, and the like. However, the moment one questions the norms and principles upon which such judgment is based, it is possible that oneself, not the other, is morally culpable.

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[1] Silvers, 37.

[2] Carl Elliot, "A New Way to Be Mad," in *The Atlantic* (2000).

[3] Ian Tuttle, "People Who Cut Off Their Own Limbs (and Their Enablers)," in *National Review* (2015).

Before I further address the role of pathologization with respect to transability, an important caveat is in order. I above defined BIID as a “rare condition characterized by an intense desire or need to move from a given state of ability to one of relative impairment, often through amputation.” I used the term impairment as a way of signaling reference to the “social model” of disability. To repeat from above, the latter indicates one’s embodied condition and the former the social ramifications (ranging from stigma to oppression to numerous forms of inaccessibility) of a given impairment. With that distinction in mind, no one with BIID, as far as I’m aware, describes a desire for disability *per se*. Yet, tellingly, part of the resistance to support for surgery for people diagnosed with BIID is precisely through a conflation of that distinction. People living with disabilities who experience typical disability stigma might feel as though one with BIID who desires impairment is not sensitive to the extent to which that impairment will bring about significant negative social effects. However, testimony from people with BIID suggests this concern is ill-founded.[1]

Given the prevalence of different types of disability-based cultural practices and identities, from various disability sports to the Neurodiversity movement to Deaf culture, why don’t more people with BIID explain their experience in terms of a cultural identity (as opposed to solely needing or desiring to change their bodily form to fit how they feel “in” their body)? One explanation has to do with the current state of medical institutions, which are constitutively formed by what Jennifer Scuro terms the “ableist affections” of “neoliberal politics,” the consumerist swath of neoliberal values, and the multitude of neoliberalism’s geopolitical effects.[2] Given this state of affairs, it is only through the

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[1] In addition to her other work cited above, this is especially clear in Davis, "Narrative Constuction."

[2] See Jennifer Scuro, "The Ableist Affections of a Neoliberal Politics," *APA Newsletter on Philosophy and*

pathologization of the experience of BIID that such people can take safe steps to bring their bodily identity into alignment with their bodily form. Insurance, for example, typically won't cover procedures if they are not officially related to a given "condition."

Another explanation is that even for this unique set of people who are seeking to impair themselves and, upon doing so, will also move into a state of disability in the social sense, even they are under the influence of various forms of disability stigma. Alternatively, perhaps instead of mere disability stigma, they are under the influence of broader ableist assumptions that anything deemed a "disability" is intrinsically defined by and experienced as a "lack" and thereby a harm with respect to potential wellbeing.[1] For example, while it may be possible for there to be a blind community (based upon shared experiences), the idea of blind culture (the gainful, rich, and unique experiences relating to blindness that those who are sighted *lack*) might remain doubtful under such auspices. But, given evidence from the lives of people who experience blindness, that doubtfulness is itself doubtful and, I would argue, ultimately grounded upon ableist assumptions.[2] Having now explained BIID and a number of ethical questions it raises, I will turn to analyze arguments from harm against surgery designed to address it.

§6.2 Arguments from Harm Against BIID Surgery

> Although harm is undeniably a central moral notion, it is not yet well understood.
> —Guy Kahane & Julian Savulescu[3]

Medicine (Current Issue); "Thinking of Bhopal: Women's Bodies as Waste-Sites," *International Studies in Philosophy* 40, no. 2 (2008).

[1] I am grateful to David Peña-Guzmán for pushing me on the possibility of a more general ableism (beyond mere disability stigma) potentially at work in the lack of identification with "disability" by those diagnosed with BIID.

[2] On this point, see Reynolds, "On Being Outside the (Normate) Body: Merleau-Ponty's Aveugle and Crip Phenomenology."

[3] Kahane and Savulescu, 318. On the leading body modification website, "Modblog," a person going under the pseudonym Jason is interviewed about the "accident" he successfully staged in order to cut off his right arm below the elbow with a power tool. Jason identities himself as a "body-integrity-disorder (BIID) dude"

Arguments against surgery for BIID are often based on the principle of nonmaleficence, which holds that an HCP should not cause harm or injury to a patient, whether by acts of commission or omission.[1] This principle, enshrined in bioethics literature by Beauchamp and Childress' field-defining *Principles of Biomedical Ethics*, dates at least back to the Hippocratic Oath.[2] An influential article from 2009 in *The American Journal of Bioethics* by Sabine Müller, entitled "Body Integrity Identity Disorder (BIID)—Is the Amputation of Healthy Limbs Ethically Justified?", draws upon this principle in order to argue against a symptomatic approach to BIID. Müller contends that while surgery for elective amputation cures the primary symptom of BIID (the *feeling* of having an unintegrated limb), it does not address its underlying neurological cause.[3] She thus ultimately argues against surgery for BIID patients. Of the seven responses to Müller's article, just three definitively support the surgery, either as a last resort or as the only viable resort available today.[4] Those that do not support the surgery rely more heavily upon the concept of harm.[5]

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and says, "for sure it's not rational to want to cut off your arm or leg. There's no argument you can make that life will be easier, or that you'll be more capable doing anything." Shannon Larratt, "One Hand Jason: Biid Interview in Bme/News," in *ModBlog* (2008).

[1] Some scholars distinguish between disadvantage and harm, a practice I will not follow here.

[2] Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 7th ed. (New York: Oxford University Press, 2013). What is called the "harm principle" originates from John Stuart Mill. John Stuart Mill, *On Liberty*, The Library of Liberal Arts (New York: Liberal Arts Press, 1956), 13. In political philosophy since, including offshoots or variations ranging from critical theory to critical international relations theory, there is significant discussion over the role and nature of this principle and the concept of harm it assumes. I cannot address these issues here. See, e.g., Shannon Brincat, "The Harm Principle and Recognition Theory," *Critical Horizons* 14, no. 2 (2013).

[3] She assumes such neurological research to have reached sufficient consensus for biomedical decisions to be made based upon that research.

[4] Jozsef Kovacs, Jenny Slatman & Guy Widdershove, and Neil Levy. Avi Craimer leaves open whether surgeons are morally permitted to perform the surgeries. See Volume 9, Issue 1 of the *American Journal of Bioethics*.

[5] Because of the breadth of literature on BIID and given the space and aims at hand, I will focus here on examples of how harm is used from this set of articles (Müller's target article and the seven responses to it). While my aims with respect to an analysis of harm in extant literatures are thus modest, I take the

For example, in their response to Müller's piece, Jolkowitz and Zivotofsky, write: "the majority opinion [in Jewish Law, the perspective out of which their article is framed] permits cosmetic surgery based on the obligation to 'love your neighbor like yourself'—in our mind, it is hard to argue that therapeutic amputation is an act of 'loving your neighbor.'" (56). The implication is that therapeutic amputation is neither an act of love, nor a neutral act, but one of harm. No argument is given for this claim. To appreciate why this act would be considered an obvious harm, one need only refer to Müller's article itself. In a paragraph explaining the difference between GID and BIID, she writes, "genital surgeries on transsexuals aims for a normal, social [sic] accepted, not disabled form of human existence" (w4). Müller appears to here uncritically utilize the widely assailed medical model of disability, under which disability is considered an individual misfortune or tragedy resulting from genetic or environmental insult. Therapeutic amputation constitutes a harm for Müller because, unlike genital reassignment surgery, it seeks disability: that which is presumably a harm, abnormal, and not socially accepted.

Upon critical reflection concerning the meaning of "normal" and "socially accepted," it is not clear how Müller's argument holds up. While, for the sake of argument, one could claim that the end-goal of genital surgery correlates to a "normal" sex/gender binary, the desire to surgically change one's sexual anatomy, in and of itself, is today neither generally "normal," nor "socially acceptable" in any meaningful sense of those terms.[1] Furthermore, depending upon social judgment of one's physical appearance, dressing in clothing that aligns with social norms corresponding to a sex-

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implications I draw, if convincing, to have significant ramifications for the concept of harm in general and its use across bioethics in particular.

[1] Despite, as I argued above, being "thinkable"—being something which *at least some* cultural spaces deem legitimate and defensible.

assignment surgery might make one a target for hate crimes and, on the whole, significant social ostracization. By deploying a concept of disability wherein disability necessarily entails harm (whether the "harm" of genetic defect, acute injury, chronic disease, or what have you), Müller's arguments traffic in ableism and disability stigma. The argument is ableist, to be clear, insofar as it assumes, without evidence or argumentation, that the "standard" able-body is, *ceteris paribus*, in and of itself better.[1]

Some scholars distinguish between action-relative and effective-relative forms of harm. On an action-relative account of harm, "harm" picks out cases where an action makes one worse off than one would have been in the absence of that action. On an effect-relative account of harm, "harm" picks out cases where the effects of an action are held to bear negatively on one's well-being irrespective of how would fare in the absence of that action.[2] It is instructive to note that scholars arguing about BIID seem to slip between these two senses of harm or be unaware of the distinction entirely. Some hold therapeutic amputation for BIID to constitute a harm *even if* the person with BIID claims they are better off after it: an effect-relative account of harm. Others hold therapeutic amputation for BIID to be a harm insofar as they find it implausible that it will make that person's life better off than it would be in the absence of the amputation: an action-relative account of harm. Because all those in the debate hold amputation to be a harm in some sense (unlike views on many forms of body modification), proponents of therapeutic amputation employ an action-relative account of harm and argue that we have

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[1] On the multiple issues such ableism raises especially in a biomedical decision-making context, see Reynolds, "The Ableism of Quality of Life Judgments in Disorders of Consciousness: Who Bears Epistemic Responsibility?."

[2] I found the following article very helpful on this topic: Molly Gardner, "On the Strength of the Reason against Harming," *Journal of Moral Philosophy* (2015).

reason to believe it *will* make that person's life better off. I find much more to be said on this topic, but there is not space to do so here.

To take another example, Jozsef Kovacks, also working with a medical model of disability, argues against Müller that *both* GID and BIID create "from a healthy body a seriously disabled one" insofar as GID causes an "invisible, but very serious disability" by depriving an otherwise "healthy person from the possibility to reproduce" (44). Setting aside for a moment whether or not—or how—GID is an instance of disability, a claim I find either absurd or deeply misguided even given a significant desire to reproduce, Kovacks then goes on to clarify that since most HCPs support sex-reassignment surgery, the "paternalistic prohibition to provide surgery for BIID patients mirrors our own aversion of physical disabilities" (45). Kovacks concludes, "if BIID is a valid psychiatric disorder, then BIID sufferers do not exchange their health for disability. They exchange the suffering caused by their mental disorder for the suffering caused by a physical disability" (45).

Although I find Kovacks' argument more convincing than Müller's and less problematic in certain respects, the lack of rigor and awareness with respect to the concept of disability is glaring in the work of both authors. As the disability rights movements since the last half of the twentieth century as well as disability studies' work in the academy have evidenced, in numerous cases of disability it is societal conditions that centrally, negatively affect the flourishing of people with various impairments.[1] Especially once one takes into serious consideration the empirical contingency of current forms of material-social environments and the various accesses they afford, hinder, or

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[1] To repeat arguments from chapters one and two, this is by no means true for all cases of disability, especially those concomitant with severe illness or chronic pain. See, e.g., Reynolds, "Feeding Upon Death: Pain, Possibility, and Transformation in S. Kay Toombs and Kafka's the Vulture."; Patsavas.

prohibit, the harm is often less the impairment, if at all, and more the societal configuration and responses to non-normate embodiment. The assumption that the primary differences introduced by therapeutic amputation-related impairments are due to individual physiology and not societal conditions ignores the very foundation of theoretical work done on disability for the last fifty years ranging across the humanities and social sciences. Taking this seriously would mean, for example, that one is also or perhaps even more concerned about wheelchair accessibility, disability rights, and social discrimination for a post-amputation Chloe-Jennings White than one is about the ethics of that amputation.

§6.3 Normality & Harm

> "Difference engenders hatred."
> —Nietzsche

If, as the discussion above demonstrates, some bioethicists deploy an uncritical concept of harm in relation to understandings of disability and, by extension, BIID, what of those who analyze the concept of harm itself? In "The Concept of Harm and the Significance of Normality," Guy Kahane and Julian Savulescu [K&S] work to understand the normative difference between varying phenomena people claim as harmful or potentially so.[1] They note that while there is strong intuitive or common sense support for claims that (1) the presence of severe intellectual impairment, paraplegia, blindness, or early death are harms, claims that (2) lacking a statistically high IQ, great artistic talent, or longevity below 130 do not have such support. The relevant difference in the examples, they argue, appears to be biological normality. Yet, and this is crucial, they dismiss biological normality outright as normatively relevant. "The moral insignificance

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[1] Kahane and Savulescu. Citations to this article are in text hereafter.

of biological normality and abnormality seems so obvious on reflection, is so widely accepted, and has been vigorously and, to our mind, conclusively argued, that we will simply assume it here" (320).

They instead argue that while "normality does matter," it doesn't do so in "the way many assume." There is "no *deep intrinsic* normative difference between the items on (1) and (2), yet [one can] still hold that there are nevertheless morally important differences between the two lists." "Statistical normality," they continue, "while lacking inherent moral significance, can nevertheless matter *derivatively*." I'll call this the *weak statistical normativity* argument: statistical normality provides or at least tracks a thin, derivative, and "non-intrinsically moral" measure for normative judgments (323). My aim is to show that the weak statistical normativity argument is not normative; statistical normality is merely descriptive. Like biological normality, it should be dismissed outright as a normative ground.

What, precisely, is weak statistical normality derivative of? It can't be derivative of biological normality, since that was rejected by K&S as having any moral significance. Is it derivative of the intuitions in question? If so, it holds no more normative weight than any set of intuitions do, and intuitions, in and of themselves, hold no prima facie normative weight, whatever their descriptive value.[1] Even if one takes moral intuitions as bearing upon the methodological origins of a naturalized ethical inquiry into normativity, that they are intuitions about a *historically oppressed group* makes them suspect for any

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[1] To be clear, this is not to say that intuitions are not useful for descriptive ethics and thereby for an origin point of inquiry into normative concerns—it's just to say that they do not in and of themselves have normative weight simply by virtue of being intuitive to a given set of people. For those who would immediately invoke debates over the is/ought distinction, the "prima facie" qualification I employ is extremely important for the specific arguments I make here as well as my general positions regarding that relation more generally (which, given the space and aims at hand, I cannot detail).

critical inquiry, naturalized or not. Given the horrifying and deeply entrenched history of ableism across intellectual traditions, East and West, any responsible ethicist should be profoundly distrustful of philosophical intuitions about disability and, *a fortiori*, intuitions about disability originating from non-disabled people.[1] And, as I argue in more detail below, the concept of harm (as with the concept of "severity" or "disease" or a host of other terms deployed throughout bioethics literatures without sufficient critical analysis) is long overdue for critical inquiry if it is to avoid not only the ableist, but also the racist, sexist, and classist, et al., medical practices and theories against which bioethics historically arose as a distinct discipline in the first place.

While there is much to appreciate in K&S's article and in their genuine efforts to engage research in disability studies as well as testimony from people living with disabilities throughout their inquiry, I am not convinced that there is a meaningful moral distinction between biological normality and statistical normality. After discussing how the *descriptive* nature of statistical normality accounts for its theoretic use (its use for providing explanations and predictions of wellbeing), K&S turn to discuss its normative use, which they gloss as its ability to mark reasons for action and attitude (323-24). They note that "harm and disadvantage are not only explanatory notions. They also typically have normative significance" (324). "Typically" with respect to who and what domain? I agree that such concepts are typically *thought* by many bioethicists to have normative significance. But the application of the concept of harm to justify all sorts of horrors across biomedical history suggests that the way in which harm and disadvantage *typically*

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[1] E.g., see Tremain, *Foucault and the Government of Disability*; Licia Carlson, *The Faces of Intellectual Disability: Philosophical Reflections* (Bloomington: Indiana University Press, 2010).

have and have had normative significance is itself fraught and should precipitate prima facie suspicion, not support.

The fulcrum of the weak statistical normativity argument appears shortly thereafter: “limitations of resources mean that we can rarely promote wellbeing in all possible ways. We have to choose…this is a question about distributive justice” (325). But limited resources mark an empirical condition pertaining to the application of normative principles—*that* there are limited resources does not help one determine *which* resources should be allocated to whom or in what quantity. Thus, I agree that statistical normality is important, but it is important for descriptive ethics, not normative ethics. Because K&S, it seems to me, ultimately end up slipping from the descriptive to the normative in their assessment of the worth, however limited, of statistical normativity—of the way and extent to which it “matters,” as they put it—they oversell its import. To take another example, they claim, “to the extent that items on (1) tend to make people’s lives significantly worse than the lives of *most* others, considerations of justice might give priority to the prevention or correction of these conditions.” That would be a consideration derived from descriptions of states of affairs in the world, not normative considerations or principles.[1] It might suffice as grounds for policy-makers or politicians who seek to appease what they imagine as their constituency, but it is not a ground for ethicists.

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[1] There is yet another issue that impedes the weak statistical normativity argument. The examples of both (1) and (2) are both biologically and statistically exceptional—they fall on the edges of the phenotypical bell curve for homo sapiens. As the authors note at one point, substances or genetic manipulation could make the abilities of (2) a live option for those with enough societal and economic resources in the near future. That the examples of (2) could quickly move closer to being of a kind with (1) should give even more pause to the merit of statistical normativity. In short, while biological normativity is little more than dogmatic prejudice, statistical normativity is little more than such prejudice held in the sway of an ethics of comparativity.

All sorts of things *tend* to make people's lives significantly worse under current states of affairs (some such things, for example, pertain to race, gender, ethnicity, religion, geographical location, etc.), but ethicists today do not attribute intrinsic moral worth to many such tendencies, including all those listed in parentheses, and for good *normative* reasons. To repeat from above, given the prevalence of ableism, ethicists concerned about questions pertaining to disability and normativity should have a prima facie distrust of descriptive accounts of well-being pertaining to disability originating from or primarily informed by the experience of the non-disabled. This holds as well for accounts originating from people with disabilities who have not been exposed to anti-ableist ways of thinking and disability-positive communities.

Disabled or non-disabled, our intuitions are deeply unreliable as normative grounds. Humans exhibit *durability bias*, the tendency to overpredict the duration of affective reactions, however grounded, to future events. Furthermore, this is due in part to *focalism*, the tendency to focus too much on an event in one's immediate attentional field and not consequences of other future events.[1] In short, we *predictably* misremember, misrepresent, and mispredict both past and future states of happiness and sadness, pleasure and pain, in relation to singular events, not to mention complex sets of events.[2] Focalism contributes to *pain catastrophizing*, the fact that we regularly overestimate the intensity and duration of pain.[3] This further suggests that we significantly mischaracterize, mispredict, and generally misestimate the meaning of any phenomenon

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[1] Timothy D. Wilson et al., "Focalism: A Source of Durability Bias in Affective Forecasting," *Journal of Personality and Social Psychology* 78, no. 5 (2000). See also discussions of *focusing effect* in David A. Schkade and Daniel Kahneman, "Does Living in California Make People Happy? A Focusing Illusion in Judgments of Life Satisfaction," *Psychological Science* 9, no. 5 (1998).

[2] Timothy Wilson, Jay Meyers, and Daniel Gilbert, ""How Happy Was I, Anyway?" A Retrospective Impact Bias," *Social Cognition* 21, no. 6 (2003).

[3] Day and Thorn.

we *assume* to cause pain; this includes the vast range of phenomena we categorize as "disabilities," phenomena we, thanks to the ableist conflation, fallaciously associate or equate with pain and suffering. To the extent that we deploy applications of abstract statistical norms to our own happiness and thereby pose normative determinations concerning its attainment, we—given psychological evidence about our memory and prognostications concerning well-being—are not relying on *thin* knowledge or *thin* norms: we are relying on little more than fictions. Statistical normality is not sufficient for predictions of happiness and, *a fortiori*, sufficient as a ground for normative judgment, even if only in reference to questions of distributive justice.

As K&S themselves note, the ultimate problem that efforts of such a kind face is the fact that "it's not especially clear how to draw a distinction between good and bad lives, as opposed to better and worse ones. It is controversial whether and how to draw a line between those lives that are worth living and those that are not—but it's at least clear that the latter must contain extreme, unremitting suffering that can't be relieved" (322). If that (absolutely crucial) distinction is *not especially clear*, then is not the ethicist in the same position as any other researcher before a complex, ambiguous, and normatively fraught phenomena? Given the remarkable unreliability of intuitions, especially as they relate to hedonic considerations, one must substantially engage empirical and reflective research on these issues, both positive and critical in nature. One must also, given the entrenchment of ableism, give extra weight to the testimony of those who actually experience the conditions, states, or forms of life to which bioethicists refer. I hope to have demonstrated that more engagement with the body of work across critical disability studies and philosophy of disability would benefit a host of bioethical debates, especially those involving concepts of harm and well-being.

§6.4 Taking Ableism in Ethics Seriously

A naturalized ethics, one which grounds its principles in the concrete experiences of the beings for whom its prescriptions are thought to bear, is an ethics beholden to the structures and singularities of experiences. Thus, while I do not deny that statistical normality plays a role *in praxis* with respect to normative judgments, I think a better route to ground such judgments is through a critical synthesis of empirical and reflective evidence and research about lives attested to be worth living and lives attested not to be. Given the pervasiveness of ableism, substantial disability education (including, but not limited to, literatures in critical disability studies, disability life writing, and philosophy of disability) is needed to *even begin* to understand what it might mean, for example, to live a life involving continental blindness, much less the normative considerations concerning the possibility of selecting for or against such a life or the conceptual frames requisite to fairly include people with blindness in various theories of justice.

If a naturalized ethics wishes to ground its normative claims, it cannot do so primarily through appeal to a second-order, quantitatively-produced metric. The evidence which it brings to bear must be thicker, must be grounded more concretely in the experience of the lives to which it is beholden and for which it crafts its prescriptions. Thus, while I do not deny that statistical normality plays a practical role with respect to normative judgments, I think a better route to ground such judgments is through a critical synthesis of empirical and reflective evidence about lives attested to be or not be worth living. Given the pervasiveness of ableism, substantial disability education (including, but not limited to, literatures in critical disability studies, disability life writing, and philosophy of disability) is needed to *even begin* to understand what it might mean to live a life involving congenital blindness, Ehlers-Danlos syndrome, or specific forms of autism, for example, much less the normative considerations concerning the possibility of selecting for or against such forms of life.

I agree with K&S that "we need the concept of harm for both explanatory and predictive purposes (its theoretical use), and to mark certain kinds of reasons for action and attitude (its normative use)" (323). But, as I hope to have demonstrated, the use of "harm" to discount therapeutic amputation for people with BIID is an instructive counterexample to both the normativity of statistical normality and the common-sense deployment of harm as a prescriptive principle. Even more problematically, there are a host of conditions that were previously thought to be suffered that, with critically-informed research, prove fruitful and gainful.[1]

If it is indeed the case, as I find it to be, that "it is controversial whether and how to draw a line between those lives that are worth living and those that are not," then we need much more critical empirical and reflective work on the experience of lives walking or near that line—a line, it should be emphasized, that is more often than not drawn intuitively and thus very problematically. Across academic scholarship, there is consensus, if any can be said to exist, about a very small subset of lives not worth living. This should give bioethicists serious pause about the confidence with which they judge a given life as not worth living or as having an instrinsically, necessarily low QOL. There is an alarming lack of what Eva Kittay insightfully terms *epistemic responsibility* and

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[1] John D. Lantos, "Trisomy 13 and 18--Treatment Decisions in a Stable Gray Zone," *JAMA* 316, no. 4 (2016).

epistemic modesty on the part of a wide swath of bioethicists when it comes to judgment about non-normate lives, about lives lived with disability.[1] There needs to be, specifically and especially for able-bodied bioethicists, what Lauren Guilmette terms “curiosity deployed in the mode of care” for the myriad and vast range of experiences of disability.[2]

The majority of disability-related political activism in the United States over the last fifty years tends to emphasize structural oppression and minimize individual impairment through a minority identity framework modeled on the civil rights movement. Pain support groups and advocates, on the contrary, tend to neglect structural oppression and emphasize individual, physical impairment. Transabled support groups and advocates, however, tend to neglect structural oppression and emphasize *psychological* impairment—viz., the suffering caused by feeling as though they are in the wrong bodily state. While all three of these groups deploy different political strategies, the affective appeal underlying each is similar: the appeal to suffering.[3] This is thought to be effective because it is assumed that people are averse to anything they identify as genuine suffering. This is thought to be effective because appeals to suffering assume the normative force of the golden rule: they assume that I will treat you as I would like to be treated and that I would not like to suffer.[4] But this requires both an intellectual and affective understanding of the other; this requires my ability to judge the other’s experience as a genuine experience. The golden rule gains normative traction through

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[1] Kittay.

[2] Lauren Guilmette, "Feminist Philosophies of Disability, Foucault, and the Ethics of Curiosity," *APA Newsletter on Philosophy and Medicine* (Current Issue); "In What We Tend to Feel Is without History: Foucault, Affect, and the Ethics of Curiosity," *Journal of Speculative Philosophy* 28, no. 3 (2014).

[3] Though impairment, in contradistinction to disability, does not in and of itself entail that one suffers, neither does it preclude the possibility of suffering caused solely or primarily by the impairment. See footnote 20 above.

[4] A fuller exploration of these topics would require, among other things, engaging Alexis Shotwell, *Knowing Otherwise: Race, Gender, and Implicit Understanding* (University Park, Pa.: Pennsylvania State University Press, 2011); Samuels.

both intellect and affect, and it is the normative force of both that all reflexive political strategies ultimately seek.

In the world of flesh-and-blood beings, for ethico-political prescription to have what Mill calls a "binding force," it can be neither merely logically possible, nor probable.[1] It must claim one within the orbit of one's "living options," to use William James' discerning phrase.[2] Such claims bind one differentially when contextualized by one's race, gender, sexuality, class, indigeneity, generational history, culture, epoch, and so on. The context I have focused upon is that of dis/ability. I argued above that the function of the golden rule is to evoke the imagination such that one's praxis is transformed. Insofar as the imagination interrupts the expected or smooth functioning of pre-existing expectations, the golden rule upsets our sense of control over the conditions of our existence by expanding the domain of our concern and possible experience. What we commonly think of as our "abilities" are really names for various perceived and assumed functions of control over relevant concerns. Yet, insofar as the golden rule forms part of normative ethical theories, it keeps to the canonical trend of focusing its theoretical labors on a principle or ideal. The golden rule articulates an *ideal* of moral imagination. Cultural responses to transability suggest that ideal normative efforts in fact prove weak in upsetting our sense of control and prove weak in actually expanding the domain of our concern. More specifically, they prove weak in such a manner when *one cannot imagine the other's situation or desires as desirable*.

§6.5 The Future of Anti-Ableist Philosophy

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[1] Mill and Bentham, Chp. 3.

[2] William James, "The Writings of William James: A Comprehensive Edition," ed. John J. McDermott (New York: Random House, 1967), 718.

One may, at this point, still be unconvinced. Isn't cystic fibrosis very difficult to deal with? What about the unique struggles of certain intellectual disabilities, especially those like schizophrenia whose lived experienced is articulated in terms of suffering ? Wouldn't one rather walk than not? Wouldn't one rather talk than not? Surely, one might rebut, the ableist conflation contains some truth. There are ongoing debates within disability studies about the meaning, import, and turbulent politics of distinguishing between unhealthy disability and healthy disability. As I argued in chapters three and four above, the experience of stuttering or congenital lack of an appendage or that of Tay-Sachs vs. deafness (congenital or non-congenital) are significantly dissimilar. They are especially dissimilar insofar as only one of each of those pairs renders one's life as constitutively painful or ill.

As discussed above, Susan Wendell has argued, both in her seminal work *The Rejected Body* and later pieces, that disability studies needs to take more account of the stigmas and oppressions faced by those with chronic illness and/or chronic pain—the so-called "unhealthy disabled" who do not represent "the paradigmatic person with a disability who is healthy disabled and permanently and predictably impaired."[1] What if all ethicists and bioethicists made such a distinction? What would it mean to categorically differentiate between such experiences of disability? The epistemic work involved in making such a distinction, I think, is a crucial, albeit initial, step in avoiding the errors of the ableist conflation. Experiences of disability suggest that one should, at minimum, consistently distinguish between the following forms of disability:

Congenital vs. Non-Congenital

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[1] Wendell, "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities." See also Donna Reeve, "Psycho-Emotional Disablism and Internalised Oppression," in *Disabling Barriers - Enabling Environments*, ed. J. Swain, et al. (London: Sage, 2014).

Healthy vs. Unhealthy
Visible vs. Invisible
World-Creating vs. Non-World Creating
Trauma-Induced vs. Non-Trauma Induced
Degenerative vs. Non-Degenerative
Suffered vs. Non-Suffered[1]

For example, cystic fibrosis is an unhealthy disability insofar as its inhibition of lung function creates significant and corporeally intrinsic difficulties and pains. On the contrary, the “lack” of one’s right hand, for example, is a healthy disability insofar as the primary difficulties one encounters will likely be due to the world being *contingently* crafted for people with two hands. Add line about visible vs. invisible disabilities; cite questions of passing. Moving down the list, blindness is a world-creating disability.[2] Even if non-congenital, people report experiencing blindness as a total, rich, and unique form of living in the world, not one defined by lack from the phenotypical “norm.”[3] If one is congenitally sighted and becomes blind through a traumatic event, their experience will be expectedly different. It may take a long time for them to experience blindness as world-creating and, depending upon their attitude, education, and the societal conditions around them, they may or may not come to experience it in such a manner.

Aging, depending upon the characteristics in question, can be experienced relatively gracefully or starkly. If traumatic, one’s experience of the “normal” processes in question can be fundamentally different from one who more slowly, knowingly, and lithely transitions into such experiences. It cannot be overstated how much one’s

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[1] This list is, of course, a heuristic and an incomplete one at that. By at least starting with such distinctions, I believe it will help one to push against the tendency to think in terms of the ableist conflation and the numerous epistemic practices of disability stigmas which result from it.

[2] Reynolds, "On Being Outside the (Normate) Body: Merleau-Ponty’s Aveugle and Crip Phenomenology."; Kleege; Hull.

[3] As John Hull makes clear, whether one experiences non-congenital blindness as a lack is largely in relation to the extent to which one successfully transitions into that new form of experience and works to shed the ableism of which we are all so indoctrinated and socially saturated. See his .

perception of the transitions of one's body bears upon one's experiences of bodily transitions, traumatically induced or not. With respect to the fifth distinction—which clearly relates to the fourth—if one is obsessed with beauty and youth, one can, for example, *suffer* aging, a natural and inevitable process. Without disability education, we are curiously fickle in our interpretation of our fundamental corporeal variability. Simply *that* one experiences a given bodily variation or transition as an experience of suffering does not in and of itself mean that such an experience is normatively negative.

The semiosis of pain discussed above, whether it marks a harm subjectively known or unknown, here acts as a backdrop to definitively judge the value and fate of a life. When the distinction between pain and disability is made, the ableist conflation loses its power, and the expansive breadth of *lives with disability worth living* comes to the fore. This transformation in the conceptualization of disability provides the first step for practitioners to address widespread disability stigma, disability discrimination and oppression, as well as the inertia of what Robert McRuer calls "compulsory able-bodiedness."[1]

It is incumbent upon all, especially those working in normative and applied fields, to listen to the largest group of marginalized people in the world. Yes, to reprise a fact that should be known by all, *people with disabilities are the largest minority group in the world.* Numerous disability communities and cultures, such as Deaf culture, provide rich and valuable ways of knowing and being in the world. One of the more crucial ways to combat disability stigma is by decoupling disability from pain, decoupling unhealthy disability from healthy disability, and educating patients about the multiplicity and richness of disability experiences and disability communities. One should learn to

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[1] McRuer.

interpret ableism and the ableist conflation at work in stories of disability, in stories about fear or resilience in the face of illness, and in all storytelling and communication about the experiences of bodily variation, whether expected or unexpected. It is then that the expansive breadth of lives with disability worth living can come to the fore.

Guy Keane and Julian Savulescu have argued that “it’s not especially clear how to draw a distinction between good and bad lives, as opposed to better and worse ones. It is controversial whether and how to draw a line between those lives that are worth living and those that are not—but it’s at least clear that the latter must contain extreme, unremitting suffering that can’t be relieved.”[1] This dissertation has been an attempt to understand how to draw that line. By linking certain forms of disability to pain through an uncritical conceptualization of pain’s semiosis, the lives of people with disabilities are in too many cases considered to be pitiful, to be undesirable, or to constitute a life not worth living—even to the point of warranting death. All those committed to social justice and interested in doing their part to mitigate widespread social injustices against people with disabilities must learn to identify and contest the error of the ableist conflation.

If left unchecked, history suggests that the ableist conflation will maintain its hold. If left uncriticized, arguments based upon it will continue to reappear in the vast majority of able-bodied patients and even some patients with disabilities. Whether captured in the thought “I’d rather be dead than disabled,” a thought still far too present in the atmosphere of patient-provider interactions, or captured in globally negative attitudes towards disability, providers have a unique power and unique voice to support disability justice. I hope that by clarifying the structure of the ableist conflation, I have

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[1] Kahane and Savulescu, 321.

offered ethicists, activists, and practitioners a tool to better address the injustices and stigmas people with disabilities face.

Some people experience their particular fluidity of bodily possibility in profoundly negative ways. When people think or say, as is quite common, “I’d rather be dead than disabled” or “I’d rather die than suffer or be in pain,” when people speak about defective and non-defective babies like they are talking about TV sets, when professional philosophers and bioethicists like Peter Singer argue that killing these “defective,” disabled babies via infanticide is in certain cases reasonable[1]—in those cases, the corporeal variability of the human is not simply being misunderstood or ignored. It is being feared, dreaded, and demonized.

In such cases, our failure to appreciate the fluidity of bodily differences is in fact leading to the justification of *killing off* those differences. The question of our abilities and disabilities—how we define these, how we deal with these—touches every single one of us to the core *from the womb to the grave*. But the fact that it unquestionably touches some lives more than others, that it has been and is still today used to justify the exclusion and even deaths of others, that is a momentous question, a question of justice, and a question about which ethicists should be far more concerned.

The answer, perhaps, to the question of the life worth living is found in its questioning, is found in the disbelief that one will never have that answer. The answer is found in the hope of difference, for many lives and many ways of living intertwine to lace the thick texture we call worth. Lives lived with, in, through, and for disability are lived twinings from which we might best glean the depth and richness of that texture. If so, then let us discuss this, again, *starting from the beginning*.

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[1] Singer, 164.

TABLES AND FIGURES

Theories of Pain

Theory	**Religious-Moral**	**Neurobiological**	**Humanist**	**Existential**	**Medical**
Domain	Theology	Biology	Axiology	Ontology	Symptomatology
Function	Judgment	Adaptive	Normative	Disclosive	Diagnostic
Power	Injunctive	Organic	Valent	Reflective	Etiological
Effect	Allostatic Reg.	Allostatic Reg.	Allostatic Reg.	Allostatic Reg.	Allostatic Reg.

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Models of Pain

Component Pain	**Constitutive Pain**	**Consuming Pain**
Feeling Pain, Being In Pain	Suffering, Constitutive Suffering	Extreme Suffering

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Nagi Disablement Theory

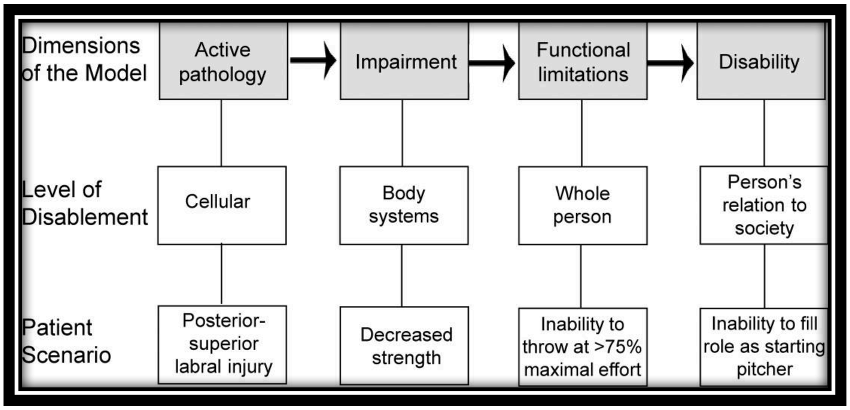

Figure 3: Nagi Disablement Theory

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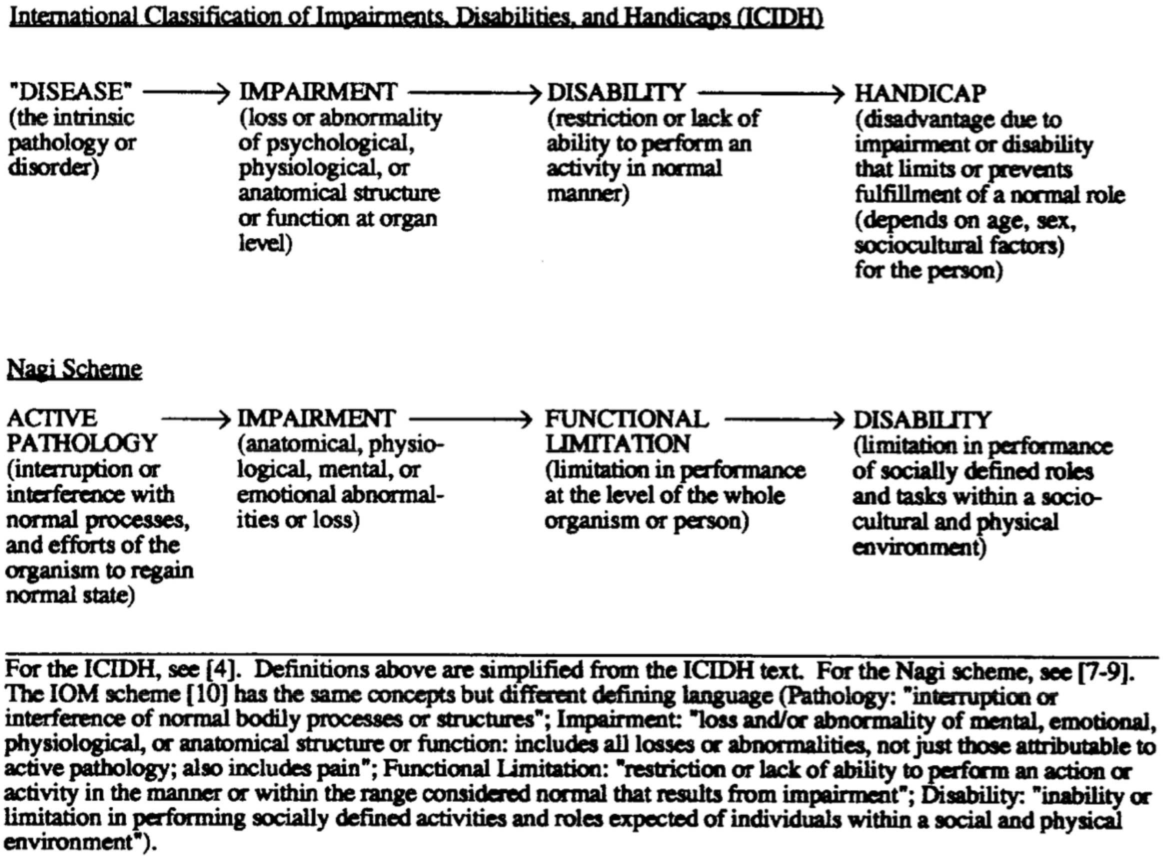
ICIDH vs. Nagi



International Classification of Impairments, Disabilities, and Handicaps (ICIDH)

"DISEASE" → IMPAIRMENT → DISABILITY → HANDICAP

"DISEASE" (the intrinsic pathology or disorder)

IMPAIRMENT (loss or abnormality of psychological, physiological, or anatomical structure or function at organ level)

DISABILITY (restriction or lack of ability to perform an activity in normal manner)

HANDICAP (disadvantage due to impairment or disability that limits or prevents fulfillment of a normal role (depends on age, sex, sociocultural factors) for the person)

Nagi Scheme

ACTIVE PATHOLOGY → IMPAIRMENT → FUNCTIONAL LIMITATION → DISABILITY

ACTIVE PATHOLOGY (interruption or interference with normal processes, and efforts of the organism to regain normal state)

IMPAIRMENT (anatomical, physiological, mental, or emotional abnormalities or loss)

FUNCTIONAL LIMITATION (limitation in performance at the level of the whole organism or person)

DISABILITY (limitation in performance of socially defined roles and tasks within a sociocultural and physical environment)

For the ICIDH, see [4]. Definitions above are simplified from the ICIDH text. For the Nagi scheme, see [7-9]. The IOM scheme [10] has the same concepts but different defining language (Pathology: "interruption or interference of normal bodily processes or structures"; Impairment: "loss and/or abnormality of mental, emotional, physiological, or anatomical structure or function: includes all losses or abnormalities, not just those attributable to active pathology; also includes pain"; Functional Limitation: "restriction or lack of ability to perform an action or activity in the manner or within the range considered normal that results from impairment"; Disability: "inability or limitation in performing socially defined activities and roles expected of individuals within a social and physical environment").

Figure 4: ICIDH v Nagi Disablement Models

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Theories of Disability

Theory	**Individualist**	**Social**	**Post-Social**
Domain	Moral	Politico-Juridical	Diffusive
Function	Judgment	Adaptive	Heuristic
Power	Injunctive	Normative	Reflective
Effect	Exteriorize	Politicize	Problematize

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Charmed Circle of Ability

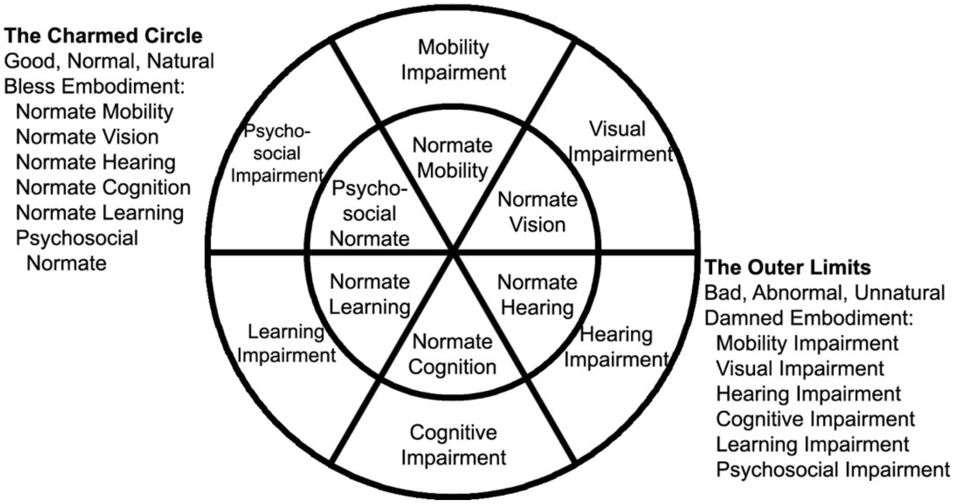

Fig. 1: The Ability Hierarchy - The Charmed Circle v. The Outer Limits

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Pendulum

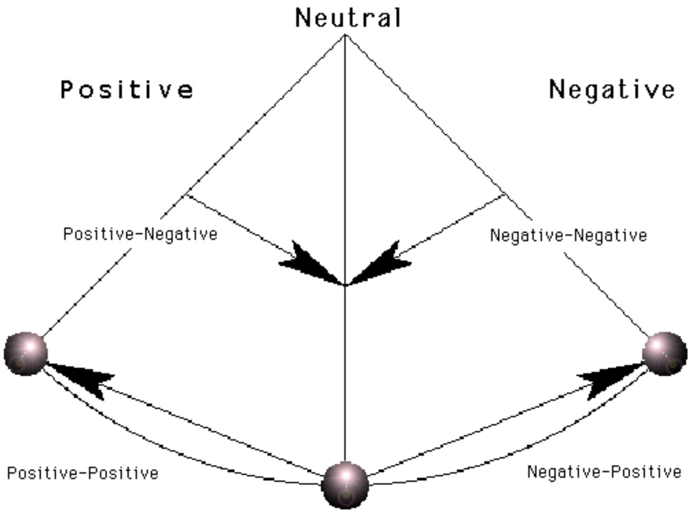

Fig. 2: Physics of Vibration as a Pendulum

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Pendulum of Health

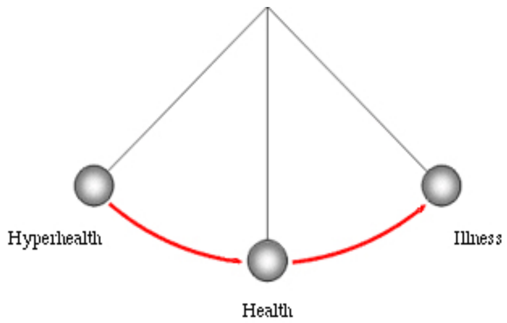

Fig. 3: The Pendulum of Health

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Pendulum of Regard

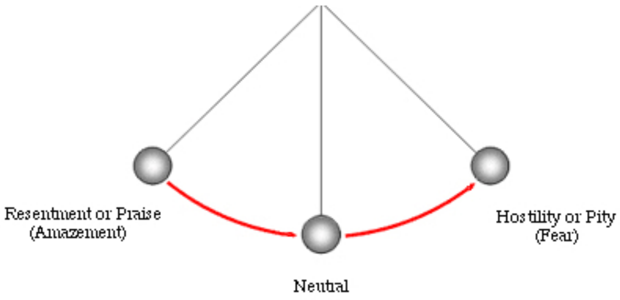

Fig. 4: The Pendulum of Regard

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Pendulum of Control

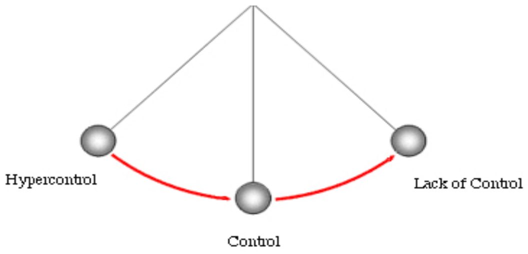

Fig. 5: Pendulum of Control

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