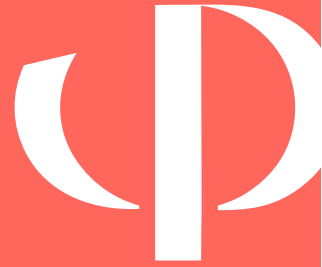


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that, despite the wide variation across and within disability categories, most disabilities are neither intrinsically good nor intrinsically bad for an individual. With some possible exceptions,<sup>9</sup> they are intrinsically neutral. This should not be a very controversial claim in light of the fact that the leading theories of well-being (hedonism, desire-fulfillment theory, perfectionism, and objective list theory), which purport to tell us what things are intrinsically and basically good or bad for us, do not identify disabilities as being intrinsically good or bad for us.<sup>10</sup> So, the Standard View is false on the intrinsic interpretation as well.

#### 4. CONCLUSION

The Standard View tells us that being disabled tends to be a bad for a person. We have offered a partial explanation of why we cannot make true generalizations about disability's instrumental or comparative goodness, badness, or neutrality. This gives us reason to reject the Standard View on the instrumental and comparative interpretations. The intrinsic interpretation of the Standard View should also be rejected, though not because it is impossible to make a true generalization about the intrinsic value of disability. The reason is simply that it is far more plausible that most disabilities are intrinsically neutral. Beyond that claim, we should resist the temptation to make broad and simple generalizations about the relationship between disability and well-being.

#### NOTES

1. Ron Amundson, "Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics," 103.
2. See Stephen M. Campbell and Joseph A. Stramondo, "The Complicated Relationship of Disability and Well-Being," which is forthcoming in a special issue of *Kennedy Institute of Ethics Journal*. In that essay, we offer a systematic and detailed critique of the Standard View, discuss a probabilistic variant of the Standard View, and examine some practical implications of our conclusions about the relationship between disability and well-being.
3. Here we follow Barnes, "Valuing Disability, Causing Disability."
4. This is a variation of an example presented in Amundson, "Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics," 109.
5. Granted, it is possible to have a high-impact trait whose effects are so harmful (e.g., causing agony and an early death) that it will consistently ruin the life of anyone who has it. Those can be cases where a high-impact trait and variations needn't yield great variation in well-being. However, a modest amount of empirical observation reveals that most disabilities are not like that. They are compatible with achieving many of the things widely regarded to be the goods of life, and there are countless cases in which individuals with disabilities have lives that would be regarded prudentially good on any remotely plausible view of well-being.
6. To qualify as *overall* instrumentally bad for a person, a thing must involve a greater balance of instrumental harm (leads to intrinsic bads, prevents intrinsic goods) over instrumental benefit (leads to intrinsic goods, prevents intrinsic bads). A similar qualification applies to intrinsic badness.
7. A clarification about our use of "neutral." In the context of discussing well-being, this term is most naturally taken to refer to the space between prudential goodness (what is good for a person) and prudential badness (what is bad for a person). To say that a trait is neutral in this sense is to say that it is either (i) neither good nor bad for a person, or (ii) good and bad for the person to roughly the same extent. This is how we will understand and use the term "neutral."

8. The so-called "Non-Identity Problem" introduces further reasons why it is difficult to generalize about disability's comparative value, though this issue is beyond the scope of this essay.
9. Some disabilities may essentially involve features that are, arguably, intrinsically good or bad for a person. Examples may include fibromyalgia or major depression.
10. For more discussion of this point, see Campbell and Stramondo, "The Complicated Relationship of Disability and Well-Being."

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## Toward a Critical Theory of Harm: Ableism, Normativity, and Transability (BIID)

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#### ABSTRACT

Body Integrity Identity Disorder (BIID) is a very rare condition describing those with an intense desire or need to move from a state of ability to relative impairment, typically through the amputation of one or more limbs. In this paper, I draw upon research in critical disability studies and philosophy of disability to critique 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 notions of biological and statistical normality, and I contend that each fail to provide normative guidance. I then propose a critical theory of harm, one marked 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 how it might enrich ongoing debates in bioethics, philosophy of disability, and the health humanities more broadly.

#### KEYWORDS

Harm, BIID, Transability, Ableism, Disability, Philosophy of Disability, Bioethics

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<sup>1</sup>

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<sup>2</sup>

Normative ethical theories have historically emphasized their principles while deemphasizing their exemplars.<sup>3</sup> 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.<sup>4</sup> This is not merely to say that 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.<sup>5</sup> Such neglect has led to wide-ranging oppression and discrimination, including and especially the historical, systematic exclusion of people with disabilities from all canonical models of flourishing.

Normative theories implicitly assume that ethical exemplars (whether Aristotle’s *phronimos*, Kant’s good-willed rationalist, or Mill’s sensing calculator) possess certain abilities. Although typically underdetermined and undertheorized, these abilities 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. In this paper, I focus on experience that in many respects blurs the lines of ability and disability: transability or 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.<sup>6</sup> 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 how it might enrich ongoing debates about the relation of disability to harm and well-being in bioethics, philosophy of disability, and the health humanities more broadly.

## I. 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.<sup>7</sup>

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.<sup>8</sup> As Sabine Müller notes, “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 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.”<sup>9</sup> 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.<sup>10</sup> It should be noted that the scientific 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 or cystic fibrosis; none desire an “invisible” disability or an “unhealthy” disability, to use Susan Wendell’s indispensable distinction.<sup>11</sup> The question of the *desirability* of a given embodied condition is thus front and center. There is disagreement whether those with BIID simply desire (or need) 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 are 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 factors; or whether the desire is something else entirely. Bioethics literature, however, by and large assumes this desire to be pathological in nature, whatever its explanation.

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 numerous people 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 wanting to select for a child with deafness for an IVF procedure.<sup>12</sup> 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?<sup>13</sup>

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 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 choice.<sup>14</sup> 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.<sup>15</sup> 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 unto others as you would have them do unto you. Bracketing whether or not healthcare 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.<sup>16</sup> 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 of being disabled forestalls our understanding the disabled from their perspective.”<sup>17</sup> Indeed, it forestalls our 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 testifies to experiencing it. 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 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.”<sup>18</sup> 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 uses the example of transabled surgery to discount transgender surgery.<sup>19</sup> If one can only image a desire as pathological, one cannot imagine that desire as authentic. 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.

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 the distinction common in disability studies between “disability” and “impairment,” typically referred to as the “social model” of disability.<sup>20</sup> “Impairment” indicates one’s particular embodied condition and “disability” names the social ramifications of a given impairment, ranging from stigma to oppression to numerous forms of inaccessibility or unequal access. 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.<sup>21</sup>

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,” i.e., the ableism embedded in the consumerist swath of neoliberal values and the multitude of its geopolitical effects.<sup>22</sup> Given this state of affairs, it is only through the 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 documented and medically accepted “condition.” Another explanation is that even for this unique set of people who are seeking to impair themselves and thereby 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 the more encompassing ideology of the ableist conflation: the assumption that anything deemed a “disability” is intrinsically defined by and experienced as a “lack” and thereby a harm with respect to potential well-being.<sup>23</sup> 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.<sup>24</sup> Having now discussed BIID and some of ethical issues it raises, I will turn to analyze arguments from harm against surgery designed to address it.

## II. ARGUMENTS FROM HARM AGAINST BIID SURGERY

Although harm is undeniably a central moral notion, it is not yet well understood.

—Guy Kahane and Julian Savulescu<sup>25</sup>

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.<sup>26</sup> This principle, enshrined in bioethics literature by Beauchamp and Childress' field-defining *Principles of Biomedical Ethics*, dates at least back to the Hippocratic Oath.<sup>27</sup> 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.<sup>28</sup> She thus ultimately argues against surgery for BIID patients. Of the

seven published responses to Müller's article, just three definitively support the surgery, either as a last resort or as the only viable resort available today.<sup>29</sup> Those that do not support the surgery rely more heavily upon the concept of harm.<sup>30</sup>

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.’”<sup>31</sup> 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. Müller appears, at times, to hold a similar view. 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.”<sup>32</sup> 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.<sup>33</sup>

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 “normal,” nor “socially acceptable” in any general sense of those terms.<sup>34</sup> Furthermore, depending upon social judgment of one's physical appearance, dressing in clothing that aligns with social norms corresponding to a sex-assignment surgery might make one a target for hate crimes and significant social ostracization because of an “abnormal” and socially “unacceptable” appearance. By deploying a concept of disability wherein disability is conflated with harm—whether the “harm” of genetic defect, acute injury, chronic disease, or what have you—Müller's arguments traffic in ableism and disability stigma, however unwittingly. 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 than the non-standard, disabled body.<sup>35</sup>

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.”<sup>36</sup> Setting aside whether or not—or how—GID is an instance of disability, 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.”<sup>37</sup> 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.” 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. The assumption that the primary or most relevant differences introduced by therapeutic amputation-related impairments are questions of individual physiology and not societal conditions ignores the very foundation of the disability rights movement as well as over fifty years of disability studies scholarship ranging across the humanities and social sciences. This body of work and activism suggests that in numerous cases of disability, it is societal conditions that primarily and negatively affect the flourishing of people with various impairments.<sup>38</sup> That is to say, 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 prohibit, the harm is often less the impairment, if at all, and more the societal configuration and responses to non-normate embodiment. 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.

### III. NORMALITY AND HARM

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.<sup>39</sup> 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 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* [WSN] 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 WSN is not normative; statistical normality is merely descriptive. Like biological normality, it should be dismissed as a normative ground.

Of what, precisely, is weak statistical normality derivative? It can't be derivative of biological normality, since that was rejected as having 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 I am not convinced intuitions, in and of themselves, hold any *prima facie* normative weight, whatever their descriptive value.<sup>40</sup> 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 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.<sup>41</sup> 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 today by too many bioethicists 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.

The fulcrum of the WSN 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 itself 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 normality—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) [severe intellectual impairment, paraplegia, blindness, or early death] 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.<sup>42</sup> 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.

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/sex, ethnicity, religion, class, geographical location, etc.), but ethicists today do not attribute intrinsic moral worth to many such tendencies and for good *normative* reasons. To repeat, given the prevalence of ableism, ethicists concerned about questions pertaining to disability and normativity should have a *prima facie* distrust of descriptive accounts of wellbeing 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.<sup>43</sup> 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.<sup>44</sup> Focalism also contributes to *pain catastrophizing*, the fact that we regularly overestimate the intensity and duration of pain.<sup>45</sup> This further suggests that we significantly mischaracterize, mispredict, and generally misestimate the meaning of any phenomenon 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.<sup>46</sup> 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.

#### IV. TAKING ABLEISM IN (BIO)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 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 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. Relatedly, we should be very worried that there are a host of conditions that were previously thought to be suffered and constitute harm that, with critically informed research, prove, in fact, fruitful, gainful, and rich forms of life.<sup>47</sup> 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 on or near that line—a line, it bears continually repeating, that is more often than not drawn intuitively by the able-bodied and thus drawn with what should be *prima facie* suspicion, not support.

Across academic scholarship, especially of a critical sort, there is consensus, if any can be said to exist, about a very small subset of lives not worth living. Accordingly, bioethicists should have very little confidence in judgments over lives deemed not worth living or lives said to have intrinsically or necessarily low QOL. There is an alarming lack of what Eva Kittay insightfully terms *epistemic responsibility* and *epistemic modesty* on the part of a wide swath of bioethicists when it comes to judgment about non-normate lives, about lives lived with and through disability.<sup>48</sup> If bioethicists and ethicists more generally wish to have a better grasp on the conditions and particularities of lives worth living, more critical reflection is required concerning the way in which the concept of harm has historically been used to end lives, not enrich them.

#### NOTES

1. Johnson, *Moral Imagination: Implications of Cognitive Science for Ethics*, 199.
2. Brennan, *The Transmission of Affect*, 119.
3. This paper is a significantly revised and expanded form of 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 of the project. David Peña-Guzmán and Katherine Davies also provided extremely helpful comments on its penultimate draft. This piece forms part of a much larger project, stemming from my dissertation and its revision into monograph form, that focuses on the history of what I call the "ableist conflation": the conflation of disability with pain and suffering. More specifically, this is the assumption—attested across myriad philosophical traditions and epochs—that disability is a harm and concomitant

with pain and suffering. See also Joel Michael Reynolds, "'I'd Rather Be Dead Than Disabled': The Ableist Conflation and the Meanings of Disability" (forthcoming).

4. Philosophers including Eva Kittay, Anita Silvers, Licia Carlson, Martha Nussbaum, and Shelley Tremain have each done significant work critiquing and/or amending such ideals.
5. Wolbring, "Ethical Theories and Discourses through an Ability Expectations and Ableism Lens: The Case of Enhancement and Global Regulation"; Wolbring, "Ability Privilege: A Needed Addition to Privilege Studies," *Journal for Critical Animal Studies*.
6. Stramondo, "Why Bioethics Needs a Disability Moral Psychology."
7. 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 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. See note 10 below. 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.
8. 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 percent of the population.
9. Muller, "Body Integrity Identity Disorder (BIID)—Is the Amputation of Healthy Limbs Ethically Justified?"
10. 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 this paper, I became aware of the dissertation of Christine Marie Wieseler, "A Feminist Contestation of Ableist Assumptions: Implications for Biomedical Ethics, Disability Theory, and Phenomenology" (University of South Florida, 2016, <http://scholarcommons.usf.edu/cgi/viewcontent.cgi?article=7629&context=etd>). 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. 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." With respect to neurological literature, one of the first studies is Brang, McGeoch, and Ramachandran, "Apotemnophilia: A Neurological Disorder." The following article attempts to bring together the psychological and neurological findings: First and Fisher, "Body Integrity Identity Disorder: The Persistent Desire to Acquire a Physical Disability." For a critique of the epistemology of neurological etiologies with respect to such phenomena, see Fisher and First, "Examining the 'Neuro-' in Neurodiversity: Lessons from Body Integrity Identity Disorder." For key pieces in queer and trans\* studies, see especially, Susan Stryker and Nikki Sullivan, "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; Baril, "'How Dare You Pretend To Be Disabled?' The Discounting of Transabled People and Their Claims in Disability Movements and Studies"; Baril, "Needing to Acquire a Physical Impairment/Disability: (Re)Thinking the Connections between Trans and Disability Studies through Transability"; 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)"; Arfini, "Transability." For work in critical disability studies, see Noson, "From Superabilità To Transabilità: Towards An Italian Disability Studies"; Stevens, "Interrogating Transability: A Catalyst to View Disability as Body Art." In sociology, Jenny L. Davis has written insightfully and extensively on the topic: Davis, "Morality Work Among the Transabled"; Davis, "Narrative Construction of a Ruptured Self: Stories of Transability on Transabled.org"; Davis, "Prosuming Identity: The Production and Consumption of Transableism on Transabled.org." In legal studies, see Mackenzie and Cox, "Transableism, Disability and Paternalism In Public Health Ethics: Taxonomies, Identity Disorders, and Persistent Unexplained Physical Symptoms"; Mackenzie, "Somatechnics of Medico-Legal Taxonomies: Elective Amputation and Transableism."
11. Wendell, *The Rejected Body: Feminist Philosophical Reflections On Disability*; Wendell, "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities."
12. Spriggs, "Lesbian Couple Create a Child Who Is Deaf Like Them."
13. Bauman, *Deaf Gain Raising the Stakes for Human Diversity*. I will return to the question of disability-gain or what Elizabeth Barnes calls "good-difference" views of disability below. Barnes, *The Minority Body*, Studies In Feminist Philosophy Series. I should add that I highly, highly recommend that book for anyone wishing to educate themselves concerning ongoing arguments in philosophy of disability.
14. "Why Chloe Needlessly Spends Her Life in a Wheelchair," on *Anderson Cooper 360°* (CNN, 2012).
15. Fiona Kumari Campbell, *Contours of Ableism: The Production of Disability and Abledness* (New York: Palgrave Macmillan, 2009). Part of this relates to the question of the relationship of BIID to erotic desire. See De Preester, "Merleau-Ponty's Sexual Schema and the Sexual Component of Body Integrity Identity Disorder."
16. Gensler, *Ethics and the Golden Rule*; Wattles, *The Golden Rule*.
17. Silvers, "Reconciling Equality to Difference: Caring (F)or Justice for People with Disabilities," 37.
18. Elliot, "A New Way to Be Mad."
19. Tuttle, "People Who Cut Off Their Own Limbs (and Their Enablers)."
20. There are, in fact, multiple social models, and for any given form of it, there is vigorous debate across the breadth of disability studies' scholarship over its meaning, scope, etc. There is a copious literature debating the merits and many meanings of this distinction which I cannot engage here. As a primer, see Davis, *The Disability Studies Reader*, 4th ed. The newest, fifth edition of the DSR is forthcoming.
21. In addition to her other work cited above, this is especially clear in Davis, "Narrative Constuction."
22. See Scuro, "The Ableist Affections of a Neoliberal Politics," *APA Newsletter on Philosophy and Medicine* (Current Issue); Scuro, "Thinking of Bhopal: Women's Bodies as Waste-Sites."
23. I address the conflation of various forms of disability with lack and harm at length in Reynolds, "'I'd Rather Be Dead Than Disabled.'" See note 3 above. 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.
24. Despite the large amount of research on BIID, I find that more analyses of the lived experience of people with BIID is requisite, especially qualitative sociological and critical phenomenological research (see note 10 above, especially the work of Jenny L. Davis). In relation to my claim regarding blindness, see Reynolds, "On Being Outside The (Normate) Body: Merleau-Ponty's Aveugle and Crip Phenomenology," forthcoming.
25. Kahane and Savulescu, "The Concept of Harm and the Significance of Normality," 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 identifies himself as a "body-integrity-disorder (BIID) dude" 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." Larratt, "One Hand Jason: BIID Interview in BME/News."
26. Some distinguish between disadvantage and harm, a practice I will not follow here.
27. Beauchamp and Childress, *Principles of Biomedical Ethics*, 7th ed. What is called the "harm principle" originates from John Stuart Mill (*On Liberty*, 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., Brincat, "The Harm Principle and Recognition Theory."



28. She assumes such neurological research to have reached sufficient consensus for biomedical decisions to be made based upon that research.
29. Jozsef Kovacs, Jenny Slatman, and Guy Widdershove, and Neil Levy. Avi Cramer leaves open whether surgeons are morally permitted to perform the surgeries. See Volume 9, Issue 1, of the *American Journal of Bioethics*.
30. Because of the breadth of literature on BIID and given the space and aims at hand, I 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 implications I draw, if convincing, to have significant ramifications for the concept of harm in general and its use across bioethics in particular.
31. Jotkowitz and Zivotofsky, "Body Integrity Identity Disorder (BIID) and the Limits of Autonomy," 56.
32. Müller, "BIID—Aqua Fortis for Scientific Explanations of Psychic Phenomena?," w4.
33. 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. I found the following article very helpful on this topic: Gardner, "On the Strength of the Reason Against Harming." 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 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.
34. Despite, as I argued above, being imaginable, being something which *at least some* cultural spaces deem legitimate, defensible, and/or understandable.
35. 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?"
36. Kovacs, "Whose Identity Is It Anyway?," 44.
37. *Ibid.*, 45.
38. As my phrasing indicates, 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 Metamorphosis*"; Patsavas, "Recovering a Cripistemology of Pain: Leaky Bodies, Connective Tissue, and Feeling Discourse."
39. Kahane and Savulescu, "The Concept of Harm and the Significance of Normality." Citations to this article appear in text hereafter.
40. 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 the content of intuitions do not in and of themselves bear 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).
41. E.g., see Tremain, *Foucault And The Government of Disability*; Carlson, *The Faces Of Intellectual Disability: Philosophical Reflections*.
42. There is yet another issue that impedes the WSN. 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. In another passage, after discussing how the *descriptive* nature of statistical normality accounts for its theoretic use (its use for providing explanations and predictions of wellbeing), Kahane and Savulescu 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, to repeat a point from above, 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* have and have had normative significance is itself fraught and should precipitate *prima facie* suspicion, not support. While, to be clear, there is much to appreciate in Kahane and Savulescu'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 left unconvinced that there is a meaningful moral distinction between biological normality and statistical normality.
43. Wilson et al., "Focalism: A Source of Durability Bias in Affective Forecasting." See also discussions of *focusing effect* in Schkade and Kahneman, "Does Living in California Make People Happy? A Focusing Illusion in Judgments of Life Satisfaction."
44. Wilson, Meyers, and Gilbert, "'How Happy Was I, Anyway?'" A Retrospective Impact Bias."
45. Day and Thorn, "The Relationship of Demographic and Psychosocial Variables to Pain-Related Outcomes in a Rural Chronic Pain Population."
46. See notes 23 and 3 above.
47. Lantos, "Trisomy 13 and 18--Treatment Decisions in a Stable Gray Zone."
48. Kittay, *Love's Labor: Essays on Women, Equality, and Dependency*. Put otherwise, 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. Guilmette, "Feminist Philosophies of Disability, Foucault, and the Ethics of Curiosity"; Guilmette, "In What We Tend to Feel Is Without History: Foucault, Affect, and the Ethics of Curiosity."

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