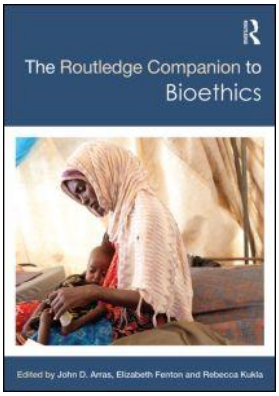

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BODY INTEGRITY IDENTITY DISORDER (BIID) AND THE MATTER OF ETHICS

Nikki Sullivan

Over the past decade or so there has been increasing interest amongst psychiatrists, psychologists, philosophers, medical ethicists, cultural theorists, neurologists, and others in a range of desires for what we might think of as "non-normative" forms of embodiment, that is, for bodies with less than a "full complement" of limbs, for bodies that are, to varying degrees, paralyzed, deaf, blind, and so on. Such desires are now widely regarded as symptomatic of what psychiatrist Michael Fine calls body integrity identity disorder (BIID), a condition defined primarily by a consistent sense of non-contiguity between body and self. The vast majority of people who identify with the phenomenological sense of bodily being that defines BIID call for access to surgery in order that their desired mode of corporeality be realized, and the dysphoria from which they suffer overcome. Such calls raise a range of questions about the ethics of amputating a healthy limb, injuring a healthy spinal cord, producing deafness, and so on, or, alternately, of refusing to conceive surgery as a viable treatment protocol. This chapter will consider current debates regarding the ethics of "elective amputation"—since this is the procedure which has garnered most interest to date—and at the same time, will attempt to critically interrogate the constitutive effects of the (bio)ethical principles brought to bear on BIID. In other words, rather than simply applying ethical principles to BIID, this chapter strategically deploys the (desire for) "non-normative forms of embodiment" associated with BIID in an attempt to problematize some of the assumptions that underpin what Margrit Shildrick refers to as "conventional bioethics."

Shifting Conceptions of the Desire for Amputation

The desire for the amputation of a healthy limb or limbs has been understood historically as symptomatic of one of a range of pathological conditions.[1] For example, in a 1977 publication John Money et al. conceived the desire for amputation as primarily sexual and thus coined the term apotemnophilia.[2] In the late 1990s Richard Bruno proposed that those who desire amputation, "pretend" to be amputees, and/or are sexually attracted to amputees, constitute a diagnostic grouping that could be called factitious disability disorder (1997: 257). By the early twenty-first century such desires came to be

understood as disorders of identity: Robert Smith and Greg Furth introduced the term amputee identity disorder in a 2000 publication, and in 2005 Michael First coined the now widely used term body integrity identity disorder. More recently, Paul McGeoch and his colleagues at the Centre for Brain Cognition, University of California, have formulated the term xenomelia to refer to a neurological "disorder of body image" which they associate with right parietal lobe damage and/or dysfunction (2011).[3]

Whilst the naming of desires for non-normative forms of embodiment may seem somewhat trivial in the face of the suffering experienced by those whose access to surgeries which may give them the bodies they feel themselves to be is currently blocked, diagnostic nomenclature is inextricably bound up with ideas about what causes such desires, and how they might be appropriately treated. Currently, as Christopher Ryan notes, there "is no consensus on what constitutes BIID, nor even that BIID exists as an independent entity" (2009: 22).[4] But despite this, Sabine Müller asserts that "understanding . . . the causes for BIID is crucial for the development of an appropriate treatment" (2009: 109), and Ronald Pies agrees, arguing that an effective treatment protocol can only be determined on the basis of a clear understanding of disease process (2009: 179). Before examining in more detail competing accounts of desires for and treatment of non-normative morphologies, it is perhaps worth noting here that despite their differences each of the authors cited thus far embrace the assumption that such desires are "abnormal" and/or in need of explanation. Such an assumption has, as will become apparent in due course, been problematized by analyses that draw attention to the discursive character of desires and their regulation, and to the generative effects of naming.

BIID

In his first published study of the desire for limb amputation, First set out to determine whether such desires are paraphilic, symptomatic of psychosis, or indicative of a "new type of identity disorder" (2005: 919). The data gathered during interviews with 52 "wannabes"[5] led him to conclude that the desire for amputation is not primarily sexual, nor is it, in the vast majority of cases, an effect of psychosis.[6] Rather, it is most often motivated by the desire for wholeness, for a sense of contiguity between the self and the body (which is experienced as "wrong"). First also reported that most of the interviewees had desired amputation since an early age; that the location of the amputation is often extremely specific and unchanging; that 92 percent of those interviewed had been involved in "rehearsal" activities; and that in the majority of cases the respondents' present bodily state is experienced as disabling. In terms of treatment, First, like many others who have worked directly with those desiring non-normative morphologies, claimed that whilst therapy and psychotropic drugs may, in some cases, have some positive effect on general wellbeing, both have proven to have no impact on the desires themselves, or the associated feelings of dysphoria, or a disjunction between body and self.

On the basis of these findings, First argued that whilst the clinical profile that emerges does not fit any of the existing diagnostic categories found in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR), it closely resembles the phenomenology of gender identity disorder (GID), a "condition" whose key diagnostic features include discomfort with an aspect of anatomy; onset in childhood or early adolescence; frequent mimicking of the desired identity; sexual fantasies and/or arousal

around the image of a post-surgical self; and successful treatment by surgery (2005: 926). Like the desire for amputation, GID has no known etiology, and whilst the standard treatment for those meeting the criteria is now surgery, such treatment was once held to be highly contentious.[7] These parallels lead First to formulate the diagnostic category BIID, to suggest that BIID should perhaps be included in the DSM-V and the ICD-II, and to note that that such inclusion may facilitate the development of treatments including, for some, amputation (2005: 927).

In a 2012 paper co-authored with Carl E. Fisher, First reiterates these claims regarding classificatory nomenclature and treatment, and develops diagnostic criteria for BIID which include "an intense and persistent desire to become physically disabled in a significant way" and "persistent discomfort or intense feelings of inappropriateness concerning current nondisabled body configuration" (2012: 12). This shift in First's conception of BIID from a desire for "wholeness" to "a persistent desire to acquire a disability" (2012: 3) may be useful insofar as it poses a challenge to neurological accounts of the etiology of desires for non-normative morphologies.[8] However, at the same time, it is troubling in its reiteration of normative perceptions of dis/ability and ab/normalcy which ultimately work against the desires of which First speaks, and more particularly, against their safe surgical realization, as will become apparent as my discussion of the deep-seated association of "disability" with "undesirability" unfolds.

Desiring the Undesirable

Having researched and taught courses on a wide range of modificatory technologies for a number of years, it has become clear to me that most people's initial response to desires for amputation, blindness, paraplegia, and the like, is one of horror and disbelief. Such responses are tellingly different from those elicited by, for example, the desire for and practice of breast enhancement, labiaplasty, or procedures associated with gender confirmation (or sex reassignment as it is sometimes known). This differential response is particularly interesting given that the desires—or perhaps more accurately, the need—for non-normative corporealities and access to the surgical procedures that may enable their realization, are more often than not articulated, as John Jordan notes, in terms "that are nearly identical to mainstream plastic surgery applicants, but they are not granted the same legitimacy" (2004: 329). The same could be said of the asymmetrical responses by medical practitioners to the use of the "wrong body" narrative by wannabes and by those experiencing so-called gender dysphoria (Sullivan 2008): Whilst the feeling that one is or has the "wrong body" is taken as symptomatic of transsexualism, the claim that the body of the person desiring amputation is wrong is largely understood as indicative of wrong headedness rather than as a recognized symptom of a clinical disorder that can, or perhaps even should, be treated surgically. One might argue that what these asymmetries demonstrate is that the surgical transformation of individual bodies is regulated by idea(l)s about what constitutes desirability and/or normalcy, and that rather than being objective, such idea(l)s are culturally constructed and contextually specific: It is highly unlikely, for example, that our great, great grandparents would perceive the elective insertion of sacks of saline or silicone into subpectoral or subglandular pockets for aesthetic purposes as rational or unremarkable.

Whilst the logic of analogy is central to First's account of BIID, Dan Patrone is critical of "the master argument" which he associates with the work of First and others, and which, he claims, is reliant on "imperfect analogies" that lead to medically unethical

conclusions regarding treatment. His critique consists of two claims regarding the principles of non-maleficence and autonomy: First, that "no disability follows from the putatively non-problematic case of cosmetic surgery" (Patrone 2009: 542),[9] and second, that "those who have a disorder that causes them to desire to maim and disable their bodies cannot meet [the required] standard of voluntarily accepting the burdens of choice that makes the practice of respecting autonomy acceptable" (2009: 545). In short, then, as Patrone sees it, since amputation unquestioningly results in disability, and disability is by definition undesirable,[10] then the desire for amputation is necessarily irrational, and the expression of a disorder which compromises the capacity of the person thus affected to make a well informed, autonomous, choice about what, at least in this regard, is in his or her best interests. Further, since "elective" amputation is disabling and medically unnecessary, its practice is, as Patrone sees it, unethical. Interestingly, Patrone's critique of "imperfect analogies" makes no mention of the analogy most commonly posited in discussions of desires for non-normative morphologies, and central to First's conception of BIID, namely the analogy with GID and gender confirmation surgeries. This oversight is perhaps not accidental since in the case of GID the association of a (relatively uncommon, long-held, and compelling) desire for a particular anatomy with a clinical disorder is not seen as compromising the patient's competency to make an informed decision about treatment, or the reputation of the surgeon who performs the desired surgery.[11]

Richard Bruno explicitly dismisses the analogy between "GID" and the desire for amputation in his articulation of what Chris Partridge refers to as "the insanity objection.[12] He writes, "the notion that a [wannabe] is a 'disabled person trapped in a nondisabled body' is difficult to justify, there being no 'naturally-occurring' state of disability that would correspond to the two naturally-occurring genders" (1997: 251).[13] There are a number of assumptions that Bruno makes that call for further consideration. First, he implies that gender is an empirical fact, that it is a natural, and therefore naturally desirable bodily state. Hence the desire for and practice of "gender confirmation" surgeries is, from his perspective, intelligible (that is, understandable and therefore rational), and justifiable. The determinist model of gender on which Bruno's argument relies has long been challenged by writers as diverse as John Money, Betty Friedan, and Judith Butler, all of whom have convincingly argued that gender is, in large part, a social phenomenon.[14] Whilst I do not have time to rehearse these arguments here, it is my contention, following Butler, that gender is the performative effect of repeated, culturally learned actions which, over time, come to feel, and to appear to others as, "natural," as the expression of an innate interiority. Gender, on this model, is simultaneously an idea(l), a practice (a set of everyday labors aimed—often less-than-consciously—at attaining an ideal),[15] and a discursive effect, rather than something we (naturally) have.

And what of disability? Bruno claims that whilst gender is "naturally-occurring," there is "no 'naturally-occurring' state of disability that would correspond to the two naturally-occurring genders" (1997: 251). Disability, in Bruno's schema is, then, the antithesis of able-bodiedness (as a natural developmental state) rather than its complement. Disability is unnatural insofar as it is the result of an accident (whether congenital or social): It is, by definition, both an aberration and an abomination and as such, is literally undesirable. Bruno's understanding of disability is one that is widely shared in the contemporary west in which, as Jordan notes, "even suggesting that an amputated body would be preferable to a healthy, full-limbed body would seem to contradict every tenet of cultural body logic" (2004: 341). And this is clearly illustrated by

Wesley J. Smith's presumptuous assertion that obviously no one "but a severely mentally disturbed person would want a healthy leg, arm, hand, or foot cut off" and that "such people need treatment, not amputation" (cited in Ryan 2009: 23).

Critical disability theorists such as Rosemarie Garland-Thomson (2002) and Lennard Davis (1995) have convincingly argued that there is nothing natural about the pervasive view of disability as unnatural and undesirable: For such writers this problematic construction of disability is symptomatic of a way of knowing/seeing that is particular to Western modernity and is itself disabling. However, in making this claim, such theorists do not reproduce the logic deployed by Bruno by arguing that in fact disability is natural and therefore, presumably, desirable. Davis, for example, argues that disability is a regulatory fiction, "a function of the concept of normalcy" (1995: 2) which shapes not only the lived bodies of those it purports to merely describe, but also those deemed able-bodied. In making such claims Davis does not, as some might suspect, negate bodily differences, but rather, focuses a spotlight on the way in which difference comes to matter. In short, Davis's insights challenge Bruno's construction of disability as the antithesis of able-bodiedness, showing that the former is integral to the latter as well as to the psycho-social imaginary that sustains dichotomous conceptions of being, and, invariably, shapes the practice of ethics.

I will return to the matter of disability and its constitution in the work of those who deploy the insanity objection in their depiction of amputation surgery as unethical throughout this paper. Now, however, I want to focus on the notion of autonomy since this has loomed large in debates about desires for non-normative morphologies and their possible realization through surgery.

Autonomy

One of the most vocal critics of "elective" amputation is Sabine Müller, who perceives desires for non-normative morphologies currently associated with BIID as symptomatic of an underlying neuropsychological problem which, she asserts, will not (indeed, cannot) be "cured" by the removal of a limb. Consequently, she argues that amputation is unethical because the desire for such is not autonomous, and because "it leads to disability" (2009: 116) thereby producing more harm than benefit. She writes: "[t]o fulfill the desire for a bodily harm of a patient with a substantial lack of autonomy is a severe violation of the medical fiduciary duty and of the principle of non-maleficence" (2009: 117). Whilst there are at least four ethical principles implicated here—autonomy, utility, duty, and non-maleficence—the principle of autonomy seems to most concern Müller: She argues, for example, that if a patient's desire for such could be shown to be autonomous, then amputation would be ethical. However, close examination of Müller's attempts to substantiate her claim that wannabes lack autonomy reveals that her perception of wannabes (and their desires) is underpinned and shaped by an obvious prejudice which links amputation with "disability," and the desire for "disability" (as, by definition, undesirable) with "madness." Let me explain. First, Müller claims that "[i]n all cases of BIID which have been investigated by psychiatrists, the diagnosis states that the amputation desire is obsessive[16] or results from a monothematic delusion,[17] comparable to anorexia, [and] Capgras' syndrome"[18] (2009: 117). For anyone who has read the existing literature on BIID, such a claim is, to say the least, questionable. Studies such as those carried out by First (2005), First and Fisher (2012), and Blom et al. (2012) explicitly deny that wannabes are delusional, and in fact, as Neil Levy notes in his response to

Müller, having delusional beliefs about the limb that a wannabe desires to have removed would necessarily disqualify him or her from the classification of BIID (2009: 50).

The second aspect of Müller's argument that requires critical attention is her account of free and unfree will. Following Kant, Müller argues that autonomy depends on a coherence of will, or of what Harry Frankfurt describes as first- and second-order mental states. An agent lacks autonomy when there is a contradiction between a first-order and a second-order desire: Imagine, for example, that I am sexually attracted to other women, and yet I desire for this not to be the case. As Müller sees it:

> in BIID patients the amputation desire is a first-order volition, whereas their wish to have no amputation desire is a second-order volition. The latter could be filled in principle in two different ways: First by amputation, second by eliminating the amputation desire.
>
> (2009: 117)

Like Levy (2009) and Craimer (2009), I find Müller's universalizing characterization of wannabes as embodying a contradiction of will unconvincing. In many, if not most, of the first-person accounts of desires for non-normative morphologies that are available on activist websites and/or cited in scholarly studies, wannabes do not express a desire *not* to desire amputation, but rather, desire that their desire for amputation, paraplegia, for deafness, for "wholeness," be satisfied.[19] Thus, as Levy notes, on Frankfurt's account wannabes demonstrate a coherence of will and thus satisfy the criteria for autonomy (2009: 50). Müller's interpretation of amputation as the fulfillment of the desire *not* to desire amputation is, then, not simply out of keeping with first-person accounts of wannabes; it is, more particularly, symptomatic of a total inability to comprehend the fact that a desire for amputation (which Müller reads as disability) is possible. And this lack of intelligibility is a direct effect of the perception of "disability" as, by definition, undesirable—a perception which is shaped by social norms (as opposed to being objective), and which produces disabling effects.

This becomes clearer still if we turn to Müller's assertion that:

> [b]ecause a mere coincidence of first-order volitions and second-order volitions is not sufficient for autonomy, it is important to refer to Kant's . . . demand for the rationality of higher-order volitions. Because the amputation desire is conflicting with many rational desires of the BIID sufferers, especially with those for health, painlessness, mobility, and social acceptance, the second-order volition to get rid of the amputation desire is rational, whereas the first-order volition to fulfill the amputation desire is irrational.
>
> (2009: 117–8)

Tellingly, Müller makes no attempt to substantiate this claim by discussing how one might determine irrationality, nor does she reference those who she alleges (rationally) desire painlessness, mobility, and so on. Given this, it seems safe to assume that Müller presumes irrationality to be self-evident and universal; an assumption which is, of course, highly questionable.

Incompetency and Irrationality

There has been much criticism in the literature on BIID of the conflation of desires for non-normative embodiment with an *a priori* inability to make an informed decision

about treatment (or, more particularly, about amputation: Those who articulate the insanity objection do not claim that wannabes are incapable of choosing "non-disabling" treatments such as cognitive behavioral therapy). For example, writers such as Savulescu (2006), Levy (2009), Dua (2010), Partridge (n.d.), Ryan (2009), Jotkowitz and Zivotofsky (2009), Bryant (2011), and Swindell (2009) argue either that the question of autonomy is, as Levy puts it, largely irrelevant (2009: 50), or that the particular conception of autonomy that informs Müller's thesis is problematic. Perhaps the most compelling critique of Müller's position is that even if:

> the BIID sufferer is not making an autonomous choice (in the philosophical sense) when she requests amputation . . . all that is needed for her choice to be respected in the medical context is 1) that she is informed and has decision-making capacity; and 2) that her choice is among the medically reasonable alternatives.
>
> (Swindell 2009: 53)

Decision-making capacity is not, argue Slatman and Widdershoven, something that can be accorded or denied BIID patients *a priori* (2009: 49). Rather, as Swindell asserts "in order to argue that BIID patients lack decision-making capacity, formal assessments of capacity should be performed by psychiatrists with the assistance of tools such as the MACCAT-T [MacArthur Competence Assessment Tool for Treatment]" (2009: 53). Indeed, individual assessment (in terms of diagnosis and competency) is central to the protocols developed by First who draws on those established in relation to GID.

Building on the view that individuals have different desires and values, and that difference should be encouraged not least because it contributes to the richness of life, Julian Savulescu likewise argues that the question of whether or not a particular practice is ethical can never be answered in any absolute or universal sense since value judgments are inherently contextual. Using the verb "to hump" as a placeholder for whatever contentious activity one might be interrogating, Savulescu writes:

> [w]hile there may be reasons in general not to hump, an individual may have most reason to hump, given a particular history and set of circumstances . . . Some individuals might have *most reason* to seek amputation. Thus not only might amputation be permissible in some situations, it might be desirable.
>
> (2006: 8–9)

This is in keeping with calls made by Slatman and Widdershoven (2009), De Preester (2011), and Sullivan (2005) for the development of phenomenological accounts of the lived embodiments of those desiring non-normative morphologies. Such analyses would, these authors argue, acknowledge that the relationship between an individual's corporeality, his or her experience of integrity (or its lack), and his or her life-world is simultaneously singular and social: It is an effect of his or her particular embodied history as well as of the cultural context in which s/he comes to be. Such an approach would have, at its heart, an emphasis on "the constitutive and always incomplete nature of embodiment, the transformatory potential of the body itself and of embodied identity," as well as an awareness of "the [(re)productive] operation[s] of a bioscientific imaginary in both professional and lay discourse" (Shildrick 2004: 150).

Elsewhere (2005) I have argued, for example, that rather than being a thing-in-itself, "integrity" (or its lack) is an embodied experience that may be difficult to discern from

"the outside."[20] Those who claim that elective amputation is unethical because it disables a heretofore "normal" body overlook this, presuming instead that integrity is visibly self-evident (the full-limbed, fully functioning body being emblematic of this), and that since the wannabe does not feel what is "true" then s/he is in some sense deluded. Such delusion is, on this model, both a symptom and an effect of an underlying pathology that is psychological, neurological, or both. In and through this constitutive perception/interpretation (of the other and his or her desires) the wannabe's bodily-being-in-the-world, his or her lived embodiment, is rendered inauthentic, as are his or her desires. At the same time, the experience of integrity of the one who perceives/evaluates is reproduced as natural, as normal, and the continual labor that is required to achieve and/or maintain a coherent embodied identity (as, for example, a cissexual[21] woman, "able-bodied," and so on) is veiled over. From this normative position, the desire for the removal of a limb, for deafness, blindness, paraplegia, for what in short appears in the normative imaginary as "disability" can only be figured as unintelligible, abnormal, and harmful. And conceding to such desires, rather than curing the pathology of which they are a symptom, can only be figured as at best misguided, and at worst, morally wrong.

If, however, we move away from universalizing assumptions about dis/ability, un/desirability, ir/rationality, in/competence, bodily integrity, and so on, and instead acknowledge that such concepts and their perception are culturally constructed and situated, we may be better equipped to concede that what may be good for one person may not be appropriate for another: We might then be able to more effectively evaluate the benefits and harms of different forms of treatment,[22] and their capacity to restore "wholeness" to different individuals. For example, deep brain stimulation (DBS), which is one of the treatments proposed by some who regard the desire for amputation as a symptom of right parietal lobe dysfunction, may be something that some individuals whose desired morphologies are currently unrealizable are prepared to try. For others, however, such treatment may appear antithetical to their needs, or even medically and/or politically spurious: Imagine, for example, a person who has, in the past, been subjected to electro-shock therapy to cure them of homosexual desires, or even a person who is aware that invasive practices like this one have occurred and who has a long-held political (and therefore affective) aversion to the continuation of such (potentially dangerous) curative measures. To propose that such a person should undergo DBS is no less ethically problematic than suggesting that a person who experiences sexual desires for people of the so-called same sex should submit to electro-shock therapy, or that people desiring EE breasts should only and ever be treated with cold-water vestibular caloric stimulation, another treatment which, it has been suggested, may temporarily relieve feelings of body dysphoria.

Accepting that amputation (for patients with BIID) may not be a universally unethical practice does not mean that amputations should or would be performed without due care, nor does it mean that surgeons opposed to such a practice would be required to perform it.[23] What it would require is, as in the case of "GID," the formulation of widely agreed-upon diagnostic criteria (such as those developed by First) and guidelines for clinical practice. If we accept that it is possible to develop such criteria and guidelines, and agree that the claim that desires for amputation constitute, *a priori*, a lack of autonomy and impaired decision-making capacity is both unsound and the effect of a profound prejudice against "disability," then is it any longer possible to argue that amputation is ethically wrong? One of the most common objections found in popular cultural discussions of BIID is the idea that amputation will result in significant costs (economic and otherwise) that society cannot be justly expected to bear. This argument is also made by

Müller who claims that not only is medical treatment and rehabilitation expensive—an argument that could similarly be made against gender affirmation surgeries, but rarely is—but, more particularly, amputation will result in diminished capacity, and increased dependence (financial, physical, and emotional) on loved ones and on the state (2009: 120), and as such, it contravenes the principle of distributive justice.

One counter to this position might be to argue for a rights-based conception of justice which would give due consideration to the individual's right to self-determination, and to the cost of denying that right, or at least a particular manifestation of that right. Whilst such a position is not without its merits, it nevertheless assumes (and reaffirms) a humanist model of the subject, the social, and the relation between them which, as I have attempted to demonstrate throughout this paper, is integral to the "problem" of "disability" as it is currently conceived/constructed. An alternative approach would be to "lay bare the psycho-social imaginary that sustains modernist" projects (Shildrick 2009: 2), and shapes the perception of difference in disabling, dichotomous terms (i.e., able/disabled, normal/abnormal, desirable/undesirable, healthy/unhealthy, and so on). Such an approach would first involve acknowledging that:

> Where physical and mental autonomy, the ability to think rationally and impartially, and interpersonal separation and distinction are valued attributes of western subjectivity, then any compromise of control over one's own body, any indication of interdependency and connectivity, or of corporeal instability, are the occasion—for the normative majority—of a deep seated anxiety that devalues difference.
>
> (2009: 2)

It would also require a rethinking of justice beyond the limits of the associative and rights-based model that I have identified above.

Conclusion

This chapter has offered an overview of the various ways in which ethical principles have been deployed in debates about how best to respond to the desires for bodily transformation associated with BIID. At the same time, it has critically engaged with the practice(s) of ethics and the effects such practice(s) produce. Whilst I have evaluated some of the claims made and positions taken by the various writers discussed, my aim has not been to develop a definitive ethical position on how to best treat such desires. Rather, I have attempted to draw attention to the ways in which debates about bodies and about ethics (as well as the assumptions that inform them) are themselves constitutive: Despite a focus on abstract concepts (such as autonomy, rights, beneficence, and so on) ethical principles shape the objects, the subjects, the desires, they claim merely to respond to, as well as the being-in-the-world of those who debate their application. Acknowledging this jams the machinery of naturalization/normalization, calling on those who practice (in the name of) ethics to give serious consideration not only to the effects of the ways in which we see, but also, to the onto-political forces that shape our perceptions. Such an approach demands that rather than repeating well-rehearsed conceptual moves, we ask how particular ways of seeing and knowing orient us such that some conceptual associations become naturalized whereas others remain unrealized and unrealizable. We might, for example, ask why the conflation of amputation with "disability" is such an easy perceptual/conceptual/constitutive move to make. And why it is that "disability" is so

widely seen as, by definition, undesirable. We also need to consider what such perceptions fail to see, what psycho-social operations they render invisible, and what ethico-cultural imaginaries they sustain. In fostering "an ethics of encounter without a commitment to resolution or closure" (Campbell and Shapiro 1999: xi, xvii) we would, I contend, be better equipped to respond sensitively and with respect to the matter of BIID.

Related Topics

Chapter 21, "Autonomy," Catriona Mackenzie
Chapter 39, "Medicalization, 'Normal Function,' and the Definition of Health," Rebecca Kukla
Chapter 42, "Transgender," Jamie Lindemann Nelson

Notes

1 See Sullivan (2009) for a discussion of the problematics of pathologization.
2 Whilst the conception of the desire for amputation as primarily sexual has fallen out of favor, there are still a small number of writers who argue for this particular interpretation. See, for example, Lawrence (2006). The separation of "the sexual" from other aspects of lived embodiment has been challenged by De Preester (2011).
3 See also Aoyama et al. (2012). Whilst not deploying the term xenomelia, the following writers argue that the desire for amputation is caused by a neurological disorder: Brang et al. (2008); Blanke et al. (2009); Giummarra et al. (2011); and Seda (2011).
4 See also Bryant (2011).
5 This is a term that those desiring amputation often use. The term is often used in conjunction with two other terms, namely "pretender," which refers to those who participate in what might be called rehearsal activities, and devotee, which is used to refer to someone who desires amputees.
6 Whilst First acknowledges that (a desire for) amputation may be associated with psychoses—for example, self-amputation has been known to be performed by psychotic individuals in response to command auditory hallucinations (see First 2005: 920)—his use of questions about general psychopathology, adapted from the *Structured Clinical Interview for DSM-IV*, suggested that none of those interviewed and evaluated were delusional (2005: 926). In cases in which (the desire for) amputation was shown to be associated with somatoform disorders, body dysmorphic disorder, panic disorder, obsessive–compulsive disorder, or psychosis, the individual would not be diagnosed as suffering from BIID.
7 See Sullivan (2008) and Stryker and Sullivan (2009).
8 By broadening the category of BIID to include amputation for non-normative morphologies that do not require amputation—for example, bodies that do not see—First troubles the idea that BIID (or xenomelia) is caused by a mismatch between anatomy and one's neurological body map due to right parietal lobe dysfunction. Whilst it is relatively easy to explain the desire for amputation (or the feeling that a limb is extraneous) in this way, desires for blindness, paraplegia, deafness, and so on do not easily fit with such an explanation.
9 Ryan et al. (2010) challenge this claim.
10 This assumption could be said to constitute what Robert McRuer refers to as "compulsory able-bodiedness" (2002: 88).
11 This was not always the case. See Sullivan (2008).
12 No date or page numbers provided for this online, unpublished article.
13 In a discussion of amputation as a possible treatment option, Ray Blanchard makes a similar claim. He states: "I can't see society in general accepting it, [a]nd I can't see medicine accepting it. Medicine is going to see it as conferring a disability on a patient. In that sense it's different from sex-reassignment surgery. Being a man or woman is not a disability" (cited in Ellison 2008: n.p.).
14 I do not mean to suggest here that these theorists share a singular position, in fact, quite the opposite is true. The models of gender (acquisition) that these writers have developed are significantly different at the same time that they are each informed by the belief that gender is never simply an empirical, biological fact.
15 Margrit Shildrick puts this well when she argues that "the so-called normal and natural body is . . . an achievement . . . a body that requires unceasing maintenance . . . to hold off the constant threat of disruption: extra digits are excised at birth, tongues are shortened in Down's syndrome children, noses

are reshaped, warts removed, prosthetic limbs fitted, HRT prescribed. In short, the normal body is materialized through a set of reiterative practices that speak of the instability of the singular standard" (1999: 80).

16 Williamson (2010) argues that the "intense and obsessive urge for amputation" that BIID sufferers allegedly experience is likely to impair their autonomy. Interestingly, no account is given of the fact that similarly intense feelings of discomfort with one's morphology, and an intense and longstanding desire for a sense of "wholeness" or congruity that can seemingly only be attained through surgery are key diagnostic criteria for GID.

17 This is the name given to a delusional state that concerns only one particular topic. Such delusions have been associated in the clinical literature with schizophrenia and dementia and also with organic dysfunction caused by brain injury, stroke, or neurological illness.

18 This is the clinical name given to the delusional belief that a close relative or spouse has been replaced by an identical-looking impostor.

19 See, for example, first person accounts by Sebastian Schmidt, Nelson, Sean O'Conner, Michael Gheen, and Andrew Becker, all in Stirn et al. (2009).

20 Similarly, Slatman and Widdershoven claim that "Bodily integrity or wholeness does not simply refer to biological, functional, or neurological intactness, but rather involves a positive identification with the body one has" (2009: 48).

21 Cissexual is a critical term developed to name an individual's self-perception of his or her body and his or her gender as congruent. For Jessica Cadwallader, *cissexual* is "a way of drawing attention to the unmarked norm against which trans* is identified, in which a person feels that their gender identity matches their body/sex" (2009: 17).

22 Bayne and Levy (2005) argue that if a person requesting amputation is shown to be competent in his or her request, then amputation may be justified on the basis that it minimizes the harm that wannabes may inflict on themselves in an attempt to achieve the bodies they feel themselves to be. In this sense, amputation would be beneficial rather than contravening the principle of non-maleficence.

23 If amputation was established as a viable treatment protocol, then Ryan (2009) contends that as is the case in the termination of pregnancy, dissenting doctors would be under no obligation to perform an amputation, but they would be under an obligation to refer the patient to another doctor whom they believe might proceed with the surgery.

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