THE LIFE WORTH LIVING

DISABILITY, PAIN, AND MORALITY

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University of Minnesota Press
Minneapolis
London

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Published by the University of Minnesota Press
111 Third Avenue South, Suite 290
Minneapolis, MN 55401-2520
http://www.upress.umn.edu

ISBN 978-1-5179-0265-0 (hc)

A Cataloging-in-Publication record for this book is available from the Library of Congress.

Printed in the United States of America on acid-free paper

The University of Minnesota is an equal-opportunity educator and employer.
For Jason and Gail
And for the principal supports without which they, and I, would not exist:
Alan, Papa Jack, and Grandma Babe
[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, The Brothers Karamazov
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Introduction

The Ableist Conflation

The history of ethics shows all too clearly how much our thinking is shaped by what our sages omit to mention.

—Midgley, “Duties Concerning Islands”

Let us discuss this, then, starting from the beginning [λέγομεν οὖν ἄρξάμενοι].

—Aristotle, final line of Nicomachean Ethics

On his death bed, awaiting the vial of hemlock that would consummate his juried execution, Socrates asks, “Is life worth living with a body that is corrupted and in a bad condition?” “In no way,” replies his friend Crito (Plato, Crito, 47e).¹ This judgment will be repeated across cultures and epochs: the corrupted body, a body many today would call a disabled body, is so undesirable that one would rather not be than bear its existence. Here, at the canonical origins of the Western intellectual tradition, one finds certainty that some forms of life are worth less than others or not worth living at all.²

In the end, the Socratic deathbed hallows an otherworldly set of values. From Plato to Aquinas, Descartes to Kant and beyond, the life of the body for the “Western canon” is so often held to be worth less than that of the mind—and the lives of certain bodies and certain minds deemed worth less still. Yet, what do the actual conditions of life, the fleshy, enmeshed conditions that forever come to us with a past, present, and future, in fact tell us? What does the constitutive variability of our bodies suggest about how we ought to treat others 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 life, and who has the right to decide it?

This work is an attempt to answer these questions by investigating the claim that some lives are not worth living. This idea has enjoyed an astonishing consensus across the history of philosophy—to the point that it often functions as an arché, a foundation for and origin of further thought, judgment, and action.

The invariable variability of human embodiment underwrites all human values, including that of life worthy of life. Disability, one name for such variability, is a touchstone for both how we are and how we ought to strive to be. In arguing so, I contend that the Socratic deathbed, a millennia-spanning metaphor for unyielding commitment to both truth and justice, is not the beginning of the examined life worth living but instead an end for countless lives, examined or not. It is an end, a deathbed, and a sentence for so many because Socrates, Plato, and the many traditions that followed failed to appreciate the meaning of disability.

Within the canonical Western history of philosophy, disability has been understood above all as lack and privation. In an example to which I will return in greater detail in chapter 3, Aristotle (Metaphysics, 2:1615/1022b27–22) 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.3

The idea that disabilities like blindness are defined by lack, defined by a violent, harmful taking away, is translated into policy in his Politics: “as for the exposure and rearing of children, let there be a law that no deformed [peperomenon] child shall live” (1335b20–21). For Aristotle, this conceptualization of a particular set of bodily forms—those that are peperomenon, “mutilated,” “deformed,” or “malformed”—is obvious. He neither offers a substantive definition of the term nor seems bothered to address limit cases.
In many ways agreeing with Aristotle, Kant will later claim, “infirmitiy of the mind [Gebrechen des Gemüths] is just such a crippled state [krüppelhafter Zustand] of mind, as infirmity of the body is a crippled state for the body. Infirmities are not hindrances of the powers [Kräfte] of mind, but a lack [ein Mangel], but the latter exists when the condition for the regular use of the powers [regelmäßigen Gebrauchs der Kräfte] of mind is lacking” (Kant 2012, 113/25:554). To the extent that one does not meet Kant’s implicit or explicit norms for mental ability, one is lacking, and lacking fundamentally as a “human.” It is telling that there are ongoing and serious scholarly arguments over whether it is possible to grant people with intellectual disability moral status within a Kantian framework, notwithstanding the fact that Kant himself didn’t think it possible.

Or take Mill’s famous judgment about happiness and satisfaction: “better to be Socrates dissatisfied than a fool satisfied” (Mill 2006, 212). Fool, in late nineteenth-century English, typically picks out what today would be called a type of “intellectual disability.” In that light, one could read Mill as in fact reiterating a variation of Socrates’s rhetorical question. A lack of intelligence, regardless of the outcome that lack has on overall well-being, is worse than not having that lack. Furthermore, Mill claims that if the fool judges their life in fact to be as satisfactory as the nonfool’s, “it is because they only know their own side of the question. The other party to the comparison knows both sides.” Does the other side know? How do they have knowledge about an experience of which they have never been privy? Assuming so is a textbook case of epistemic injustice against those with other sorts of experiences, especially intellectual disabilities with respect to which the very parameters of satisfaction may be importantly different (Dohmen 2016). This is also a paradigmatic result of what Robert McRuer calls “compulsory able-bodiedness,” wherein assumptions based in able-bodied experiences shape what counts as knowledge and knowing by default (McRuer 2006). In the (ableist) philosophical imaginary, it seems there are no limits to what the able body can know.

These are just a few instances demonstrating how ableism shapes philosophical, not to mention other forms, of thinking. Yet, tellingly, each of these instances fails for the same core reason: it understands disability as a lack, and a lack that cannot but result in reduction of happiness—a lack, in other words, that brings about pain and
suffering, as compared to an idealized able body, which is to say, the normate. One reason for philosophy’s long-standing failure to reflect carefully upon disability is the absence, devaluation, or active ignorance of the testimony of people who are disabled, of those whose bodies and minds have for so long in philosophy been considered worth less or worthless. If the question of the life worth living is to move beyond ignorance and prejudice, then philosophy itself must be reexamined through the perspective of disability.

The Ableist Conflation

The central argument of this book can be stated simply: the canonical idea that some lives are not worth living results from the ableist conflation of disability with pain and suffering. That is to say, the reason for this entrenched, tradition-spanning idea is the habit of thought wherein one conflates experiences of pain and suffering with experiences of disability—experiences whose form, mode, matter, or style of living is considered categorically outside ableist norms.

I offer the ableist conflation as a concept to capture the underlying presuppositions that guide ableist discourses and practices in philosophy; ethics; politics; medicine; local, national, and international policy; and beyond. Although it can take many forms, the ableist conflation involves some variation of at least the following four claims:

1. Disability necessarily involves a lack or deprivation of a natural good.
2. Deprivation of a natural good is a harm.
3. Harm causes or is itself a form of pain and suffering.  
4. Given 1–3, disability comes along with or directly causes pain and suffering.

The ableist conflation functions in part by capitalizing upon the ambiguity of the array of terms it involves. Disability, harm, pain, and suffering are all uncritically underdefined, as are the relations between them. A central goal of this book is to decouple disability and pain through phenomenological investigation and, by doing so, to dismantle the ableist conflation and the uncritical assumptions behind each of its operative terms.

My description of the ableist conflation synthesizes and builds
out groundbreaking claims made by disability studies scholars and, before them, disability rights activists since at least the time of the Union of the Physically Impaired against Segregation in the United Kingdom and the Independent Living Movement in the United States. These activists fought tooth and nail against both locally and globally dominant understandings of disability, namely, understandings that took disability as “something to be avoided,” that confers “pain, disease, suffering, functional limitation, abnormality, dependence, social stigma, and economic disadvantage and [limits] life opportunities and quality” (Garland-Thomson 2012, 340). To combat the ableist conflation, however, it is not enough to claim that experiences of disability and pain are separate—it also requires reflection, in a rigorous and not reflexive manner, upon how they can be related in certain circumstances and contexts.

The reality is that, historically, most scholars in disability studies and philosophy of disability have avoided the problem of pain. Impaired conditions involving pain have more often than not been left to the side in discussions both theoretical and concrete. As Margaret Price (2015, 276) puts the matter, echoing earlier work by scholars like Liz Crow and Susan Wendell, “feminist disability studies, particularly in its American iteration, has not yet contended much with pain.” But, if the thesis of the ableist conflation is correct, then failing to deal with the relation between disability and pain is failing to deal with one of the primary obstacles not only to disability justice but to justice writ large.

By taking the ableist conflation head-on, this project thus contributes to what is an old yet undying problem in disability studies and philosophy of disability in at least five respects: by

1. situating the ableist conflation in the context of the history of philosophy;
2. explaining its origins and demonstrating its failings in light of phenomenological analysis;
3. offering novel analyses of both pain and disability, including their contrasts and comparisons specifically as these bear upon disability theory;
4. expanding and refining existing concepts that distinguish experiences amid and across disability differences, ability transitions, and, most broadly of all, ability troubles of all sorts; and
5. further developing a theory of ability based on the concept of access.

If one is still at this point unconvinced that a philosophical analysis centered on disability and pain—and one methodologically rooted in phenomenology—is needed, let me place this project in what I take to be its larger philosophical context. Whether based in virtue, duty, utility, or social contract, models of flourishing in the canon of the so-called Western intellectual tradition assume a general minimization of pain to be a central goal. Pain is, in turn, thought of as a sort of constraint or lack relative to potentials of purposiveness and flourishing. All such models of flourishing also assume that the corporeal variations we today categorize as “disabilities” are, on the whole, constraints or lacks relative to those potentials, whether defined in primarily physiological or psychological terms. The ableist conflation, then, names a prevalent facet not only of historical and contemporary imaginaries but of reflective thought undergirding multiple canons and traditions as they take up the project of human life.7

In a related manner to Charles Mills’s (1994) damning claim that there exists “a conceptual or theoretical whiteness” that serves as a “pretheoretical intuition” for the discipline of philosophy, there exists a conceptual or theoretical ableism that serves as a pretheoretical intuition for the discipline of philosophy, an ableism underwritten by the framework of the ableist conflation. It is in this light that I contend that the ableist conflation is still today the most pressing and pernicious issue facing reflective thought about disabled experience and that I find ableism to be a problem that philosophy, as a whole, has yet to take as seriously as it should (Tremain 2015a).8 The ableist conflation, despite notable political and academic victories, is an old, ingrained problem whose grip on the present, and not just the philosophical present, forcefully shapes the wider global scales of cultural, sociopolitical, legal, and philosophical judgment over lives worth living.

With minimal alteration, the ableist conflation can support eugenic discourses and practices. For example, consider the following claim, one for which people across the political spectrum typically express support: “the aim of politics and ethics is to maximize flourishing, in part by reducing harms and ameliorating pain and suffering.” If claim 4 of the ableist conflation holds, then it seems to follow that individuals and the state are in certain cases justified in ending
or otherwise curtailing the lives of people with disabilities. Justice Oliver Wendell Holmes Jr. articulated this eugenic form of the ableist conflation with crystal clarity in the majority opinion for the 1927 *Buck v. Bell* U.S. Supreme Court decision: “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.” To maximize flourishing, this decision affirms that the state can forcibly call on the “unfit” not to reproduce. Their reproduction constitutes a harm against the state, so they can be sterilized against their will. For Justice Holmes, certain forms of disability don’t just trump liberal egalitarianism; they call on a liberal society to end the reproductive futures of some of its citizens. A most illiberal inference, indeed. One might think these ideas to have died out in our supposedly “posteugenic” world, but that would, sadly, be wrong.

The Case of the Problem of Ableism in Bioethics

Bioethics, a field meant to support the ethical treatment of human and, increasingly, nonhuman animal life, is rife with examples that reveal the harmful effects of the ableist conflation. Both bioethics literature and downstream biomedical practices are still today too often structured by what disability studies scholars call the medical model of disability: disability understood merely as an individual tragedy or misfortune due to genetic or environmental insult. This interpretation persists despite decades of disability activism and critical disability studies scholarship spanning the humanities and social sciences that show this model to be problematic, if not irremediable, except in highly qualified circumstances. When bioethicists do engage alternative, nonmedical conceptions of disability, such alternatives are too often conglomerated into a mere “position.” They are treated 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 type of scholarly attitude is also reflected in practical domains. For example, the extent and role of education
about disability in medical education and training are still today points of contestation (McKim 2005). Given this, it is unsurprising that people with disabilities report significantly higher inadequacies than people without disabilities in patient–provider communication (Smith 2009). It is also unsurprising that people with disabilities are disproportionately impacted by medical error (Pena-Guzman and Reynolds 2019).

Wherever operative, the ableist conflation flattens communication about disability to communication about pain, suffering, hardship, undesirable experiences, morbidity, and mortality. Take the following argument, from a text still referenced today, by four prominent bioethicists, meant to address critiques from what they call the “radical disability rights advocates”:

We devalue disabilities because we value the opportunities and welfare of the people who have them. And it is because we value people, all people, that we care about limitations on their welfare and opportunities. We also know that disabilities as such diminish opportunities and welfare, even when they are not so severe that the lives of those who have them are not worth living, and even if those individuals do not literally suffer as a result of their disabilities. Thus there is nothing irrational, motivationally incoherent, or disingenuous in saying that we devalue the disabilities and wish to reduce their incidence while valuing existing persons with disabilities, and that we value them the same as those who do not have disabilities. (Buchanan et al. 2000, 278).

Though they don’t explain how, the authors claim to know that “disabilities as such diminish opportunities and welfare” (my italics). In the hope that one is interested in arguments, not assumptions, what is the actual relationship between disability and such “diminishments”? And insofar as lives are defined by disability along social, narrative, political, and other dimensions, and in many cases defined so with pride, what would it mean to devalue disability “as such” but not the person with disabilities? Given the intersection of one’s embodiment and social location with one’s identity, this distinction is patently specious and betrays a fundamental misunderstanding of disability experiences and, for that matter, decades of disability theory and work on embodiment and social identity more broadly.
The use and meaning of disability in Buchanan et al.’s text varies greatly and serves as a useful example of equivocation, confusion, naïveté, or active ignorance among bioethicists or philosophers on the topic. For example, the authors regularly commit the ableist conflation by using phrases like “disease and disability” (10, 51, 105, 124, 182, 345, etc.), “harm or disability” (227), and the “great burden of disability or exclusion” (321) and by grouping “disease, disorder, impairment, or disability” (106). In other words, despite being aware of and laudably engaging at least some disability studies and activism, their indiscriminate exchange of the terms impairment, disability, and disease is inconsistent and betrays an underlying acceptance of the ableist conflation.

To be clear, the situation in the field of bioethics is improving as a growing number of bioethicists seriously engage and build on disability critiques of the field (Parens and Asch 2000; Scully 2008; Garland-Thomson 2015b). In fact, if one understands “disability bioethics” as an approach to bioethics that centers the lived experiences of people with disabilities and is rooted in research from disability studies and disability experiences writ large, it is increasingly recognized in bioethics and beyond (Reynolds and Wieseler, forthcoming). As positive as this development is, the ableist conflation is a habit of thought that has proved quite recalcitrant, and greater clarity is needed if it is to be sufficiently overcome.

**Ability Trouble**

Popular discourse engaging biomedical ethics sometimes goes even further than previous examples, exhibiting the ableist conflation to such a degree that disability is taken to be essentially no different than pain and suffering. To take an especially egregious example, witness the actual variability of embodied conditions and how we use and experience our bodies, as well as the performances and scripts by and through which we all play, be leveled to the ableist ground by Steven Pinker in a 2015 *Boston Globe* op-ed:

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. . . . Slowing down research has a massive human cost. Even a one-year
Setting aside the patently question-begging nature of his argument, Pinker finds that death, suffering, and disability are so similar that they can be listed together as experiences no one wants, and obviously so. Imagine making sense of one’s life when one is labeled “disabled” under such circumstances. Imagine the limitations thereby placed upon communication and understanding about it from the outset. Insofar as Pinker appeals to common sense, a disabled person who disagrees with the aspiration of “eliminating disability” begins on defense about the experience of their own life.

Pinker’s understanding is in step with the majority of transhumanists and posthumanists. Th

inkers, activists, and others who claim such a title typically seek the total eradication of “disability” from the human species as a central goal. Yet they rarely, if ever, critically reflect on their use of that term, not to mention the copious literatures that engage it, whether reflective or empirical in nature (Hall 2016). Trans- and posthumanists conflate a whole range of corporeal variabilities categorized as “disabilities” not only with pain and suffering but also with disease, illness, morbidity, and mortality. To be fair, Pinker does not explicitly claim in the foregoing quote that disability is in and of itself a type of suffering or identical to it. Yet, the rhetorical force of his series “death, suffering, or disability” could not be clearer: these phenomena are identical in that no one desires to experience them. Pinker capitalizes on this false equalization to fan the flames of urgency in countering the “threat” this triumvirate poses to progress.

In another section from the same piece, he 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 treated interchangeably. In terms of its negative status for potential human life and flourishing, disability is here of a kind with death, crime, war, and genocide. Disability, as Pinker understands it, is a form of constitutive, if not consuming, pain and suffering. He not only commits the ableist conflation but then employs its logic to argue against ethical reflection that would halt or slow the future of biomedical technologies. This night in which all nonnormate bodies are bad leaves one wondering what the day must look like. Worry about risk on your own time, Pinker implies, because our globalized society must immediately continue reducing disability, disease, and death. Here the force of the ableist conflation to foreclose the lived experience and meaningfulness of disability—and, ultimately, the meaning of being human as such—is on full display. It is a bold-faced linking of disability with pain, suffering, and death that culminates in such a spectacle of ignorant, uncritical thinking about disability, embodiment, and flourishing.

**Undoing the Ableist Conflation**

Combating harmful ableist attitudes in philosophy, bioethics, and popular culture requires getting at the root of the ableist conflation of disability with privation, pain, suffering, and death. This project does so by providing critical phenomenological analyses of pain and of disability to see where they are distinct as well as where and how they intersect, which is to say, by critically looking to lived experience. Throughout the book, I emphasize the ways that pain and disability remain diverse and varied experiences that challenge attempts to unite them, let alone distinctively philosophical attempts to sufficiently account for them. In doing so, I show how a phenomenological understanding of disability and ability can reorient philosophy in a more genuinely ethical direction that embraces the many ways and modes of human, ever-embodied life that in fact make up our world.

In chapter 1, I analyze dominant theories of pain, detailing the meaning of pain in religious, neurobiological, humanist, existential, and biomedical theories. I show how pain functions regulatively in each of these domains: how it orients and directs one’s relationship to oneself and one’s life. There is a long-standing tension between theories that hold pain to be uniquely subjective—“no one can feel
my pain”—and those that hold it to be deeply intersubjective, for example, group-based traumas. I argue that pain vacillates between these two poles because pain is simultaneously that which opens and closes us off to the world. Pain is paradigmatic of the porous beings we are. Most theories of pain go awry by thinking of pain as a discrete quality or feeling. On the contrary, pain—like gravity—is a force. We can measure it, feel it, alter it, study it, and even exploit it, but we still don’t really know how it works, nor do we know how to hold together its many disparate meanings. At an existential level, we ultimately understand pain through knowledge of the force it exerts on our lives, for, when all is said and done, the measurer cannot disappear from the scene of measurement. In light of this conundrum, as well as that of the differential meaning of pain across its many theories, I argue that it serves a single, overarching role at the level of lived experience: pain is a command to reorient oneself.

With this thesis in mind, and following in the footsteps of recent work in critical phenomenology (Guenther 2013), I develop a phenomenology of chronic pain in chapter 2 through the case of complex regional pain syndrome. After a detailed description of living in chronic pain, I argue that chronic pain involves four general features: foreboding, beholdenness, bioreckoning, and disruption. After analyzing examples of each, I close the chapter by discussing the central problem of chronic pain and illness: though all theories of pain work to afford one a way to regain one’s sense of agency, constitutive and consuming pain is fundamentally deregulative and disorienting. Such experiences are antithetical to anyone’s sense of agency and well-being. I offer a novel set of analytic differences concerning different types of lived pain (Leder 2016; Carel 2016), and I engage wider debates over the meaning of pain, with respect to both the seminal work of Elaine Scarry and also contemporary debates in philosophy of mind (Scarry 1985; Klein 2015).

In chapter 3, I provide an overview of theories of disability. I group these according to three primary categories: personal, social, and postsocial theories. I first address the moral theory of disability by looking to its treatment in the Abrahamic traditions before turning to the much-maligned medical model, which I show to be problematically alive and well through an analysis of recent medical textbooks. I then briefly address the complex history of social models of disability,
including their origins in disability activism in the United Kingdom and United States as well as the development of biopsychosocial models, largely by those working in the social sciences, in the late 1980s to 1990s. Last, I examine two leading postsocial theories: dispersive approaches angled against identity politics, such as that of Lennard J. Davis, and genealogical approaches operating under the theoretical aegis of biopolitics, such as that of Shelly Tremain. In notable contrast to theories of pain, I show how neither personal nor postsocial but only social theories of disability afford self-regulation and assist in purposive action. Unlike experiences of pain, experiences of disability do not automatically issue regulative commands. At the broadest level, I argue that the meaning of disability is instead defined by the experience of being nonnormate.

I then contrast these theories with a phenomenology of disability in chapter 4. Drawing especially upon the life and work of S. Kay Toombs, I do so through the case of a noncongenital, late-onset, and degenerative disability: multiple sclerosis (MS). I argue that, phenomenologically, MS involves three primary, general features: attentional, personal–social, and existential reconfiguration. As a whole, this phenomenology demonstrates how even in the case of a noncongenital, degenerative disability, the link between disability and constitutive or consuming pain proves false. Corporeal alteration does not entail degradation. New normals, new goods, and new senses of self arise as others fall away. Yet, the ableist conflation’s connection of constitutive pain with disability leads to an interpretive aporia for disabled people, preemptively hindering one’s ability to comprehend and narrate one’s life lived with disability to oneself and to others and also fundamentally undercutting inclusive political goals.

In chapter 5, I bring together the conclusions of the last four chapters to defend the following argument: the ableist conflation gets experiences of disability and pain so wrong because of its implicit conception of ability—ability as personal control. This conception is indefensible. After laying out how that idea works, I then turn in chapter 6 to a phenomenology of ability. Unlike accounts of access that focus largely on the built environment (Hamraie 2017; Titchkosky 2011), on the role of normality for sociocultural knowledge, institutions, and practices (Kafer 2013; Davis 2013b), or on organism–environment relations of affordance (Gibson 1979), I offer a phenomenology that understands
access and caring systems as fundamental to human being-in-the-world. This account builds on yet goes beyond recent social accounts of disability (Barnes 2016).

I conclude by recalling the stakes of ableism for philosophy in general and ethical inquiry in particular. I return to the fact that people with disabilities and people living in pain have historically been given remarkably short shrift by philosophers. While some recent social-political philosophers have worked to address this, too many see the sociopolitical stakes of disability as primarily a question of inclusion. My research, in step with many others in disability studies and philosophy of disability, suggests that the problem is much more complex. Disability has not been included in theories of justice and models of flourishing for a simple reason: it cannot be included precisely insofar as it designates an experience of pain and suffering—that for which normative theories seek redress, not support. But that designation is false. The lived experiences of disability demand of philosophical inquiry a far richer account of human flourishing and embodiment. Honoring and following more than a half-century of work by disability studies scholars and disability activists, I call for an anti-ableist future grounded in the myriad experiences of disability and actively engaged with experiential insights concerning the profound meaning and value afforded by human corporeal (body and mind) variability.