

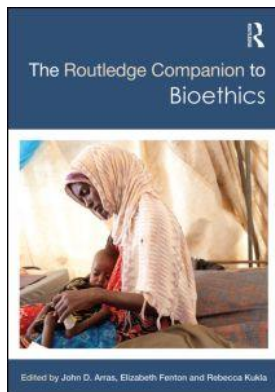
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Part VIII

EMBODIMENT

The human body is at the center of some of the most challenging debates in bioethics, yet is rarely singled out as a topic of discussion in itself. This section attempts to bring together a number of issues regarding the ways in which human bodies are perceived, understood, treated, and imagined in health and health care settings. Two themes emerge from the chapters in this section. The first is the difficulty of defining the topics being explored here. Rebecca Kukla's chapter, for example, reminds us that although everyone has an intuitive idea of what "health" is, there exists no rigorous definition of it. The term "enhancement" can be applied to everything from cosmetic procedures and neuroscientific interventions to efforts to improve one's moral capacity or status. The concept of "transgender" is just as fluid, and the question of how and whether someone can label a being along gender lines informs the ethical analysis of transgender issues.

This trouble with labeling, diagnosing, and even studying how beings see themselves as selves—how they are embodied—leads to the second theme: The importance of social justice. The limitations the authors in this section see in narrow or outmoded approaches to their topics tend to result from a lack of attention to justice considerations. In her chapter on race and bioethics, for example, Alexis Shotwell finds traditional understandings of "race" and "racism" simplistic because they fail to account for the social contexts in which those terms arose and continue to manifest themselves. And Nikki Sullivan's chapter criticizes traditional bioethical thinking for being too narrow to humanely and justly reckon with newer issues of embodiment, such as those surrounding body integrity and gender identity disorders.

The chapters in this section demonstrate that there are as many ways of thinking about embodiment as there are thinkers about it. And because one cannot think about the body without also thinking about the condition—the health—of that body, it is fitting that the opening chapter establishes a solid account of how "health" should be understood. The institutional definition of health Kukla develops accommodates current concepts of ill- and wellbeing while shedding the theoretical or practical motivations behind many accounts of those concepts. More than a purely biological/functional or purely social constructionist way of defining the term, Kukla's institutional account places health firmly within the context of collective wellbeing and presumes that bodies function *only* within a material environment; the result is a definition that automatically incorporates the social considerations that are essential to a just state. As she tests the institutional account on the problematic diagnostic label of gender dysphoria, Kukla provides a guide to understanding health and disease theory that is especially illuminating for the five chapters that follow hers.

Human enhancement is an increasingly controversial topic in bioethics, as technology continues to make real what was once only imaginable. Nicholas Agar and Felice Marshall propose a way of understanding enhancement that is broad enough to encompass the ethical intricacies of the different means, degrees, and targets of enhancement. The first part of their pluralist conception, enhancement through the alteration or selection of genetic material, has been the traditional focus of bioethicists. Yet that focus has meant that other ways of considering enhancement have been overlooked; thus, the second part of their definition of enhancement: Modification or alteration through environmental means (prostheses, neuroenhancement, even education). The authors then offer a “human enhancement consistency test” to help sort through the ethical issues surrounding the enhancement debate, from how to define the term to whether it is ever ethically permissible to enhance beyond human norms. According to the consistency test, a practice or procedure is ethical if it is comparable to—consistent with—a practice or procedure that has already been deemed ethical. Agar and Marshall apply the test to several scenarios, acquainting readers with historical and contemporary enhancement arguments, both pro and con, along the way. Proponents of genetic modification, for instance, would do well to remember last century’s eugenics movement, while defenders of morally enhanced “post-persons” must keep in mind concepts of human moral status and where they situate humans among all living beings. This latter concern also arises in Fredrik Svenaeus’s discussion of the ethics of organ transplantation, in which he wonders whether those who undergo radical moral enhancement (“those who have left the current limits of human embodiment behind”) will possess traditional human ethics at all.

Many of the underpinnings of bioethics are interwoven with cultural and legal ideas of race. Alexis Shotwell and Ami Harbin employ the concept of “racialization,” the process through which groups come to be identified as racial groups, to describe *how* bioethics and race are entwined. Using the syphilis study in Tuskegee as a backdrop, the authors show that although bioethicists have long known that race matters in every scholarly and professional endeavor, they have failed adequately to explore the ways in which it matters. Bioethicists must both move beyond simple biological constructs of race and racism (evil white doctors exploiting vulnerable black sharecroppers) and see that racial sensitivity is much more than cultural competency. They must acknowledge and evaluate the morality of an era’s prevailing systems of inequality; failure to do so can let an entire unjust system off the hook. This mode of thinking is important if the field of bioethics is to successfully confront implicit bias and stereotyping that occurs in certain sectors of health care, and it is essential if bioethicists are to understand how modern technologies (such as biobanking) intersect with racialization.

Jamie Lindemann Nelson also urges bioethicists to expand their traditional ways of thinking. Like the simplistic constructs of race that Shotwell and Harbin take to task, traditional ethical queries about transgender issues have tended to focus on the medical arena—pondering the morality of doctors “doing harm” on healthy tissue, performing “gender normalization” procedures. This has left unexplored how transgender people identify themselves, how the medical and mental health fields consider them (and whether they should be subjects of their consideration in the first place), and what can even be regarded as an “authentic” embodiment of one’s gender. Bioethical thinking would have been especially welcome, Nelson argues, in discussions of stigma resulting from transgender-oriented research, whether gender dysphoria ought to be classified as a mental disorder, and the contemporary and rapidly evolving moral issues, such as those

surrounding transgender parenthood. He also questions, however, whether the time for bioethics' influence has passed, as some transgender people today have achieved political power similar to that of the disability movement and may not need bioethicists to advocate for them against, say, the medical establishment. Still, Nelson sees a place for the bioethicist—not as an analyst of transgender issues but as a contributor to ongoing conversations about them.

Fredrik Svenaeus's development of a guide to ethical thinking about organ transplantation incorporates the themes raised throughout this section. First, transplantation touches on virtually every bioethical principle (notions of consent; the ethics of buying and selling organs and "living" donations, including the medical profession's role in removing healthy tissue; definitions of death and the interests of potential donors; and what, if anything, we may owe fellow humans in need of organs). Second, the ethics of organ transplantation cannot be investigated independent of considerations of embodiment. Once again the problem of definition arises: Are our organs commodities that we own, or do they comprise who we are? Svenaeus favors the latter view, which he calls a phenomenological idea of selfhood. It allows an understanding of self as something connected to others; organs, then, are identity-bearing parts of the processes of selfhood, and donation can be regarded as a humane act of sharing a gift rather than a commercial enterprise.

The section concludes with a discussion of body integrity identity disorder (BIID), defined by Nikki Sullivan as the feeling of non-contiguity between the body and the self. By exploring desires for elective amputation, Sullivan surveys the ethics of "non-normative"-embodiment desires—for amputation, varying degrees of paralysis, deafness, blindness, and the like—and strives to lay bare troublesome assumptions of "conventional bioethics," including classic bioethics principles and definitions of "disability" and "normal." Sullivan asks ethicists to step back and take a meta-analytical view of BIID, questioning, for example, why it is that a disability is automatically considered undesirable. This inquisitive orientation, as opposed to more results-driven approaches, can foster a more expansive and humane way of understanding BIID. Sullivan's review of efforts over the last decade to define, label, diagnose, and ethically evaluate those with BIID, especially her insights into analogies with gender identity disorder and the mental competency of those seeking elective amputation, have important resonances with earlier chapters in this section on transgender and human enhancement.

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MEDICALIZATION, “NORMAL FUNCTION,” AND THE DEFINITION OF HEALTH

Rebecca Kukla

Introduction

“Health” is an intuitive notion and not a technical term. The institutions of medicine are designed, first and foremost, to promote, restore, and protect health. The protection of health and distribution of health services is, almost all societies would agree, an important component of justice. Yet it has proven surprisingly difficult to come up with a rigorous definition of health that accommodates all of our core intuitions about what work the notion should do for us. Some theorists have tried to carve out a biological notion of health and disease based in one way or another on the “normal functioning” of the body and its systems and parts. Others have tried to understand health and disease as socially constructed notions, and have focused upon social and institutional processes of “medicalization,” wherein clusters of symptoms are identified as unified diseases and brought under medical surveillance and management. Both the biological and the social approaches to defining health face serious roadblocks and objections, as do various hybrid accounts. In this chapter, I will look at some influential attempts to define health, explore exactly why it is so difficult to come up with a satisfactory definition, and finally, propose a tentative alternative definition of health.

One reason why the various attempts to define health and disease have been so unsatisfactory is that those using the notion are driven by deeply diverse theoretical and practical goals. It seems to me that there is no reason why we should expect to be able to find a single, unified account of health or disease that meets all these disparate goals and captures the “true” meaning or essence of the terms; we may need to understand health and disease differently in the context of different kinds of projects and goals.

Consider two different kinds of theoretical projects that centrally employ a conception of health:

1. *Scientific* projects: The primary goal of such projects is to understand health and disease as respectable concepts from the point of view of the natural sciences. This is possible only if we can characterize what counts as a disease or a state of health independent of our specific, contingent social categories and practices. Such accounts avoid appeals to social or personal values, as these play no role in the

- categories and explanatory strategies of the natural sciences. Instead, they appeal to notions such as statistical normalcy, adaptive fitness, and biological function.
2. *Social justice* projects. In this context, an understanding of health and disease is a part of a specific type of *normative* project—namely, that of determining the role that health *should* play in a larger theory of social justice. Political philosophers, policy makers, and others ask questions such as: To what extent and in what sense is there a universal right to health, or health care? What counts as a fair social distribution of health resources? When does a health inequity count as a justice issue in need of moral redress? How shall we balance health needs with other social needs in a just state? To answer such questions, we need an understanding of what health *is*. But not any old understanding will do: This has to be the kind of understanding that will guide and clarify health policy and normative questions about the role of health care in a just society.

Now it seems to me that there is no *prima facie* reason to think that our best attempts to specify a scientifically rigorous definition of health and our best attempts to specify a politically and normatively useful notion of health will correspond with one another. We neither can assume that a unified, universally satisfactory definition of health exists, nor, likewise, that there is a single essence of the notion that we just need to be clever enough to ascertain. For example, from a scientific perspective, it may well be that we are best off defining *disease* as some kind of biological pathology, and then understanding health as the absence of disease. But from the point of view of social justice, the notion of disease may be less central. We want to be able to understand why, for example, poor nutrition among low-income children is a socially pressing health problem, even if it does not plausibly constitute a shared disease (but rather a state that bears complex causal relations to a wide variety of diseases). Hence in considering the best definition of health, we need to keep clearly in view the theoretical and practical purposes to which we want to put the concept, while keeping an open mind as to how unified a definition is possible.

Two Different Ways of Thinking about Health: Normal Function and Medicalization

By far the most influential attempt at a scientific definition of health and disease is Christopher Boorse's account, which focuses on the notion of statistically normal function. He defines the *normal function* of a part or process within biological members of a class as "a statistically typical contribution by it to their individual survival and reproduction" (Boorse 1977: 555). Within reference classes of members of a species of a particular sex and age, he defines health as "the readiness of each internal part [or process] to perform all its normal functions on typical occasions with at least typical efficiency" and disease as "a type of internal state which impairs health, i.e. reduces one or more functional abilities below typical efficiency" (Boorse 1977). In other words, roughly, health is statistically normal function and disease is a state leading to below-normal function.

There are various ways to challenge this definition or to demand further specification. The notion of a biological function is a vexed one (Godfrey-Smith 1993), and its place in biological science is non-obvious. Many have argued that a thoroughly naturalistic biology will eventually do away with teleological notions such as "function" and restrict itself to causal explanations (i.e., see Schaffner 1993, among others).

Others have questioned why we should accept that evolutionary adaptation for survival and reproduction are the right categories of analysis for understanding medical notions like health and disease. After all, our health goals can and often do involve both more and less than survival and reproduction (Cooper 2002). One might also wonder about how Boorse picked his reference classes. For instance, why we should accept that sex is a relevant way of constraining the reference class. Sex is a contested category to start with: Not everyone has one of the two sexes; it is not settled how to biologically define sex; sex may be changeable. For these reasons and others it is not obvious that our sex is a privileged feature of us when it comes to constraining what counts as normal function for us.

But for purposes of argument, let us assume that we can fix or fill out all the pieces of Boorse's definition and arrive at a solid definition of health as statistically typical function, as many have tried to do (for instance D'Amico 1995; Wakefield 1997). Such an account would be explicitly devoid of normative force or practical upshot. That is, as Boorse himself insists, if we accept his account we cannot assume that there are any ethical or practical implications that follow in any direct way from determining that something is a disease, or that someone (or some group of people) is (or is especially likely to be) in ill health. That something is a disease does not imply that it ought to be treated, that it is bad to have it, or anything of the sort. For instance, a part or process in me could function in a statistically below-normal way without affecting my life in any way that matters to me or to anyone else. Dysfunction, for Boorse, is a statistical notion indexed to certain evolutionary concepts that bear no direct connection to our practical or moral lives, and hence it comes along with no direct practical or ethical valence. His goal is to give a scientifically sound definition of health and disease, not an ethical or political tool. Given a pointedly non-normative, non-directive account of health, we cannot know what role the protection and promotion of health should play in a just state without adding in extra claims about how and when to value health, how health inequalities matter, what kind of a good health is, and so forth. None of this will be extractable from the definition of health itself.

At the other extreme from the scientific approach to defining health is what I will call a social constructionist approach. This approach begins from the recognition that health and disease are phenomena that are embedded in social practices and fraught with social meanings. Diseases do not merely physically impair us or make us uncomfortable; they co-travel with a variety of social possibilities, barriers, and connotations, which shift and reconfigure over time. Health is not a socially neutral state; it varies demographically and takes on meanings that are shaped by class, race, and other social markers. Clusters of symptoms may start out having no unified medical meaning, and become "medicalized" over time (of which more below), and hardened into recognizable diseases. If we start from noticing these sorts of phenomena, we might be tempted to see health and disease as in the first instance *socially constructed* states, carved out by contingent institutional practices, rather than as given natural categories that can be understood at the level of biological organisms abstracted from their social contexts.

In its most extreme form, this takes the form of what we might call a *pure social constructionist* account of health and disease: *A condition or state counts as a disease if and only if it is medicalized, where medicalization is a social and institutional process, and health is the absence of disease.* There is no formal, agreed-upon definition of medicalization. But roughly, a condition or set of symptoms or bodily features is *medicalized* when health professionals and health institutions take substantial responsibility for understanding,

identifying, managing, and/or mitigating it (Conrad 1992). The idea is that diseases are not natural kinds or biologically definable pathologies; rather, for something to be a disease is for it to be embedded within and taken up by the relevant social institutions as being one. Accordingly, on this view, something is a disease exactly when it is treated as being one by those with the social authority to settle the issue.

Which conditions are medicalized shifts over time: Clusters of behaviors and traits can come to have perceived unity and medical significance that they did not have before (as occurred with attention deficit hyperactivity disorder (ADHD) and fetal alcohol syndrome), and they can also lose this unity or this medical significance (as homosexuality did, for instance). Furthermore, typically, medicalization is not a normatively neutral process. On the one hand, it often effects a shift in moral valence: What was previously seen as a character flaw comes to be seen as a form of illness protected from the logic of personal responsibility, and requiring management by experts instead. (Consider what happened when we started thinking of alcoholism and other forms of addiction as diseases, or when we started conceiving of “hyper” children as having ADHD.) On the other hand, it can invest bodily parts and processes with direct normative statuses: The body is reconceived as a site of deformity, pathology, or dysfunction—it is to be fixed if possible. As Peter Conrad (1992) puts it, medicalization often involves a “move from badness to sickness,” replacing moral stigma with functional stigma at the level of social meaning.

One of the purest defenders of the pure social constructionist account of health and disease is Tristram Engelhardt. Diseases, for him, are “clusters of phenomena *seen as* amenable to medical assessment, explanation, and up to a point, alleviation or cure . . . Their sense, significance, and reality are cast in terms of the social and intellectual institutions of medicine” (Engelhardt 1996: 189). For instance, Engelhardt infers from the fact that masturbation *was treated as* a disease in the nineteenth century directly to the conclusion that it *was* a disease: “As masturbation became subject to medical management in the 19th century . . . the moral offence of masturbation was transformed into a disease” (Engelhardt 1996: 234). For Engelhardt, “transformation” into a disease is an entirely social process—one marked by institutional power and moral meaning.

A pure social constructionist account has not been appealing to those who wish to use the concept of health to help ground a normative social justice account, and rightly so. The process of medicalization is clearly driven in part by political and cultural forces. It is no accident that drapetomania—the “disease” wherein a slave wants to escape his or her master—ceased to be a plausible or appealing diagnosis as we came to see slavery as archaic and abhorrent, or that the demedicalization of homosexuality correlated with the sexual civil rights movement. But if what counts as health or as disease is subject to the vagaries and contingencies of social history and attitudes, and is not directly constrained by discoverable natural facts, then it is hard to see how these notions could serve as stable grounds for normative claims about rights, just social arrangements, and so forth.

On the pure social constructionist account, our notions of health and disease are thoroughly infected by the very normative notions that we are interested in critiquing. We often decide, with the benefit of hindsight, that the medicalization of a condition reflected and reinforced *unjust* social conditions and arrangements; both drapetomania and homosexuality are excellent examples. Remember, on this account, being a disease is just being recognized as one by medical institutions; there is no room for saying that they are wrong about what counts (although later we might say that they were correct

but unjust in counting something as a disease). Any principle that tries to specify when health inequalities are unjust, or whether treatment for disease is a human right, for instance, will have difficulties if the very existence of some diseases (but not others) is bound up with unjust social relations. Hence the pure social constructionist account seems an unpromising cornerstone for any normative project.

So far, both the scientific and the social constructionist approach to understanding health and disease appear unsuited to the normative projects that concern many theorists. Yet theorists with these normative interests have been loath to give up on scientific accounts. I suspect that this is because they wish to anchor their stories in a stable definition of health and disease that is constrained by natural facts about the world and not just the vagaries of value-laden, shifting social practices and attitudes. Several prominent bioethicists have tried to add normative principles to a naturalistic, scientific account of health, in order to generate a normatively fecund account. I will argue that this approach is doomed. Luckily, we are not restricted to a stark choice of scientism and social constructionism, as I will demonstrate later.

Some Important and Easily Forgotten Facts about the Body

Here are three important facts about bodies. These are often ignored or implicitly contradicted in contemporary discussions of the nature of health and disease, even though almost no one would deny them explicitly. Between them, they make it impossible to build a normative, social justice project on top of a scientific conception of health and disease.

1. *No body ever functions in a vacuum—all bodily functioning happens in some material environment or other.* How a body and its parts and subsystems function is always and necessarily relative to short- and long-term material context. The functioning of the body will vary depending on nutrition, air quality, available technology (whether the body has access to eyeglasses, insulin shots, antibiotics) the built environment (transportation options, the availability of elevators, grocery stores), and more. What a body can do and how its parts work varies depending on such things in concrete ways. Thus there is literally no answer to the question of how the body functions independent of context—it must always be in *some specific context or other*, and there is no such thing as the “neutral” context. (Nor, notice, is there such a thing as the *ideal* context. One can always imagine a yet better environment that could enhance the functioning of the body.) The body is not a closed system.
2. Some health conditions cannot be causally traced to the malfunctioning of a single part or subsystem of the body. Whether or not we can generate a technical definition of disease as a kind of dysfunction, not everything we recognize, intuitively, as a health condition can be understood as a single dysfunction or even a unified and stable set of dysfunctions. For instance, depression, morbid obesity, and malnutrition all likely involve multiple subsystems and social determinants. Infertility can have its source in a variety of systems and social factors. The fact that we cannot tell a complete or unified story about the causal genesis of such conditions in malfunctioning parts and subsystems does not impede our recognition of them as health conditions.
3. *Physicalism:* Any capability or function of a *person* supervenes on her *body* in its material environment. That is to say, the body has no spiritual capacities that function independently of its material capacities. One’s material body, in all its detail,

situated in its material environment, fully determines one's capacities. *Everything* I can do or be, I can do or be because of the body I have, in the context it is in. This includes my capacity for reasoning, my trained skills, my temperament, and so on. Physicalism is perhaps more contentious than my first two points, since there are those who believe in souls or other kinds of immaterial substance. However, it is not really contentious among most philosophers, and it is certainly not contentious among those seeking scientific groundings for their theoretical accounts. I assume physicalism from hereon in without further discussion.

In the next two sections, I look in some detail at two recent, influential accounts of the role that health and health care should play in a just state, both of which rely upon a naturalistic definition of health. I will show why, in light of these three core facts about bodies, neither can ultimately achieve its goals. I suggest that their failures are exemplary of the general problems that will be faced by any such accounts.

Norman Daniels on Justice and Health

In his book, *Just Health: Meeting Health Needs Fairly* (2007) Norman Daniels seeks to answer three "focal questions": How is meeting health needs connected with other goals of justice? What is the special moral importance of health? When are health inequalities unjust? (Daniels 2007: 11). He develops a definition of health that is specifically designed to enable us to answer these three normative questions. This is a classic example of what I have called a social justice project. Furthermore, Daniels is explicit about his goal of building his conception of health by grounding it in a scientific account and adding normative principles so as to make such an account practically useful. Hence he is a perfect test case for our purposes here.

Daniels' definition of health cleaves close to Boorse's statistical definition, modifying it only slightly for normative purposes. He defines health as the absence of *pathology*, where pathology is any *harmful* deviation of the normal functional organization of a typical member of the species, indexed to age and sex (Daniels 2007: 38–9). He is explicit about trying to stay close to the naturalistic, social-practice-independent understanding of health that Boorse offers us, while introducing just enough of an evaluative valence (through the idea of "harmfulness") to make the notion potentially useful within a normative account of justice with some practical import (Daniels 2007: 39).

Daniels' central normative move is to claim that health has distinctive moral import in a just society because pathology impacts people's access to a *normal range of opportunities*. Only those differences in opportunity that originate in *pathology* or its absence are the proper concern of a just health care system, he claims. He argues, for instance, that systematic health inequalities (as opposed to, say, systematic inequalities in ice-skating abilities or systematic hair luster inequalities) deserve social redress as a matter of justice specifically because they lead to systematic differences in opportunities. In moving from the notion of dysfunction to that of restricted opportunity range, Daniels makes the transition from the naturalistic to the normative that is supposed to enable him to place health and health care within an account of just social arrangements.

But can Daniels in fact sustain the distinctions he needs using his theoretical toolbox? Note that all sorts of features and functions of the body restrict opportunity. Having narrow hips and a thick waist restricts one's opportunity to win hula-hoop contests, for example. Daniels is not interested in *all* opportunity restrictions that issue from the body.

Rather, he needs to be able to specify which opportunity restrictions matter as a matter of justice, and he needs those to correspond in some non-accidental way with those that count as the proper concern of medicine and health institutions. Furthermore, it will not be enough for him to say that the opportunity restrictions that matter just are those that medicine can mitigate. For many seemingly non-health-related opportunity restrictions can be mitigated using medical techniques. Having small breasts restricts one's opportunities to be a stripper, *unless* one's body is altered using the tools of medicine. Yet we do not take it as the job of a just social system to mitigate these opportunity restrictions, with or without medical techniques.

So far, Daniels would agree with everything I just said. His goal is to use the notion of normal function in order to make the relevant cut between health issues that restrict our opportunities in ways that are the concern of a just state, and other sorts of opportunity restrictions. In order to make the cuts he needs, Daniels makes two important and unsupported assumptions.

First, he assumes that we can distinguish between those opportunity restrictions that are caused by pathology (given his definition of pathology) and those that are not. But remember our first and third facts about the body above. *Everything* we can do and be depends on how our body functions in a particular context—there is no such thing as how it functions independent of any context, or in a “neutral” context. Nor is there anything we do that isn't something our body does. I think that taking these uncontroversial facts seriously makes it difficult or impossible to carve the health-related opportunity-restricting dysfunctions off from the others in any plausible or pragmatically fecund way.

For instance, consider illiteracy. Being illiterate clearly restricts opportunities in important ways. Furthermore, illiteracy is a matter of the body functioning atypically, and it involves specific brain and visual deficits. Yet we do not count it as a health condition. Why not? What is the relevant difference between illiteracy and, say, asthma, which is universally recognized as a health condition? We might argue that illiteracy is not a health condition because it is not an *inherent* feature of the body; typically, it is not explained just by genetics or other innate bodily features, but also by elaborate environmental influences and deficits. But the same goes for many health conditions, including asthma, which is triggered by a combination of genes and environment, not to mention contagious illnesses and much else. Thus, once we keep in mind the contextual complexity of bodily functioning and the fact that everything we do is embodied, it is not at all obvious that we can draw a clean distinction between pathology and other opportunity restrictors, given the contents of Daniels' toolbox.

Second, Daniels assumes that once we make the *scientific* distinction between opportunity restrictions grounded in pathology and other opportunity restrictions, it will in some important sense track a *moral* distinction: The opportunity restrictions based on pathology will be distinctively deserving of social attention in a just state. To be sure, having breasts too small for a stripper will not deserve social redress in the same way as having a muscle disorder that prohibits walking. But Daniels needs it to be *systematically* true that opportunity restrictions resulting from pathology have a special moral priority over those with other causes. This is key for him, as it is what allows his naturalistic definition of health to be sutured to the notion of a restricted opportunity range in a way that has normative or political consequences.

But consider one of Daniels' own central examples, which he uses in multiple publications: Shortness and human growth hormone (HGH) treatment. Being short is, he

presumes, an opportunity disadvantage in our culture (Daniels 1992, 2007, and elsewhere).¹ Daniels claims that kids who suffer from hormonal disorders involving a HGH deficiency have a dysfunction of the right sort to count as a pathology, and hence that they have a justice claim on HGH treatment, whereas kids who are just genetically short but “healthy” have no such claim—giving them the HGH therapy would count as “enhancement” rather than treatment. This is supposed to exemplify how his scientific definition of health can be used to make normative policy distinctions as to who is owed treatment. But the example seems to me to backfire severely. If one’s abnormal height restricts opportunities, in a particular social and material context, how could the *cause* of that abnormal height have any moral significance? It is hard to imagine why or how either of two identical opportunity restrictions in two equally short kids, whose shortness has a different genesis, could possibly matter in terms of its moral or practical significance, on Daniels’ own account.² Our opportunity range is always a product of what we can do *with our body, in our environment*, and the causal genesis of these abilities seems morally irrelevant.

In trying to show how he can use his naturalistic notion of pathology as the basis of a practically fecund account of health justice, by way of the impact of pathology on opportunity, Daniels has, I think, in fact accidentally done the opposite: He has demonstrated that if opportunity is what we care about, then—although surely pathology does cause opportunity restrictions—pathology or its absence become quite irrelevant to what justice owes people. And again, that’s so even if we can stably distinguish between pathology and other opportunity-compromising bodily features, which is by no means clear.

I contend, then, that once we force ourselves to remember that everything we do is something we do with our body, and that bodily functioning is ineliminably context dependent, we can see that Daniels fails to ground a contentful theory of health justice in his scientific definition of health and disease. Furthermore, this failure is located at exactly the junctures that matter for our purposes: At the point where we distinguish health conditions from other bodily conditions, and at the point where we assign moral significance with practical consequences to having a health condition as opposed to some other kind of condition.

Powers and Faden on Dimensions of Well-Being

In their book *Social Justice: The Moral Foundations of Health and Health Policy* (2006), Madison Powers and Ruth Faden develop a theory of justice, including health justice, built on the idea that there are at least six basic “dimensions of well-being.” They argue that justice requires that society attempt to guarantee all its members a sufficiency of well-being in each dimension. These are dimensions that matter centrally to all people, regardless of their specific life plans; they are “weighty interests of special enough importance to be given protection as basic human rights” (Powers and Faden 2006: 85). The six dimensions they identify are health, personal security, reasoning, respect, attachment, and self-determination. Each dimension is, in their view, “morally distinctive” as well as conceptually separable for the purpose of designing just policy and institutions; they are also causally intertwined and interdependent in a variety of ways. While the dimensions are distinct, Powers and Faden demonstrate in detail how they create densely woven systematic patterns of inequality and disadvantage. “Inequalities beget inequalities, and existing inequalities . . . can compound, sustain, and reproduce a multitude of deprivations in well-being” (Powers and Faden 2006: 8).

According to Powers and Faden, health is a distinct and irreducible dimension of well-being. They are concerned to carve it off from the other dimensions so that it can serve as a substantive tool for designing specific health policies and just health practices. In particular, they are concerned to set boundaries around the concept of health so that it doesn't become so vague that it swallows up every facet of well-being; they wish to push back against the notoriously broad definition of health in the constitution of the World Health Organization, namely "*a complete state of physical, mental, and spiritual well-being.*" Powers and Faden point out that the WHO definition:

conflates virtually all elements of human development under a single rubric and thereby makes almost any deficit of well-being into a health deficit. Were we to adopt the WHO definition, we would lose the human capacity to maintain any distinctive interest in dimensions of human well-being such as respect, affiliation, and reasoning that we believe have independent moral significance as matters of social justice, however intertwined with health they may be.

(Powers and Faden 2006: 17)

If our notions of health and disease are to play substantive roles in normative accounts of just social institutions, then we have to be able to separate health from other forms of well-being, just as we have to be able to separate disease from other forms of dysfunction.

Given how much it matters to Powers and Faden that health be a distinct and identifiable dimension of well-being, they spend surprisingly little time defining it or defending and explaining their definition. Instead, they give a rough intuitive definition that invokes the scientific language of biological function:

We work with what is essentially an ordinary-language understanding of physical and mental health that is intended to capture *the dimension of human flourishing that is frequently expressed through the biological or organic functioning of the body.*

(Powers and Faden 2006: 16–17, italics in the original)

If we try to sharpen their definition in a way that is consonant with their goals and the rest of their account, we get into trouble similar to that Daniels faced. Remember, *everything* we can do or be is something we can do or be *with our body*, and hence in a straightforward sense every possible kind of human flourishing is *expressed through the body*. So this part of their definition is not helpfully restrictive. Presumably this is why they introduce the qualifier that it is the "biological/organic functioning" of the body that matters for health. Of course, our biological body is the only one we actually have. Hence we need some other reading of the emphasis on the biological/organic functioning of the body. Presumably Powers and Faden are here trying to separate the functioning of the body *qua* biological entity from its functioning in social and technological context. But as we saw, *there is no such thing*. The states and functions of the body are environment dependent.

Thus far, Powers and Faden's definition of health does nothing to help us restrict the notion more narrowly than human flourishing in general; they do not seem to have gotten us farther than the WHO definition they denigrate. And without this, the concept of health does not give us a tool for making substantive claims about just health institutions and practices. In order to flesh out to this worry, it will be helpful for us to look at

some of their other dimensions of well-being that are supposedly distinct from health, to see how the distinctions collapse in practice. Consider two of these dimensions: *Reasoning* and *attachment*.

Powers and Faden are surely right that impairments of reasoning and of attachment are serious compromises of human flourishing. Clearly, *some* such impairments are *also* health conditions. Consider clinical paranoia and attachment-impeding forms of autism, for instance. Just as clearly, *some* impairments of reasoning and attachment are not health conditions, in any intuitively recognizable sense. Closed-mindedness due to a narrow religious upbringing can impair reasoning (and probably attachment too). Moderate introversion can impair attachment. It should be the job of health policies to address the needs of citizens with clinical paranoia or autism; it's not specifically the business of *health* policies or institutions to address religious closed-mindedness or personality variations. Given the terms of their project, Powers and Faden must be able to distinguish the two types of case.

We cannot, of course, reason about anything or attach to anyone without our bodies; our bodies are what we reason and attach *with*. So the involvement of the body is not a criterion we can use for distinguishing health-related from non-health-related impairments of reasoning or attachment. Nor can we use the distinction between socially and biologically caused impairments to help us. One might suggest that religious closed-mindedness, for instance, is not a health condition because it is socially caused rather than properly biological, but this will not give us the cut we need. For instance, post-traumatic stress disorder and dissociative identity disorder are health conditions in which social factors play crucial causal roles (and they may impair reasoning and attachment as well).

Powers and Faden admit that any reasoning (and presumably any attachment) depends on a biological substratum—a “healthy brain.” In order to try to sustain their claim that reasoning is not a subset of health, they write:

Certain kinds of health states are necessary for reasoning, but they are not sufficient. What further distinguishes reasoning abilities from the healthy functioning of the brain is that the former also require an understanding of the world that must be *learned*.

(Powers and Faden 2006: 21)

But this is unhelpful. For learning itself supervenes on brain function; changing brain function is the mechanism by which learning occurs. We cannot separate how the brain functions “in itself” from how it functions after learning, for learning is among its most central functions. Once again, there is no stable, contextually independent background state of “brain health” to which learning is added. (This becomes exceptionally clear if we note that a healthy infant brain would be very unhealthy indeed were it to reside in an adult, since enormous amounts of learning in between are essential.)

Thus Powers and Faden have not given us theoretical resources with which we can distinguish between compromises in reasoning and attachment *per se* and compromises in health. More generally, they have offered us no mechanism for telling when facts about the functioning of the body are relevant to our health as opposed to other dimensions of our well-being. For example, they cannot help us explain why poor reasoning due to poor education and parenting is not a health condition, whereas poor reasoning due to post-traumatic stress disorder is one. But this means that their (fairly minimal) scientific definition of health does not enable them to carve out the dimensions of well-being

as distinct and independent. But a central goal, for Powers and Faden, was to earn substantive practical conclusions about justice by keeping these dimensions distinct.

Kinds of Conceptual Categories and the Institutional Definition of Health

Here's where we are so far: We are apparently caught between a social constructionist understanding of health, wherein health and disease are whatever we take them to be, and a scientific understanding of health, wherein health and disease are biological concepts. We have seen that neither yields a concept of health that is substantively useful within a normative project of deciding what just health institutions and policies would look like. As long as we think that health has to be either a natural, biological category or a mere social construction, the problem seems hopeless. Luckily, the dilemma is false.

Some conceptual categories are purely socially constructed. The independent material world does not constrain our usage of them, and our practices for using them are the only measure of their own correctness. Consider the concept of “cooties,” or of “witch” in seventeenth century Salem. Nothing determines whether you count as having cooties or being a witch (in their sense) except social agreement. It's not like there could be new evidence that could confirm or falsify someone's cootie or witchy status.

Other categories mark out scientifically relevant distinctions in the natural world, completely apart from our practices or attitudes. We *discover* their properties rather than constituting them. Gold and atomic nuclei are good examples. Whether we are in the habit of counting something as gold (Au) is irrelevant to whether it is in fact that element.³

But plenty of our categories are constrained by both the world and our social practices (Weiskopf 2011). Artifactual categories such as “scalpel” or “prosthetic” are defined in terms of their intended function. Were there no human practices, nothing would be a scalpel; scalpels exist only because we design and make them. But at the same time, not any old thing we choose can count as a scalpel. An object must be organized in the right way to count as a scalpel, and only certain kinds of material (metal but not Styrofoam, for instance) will support such organizations. Saying something is a scalpel isn't like saying someone has cooties; there are natural constraints independent of us on what can count. But it also isn't like saying something is gold. An object has to be enmeshed in human intentions and practices in the right way to count as a scalpel.

Consider now *institutional* categories such as “voting,” “paycheck,” “convict,” or “student.” The existence of such things is thoroughly dependent upon elaborate social institutions, and to be such a thing is to be embedded in these institutions in the right way. You can't be a convict without a legislative, justice, and penal system. Nothing counts as a paycheck without elaborate labor and economic institutions. And yet, things don't become or cease to be convicts or paychecks just because we choose to classify or declassify them in that way. Being either one has definite empirical consequences and preconditions. We may slowly refine or shift these kinds in accordance with our social needs. But we cannot simply discover that we were totally wrong about what a convict or a paycheck is, since our practices carved these kinds out.

With all this in mind, let's return to the question of how we should most productively understand the concepts of disease and health. I suggest that we understand health as a special sort of *institutional* concept. I will propose a definition and then take some time to spell out its meaning and consequences:

The Institutional Definition of Health: A condition or state counts as a *health condition* if and only if, given our resources and situation, it *would be best for our collective well-being* if it were medicalized—that is, if health professionals and institutions played a substantial role in understanding, identifying, managing and/or mitigating it. In turn, *health* is a relative absence of health conditions (and concomitantly a relative lack of dependence upon the institutions of medicine).

Both this definition and the pure social constructionist definition define health in terms of medicalization by health institutions. But my institutional definition differs from the pure social constructionist definition in that it talks about what we *should* medicalize, from the point of view of our collective flourishing, rather than what we *do* medicalize.

The essential idea here is that *real* health conditions are conditions for which the tools and methods and support of medicine and its institutional mechanisms are genuinely helpful, given both the natural and the social facts. This is something we can be *wrong about* and can *empirically discover*. That something is a health condition is a social fact, which is dependent on what medicine has to offer and the social context of the condition, but not a *purely* social fact. For example, it turned out that even though, as Engelhardt points out, people *thought* that the tools of medicine would be helpful when applied to masturbators, they were in fact wrong. And while many people used to think that people with schizophrenia were best served by exorcists, we now know that the tools of medicine are helpful in diagnosing and managing schizophrenia.

It is *not* a consequence of my account that all health conditions deserve medical treatment, or even that medical treatment is always the best option. Something might meet my definition of a health condition because it is best *diagnosed and classified* using the tools of medicine, but then best managed using non-medical strategies. Mild hypertension might be a candidate, for instance. Perhaps it is best, all things considered, for us to use medical tools to identify and label mild hypertension, but also best all-in to address it with lifestyle changes and self-monitoring (as opposed to pharmaceuticals, say).

It is also not a consequence of my account that an *individual* counts as having a health condition just because providing medical services to *that individual* would benefit *her or him*. I've defined health in terms of our *collective* well-being. So for example, just because an individual might personally benefit from cosmetic breast augmentation, this does not mean that having smallish breasts is properly categorized as a health condition. The question would be whether using the tools of medicine to manage small-breastedness would be better for our collective well-being, and this is much less plausible than that particular individuals might benefit.

Notice that I have left open how to understand “collective well-being.” The question of what constitutes this is far beyond the scope of this chapter; it's roughly equivalent to the question of the nature of justice. My proposed definition of health is intended to be neutral between conceptions of collective well-being. Whether one is a consequentialist, a libertarian, a Rawlsian, or whatever else, one can be invested in what I have called the normative project of figuring out how a just state should manage health policy and health needs, and my definition of health can be slotted into any such project.

The institutional definition of health is a realist one, in the sense that one can *discover* that something is properly thought of as a health condition, by *learning* that the toolkit of medicine is helpful. But what we are discovering, in such a case, are not just natural facts that are independent of human interests and practices. Whether the

toolkit of medicine turns out to be a good thing to bring to bear, all things considered, depends on all sorts of changeable and human-practice-dependent facts, including what medical techniques and interventions are available and the cultural context in which they will be used, among other factors. Whether something is rightly brought under the rubric of health institutions will change as the capacities, resources, technology, and knowledge base of medicine changes, and as the culture at large (including attitudes towards particular conditions and diseases, the self-understandings of those who have a particular condition, available resources and support networks, and so forth) changes as well.⁴

This means that even though there are all sorts of concrete facts that help determine whether something counts as a health condition, whether it counts is not a *fixed or natural fact* about it. Likewise what counts as being healthy will change as culture and medicine change; health is not an intrinsic property of a body, on this account, but only of a body in context. This is intuitively appealing: Surely what counted as being a healthy 60-year-old in medieval England is not the same as what counts as being a healthy 60-year-old in twenty-first century Norway.

Unlike Boorse, Daniels, and others, I have not defined health in contrast to “disease.” I suspect that for normative purposes, carefully separating diseases from other health conditions will not turn out to be very important (in contrast to its importance within a scientific account of health). Roughly, we can think of a disease as a repeatable, relatively stable bodily state or process that systematically causally contributes to one or more health condition. Notice that, on this definition, particular diseases may be natural kinds, definable and identifiable apart from human practices (in terms of their viral or genetic underpinning, say). But *that* a condition is a disease is an institutional fact, not a purely natural fact, as this depends on its relationship to health conditions, which are institutional concepts. And the concept of disease *itself* is likewise, here, an institutional concept.

In short, health and concomitant concepts like disease are not *natural kinds*, on my institutional account, even though they are largely *materially determined kinds*, whose extension is not simply up to us. Understanding health inherently requires more than the tools of the natural sciences; it needs the human sciences as well.

How does my account constitute an improvement over the pure social constructionist account? The key lies in my shift to a *counterfactual* definition; this shift, I claim, creates the room we need to allow the concept of health to have some substantive normative punch. For remember, on the social constructionist account, diseases are whatever is medicalized, even though we know that sometimes this medicalization does more harm than good from the point of view of justice and the promotion of collective well-being, as in the cases of homosexuality and drapetomania. On my account, unlike the pure social constructionist account, such things *never were* actually health conditions. Our classification and treatment of them as health conditions were *mistakes*; they got the world wrong. Likewise, sometimes we discover that as an empirical fact, a condition that used to be seen as non-medical is actually best medicalized—that more justice and human flourishing results from medicalizing it. Alcoholism—which used to be cast as simply a moral failing—is a plausible example. On the institutional account I have proposed, determining that something is a health condition has direct consequences for deciding how the tools of medicine ought to be used. Thus we can use health and its absence as stable normative notions for the purposes of building an account of just social arrangements.

A Brief Test Case: Gender Dysphoria

Let's look at how the institutional definition of health works in a contentious case: Gender dysphoria, also known as gender identity disorder. This is the official diagnostic category for transgender people; it marks out transgender as a unified *health condition*. The medicalization of transgender identity has rightly been contentious from the start. To simplify the debate dramatically: On the one hand, a large percentage of trans^{*5} people claim that access to the tools and techniques of medicine (hormone therapy, plastic surgery, etc.) is crucial to their embodied flourishing and mental well-being. On the other hand, first, trans* folks have been understandably resistant to the idea that they have a *disorder* or a *disease*, as opposed to just a configuration of identity that needs social and technical support in order to be successfully maintained (as do all configurations of identity, although sometimes to a less heightened degree). And second, the medicalization of trans* identity is worrisome insofar as it gives doctors the power to serve as identity "gatekeepers," who can enforce rigid criteria and set up practical hurdles that "patients" must meet before they can "count as" officially having access to the identity they experience themselves as having.

On the account I have proposed, we can find a way out of this dilemma. Whether gender dysphoria is a "real" health condition, on my account, is not a question of whether it corresponds to some substantial biological dysfunction (as on a scientific account), nor is it simply answered by noting that we treat it as one (as on a social constructionist account). Rather, the question of the "reality" of the diagnostic category is a question about whether we *should* use the tools and techniques of medicine for addressing the needs of trans* folks. And this, in turn, is a contingent empirical question that depends on the current treatments available, the specific standards of diagnosis and care, the culture and support networks available to trans* folks, and more. These are facts that are *changing* rapidly.

Not very long ago, medical interventions available for trans* folks seeking them were fairly coarse grained, and among other limitations did little to preserve sexual pleasure and function. Furthermore, access to such interventions depended on meeting a rigid set of standards for what counted, medically, as "truly" being transgender. Patients had to present as having lived out a formulaic narrative, in which they had felt "trapped in the wrong body" since early childhood and had consistently manifested highly stereotyped gendered behavior. They had to desire to "pass" as their preferred gender and be able to do so fairly successfully, and they had to crave the genitals of their preferred gender. If they did not meet all these requirements and more, they weren't "really" transgender and did not qualify for medical interventions. All this served to make the medical management of sex identity a mixed blessing at best.

There have been seismic changes recently, however (see Chapter 42 in this volume). Diagnostic criteria have broadened and become more patient centered. There is widespread medical recognition that not all trans* patients are simply interested in approximating the "normal" body of a sex other than the one they were assigned at birth; some patients may only need or desire hormone therapy, or chest surgery, or any combination of interventions, and trans* identities run the full spectrum of gender identities. A teleological march towards genital reconstruction is no longer the norm, nor is the desire to have this surgery treated by medicine as the "true" measure of sexual identity. Concomitantly, the trans* community now embraces a much wider range of body formations and self-presentations, with much less emphasis on policing a "proper" trans narrative.

On the institutional account, gender dysphoria is a legitimate medical diagnosis just insofar as bringing it under the purview of medical institutions enhances human flourishing and the ends of justice. I hypothesize (though I certainly cannot thoroughly prove here) that, *as a matter of contingent, historical fact*, it has turned out that the diagnostic category of gender dysphoria, and the medical tools and procedures that it gives access to, have increased the well-being of trans* folks (and indeed people in general), all things considered. We now have substantial experience with how trans* folks do when they have access to the medical interventions they feel they need, and it seems fairly clear that more people are able to flourish and be happy in virtue of this access. Meanwhile, public consciousness and acceptance of trans* folks and medically altered trans* bodies have skyrocketed forward. (Of course, none of that is to deny the very serious forms of discrimination and danger still faced by many trans* people.)

Thus on my account, gender dysphoria counts as a legitimate, bona fide *health condition*—a condition that is in the running for various rights of access to health services in a just state. But crucially, this is not because there is some unified, underlying *pathology* that explains or undergirds the “symptoms” of gender dysphoria. There is no reason for the claims of trans* folks on health resources, or the reality of their condition, to depend in any way on finding some sort of stable dysfunction that “legitimizes” their condition. There is no underlying natural fact that would determine whether gender dysmorphia is *truly* a health condition, and hence no reason to hook claims to health services to any story of disease etiology. Nor, however, does gender dysphoria count as a disease just because it is pathologized by the practices of medicine, as it would on a pure social constructionist account.

There are various other conditions for which it is an open question whether the involvement of medicine is all-in a good thing for justice and human flourishing. Female sexual dysfunction and ADHD are two examples upon which it seems to me the jury is out. Whether these are properly categorized as health conditions depends on contingent, complex, socially embedded facts that are not yet fully known or even fully determined—but that are also not simply up to us to decide.

Conclusions

In the early parts of this paper, I argued that dominant approaches to defining health had difficulty making a normatively fecund distinction between health conditions and other sorts of conditions. I claimed that they appeared to do so only by ignoring one or more basic facts about human embodiment: (1) That there is no way that the body functions outside of a particular material context; (2) that not all health conditions can be traced to a particular part or subsystem of the body; and (3) that everything that we do, we do with our body.

I claim that the institutional definition of health manages to carve out a normatively relevant concept of health that does not stumble over these three facts, because it does not make the reality of a health condition depend on finding a stable or underlying bodily function or part on which it can be pinned. This account lets the concept of health play a substantive role in a theory of justice (whose details are up for grabs, as far as what I have said here goes). Unlike in scientific or social constructionist accounts of health, the connection to justice is *built in* to my account from the start, through its appeal to empirical facts about what furthers our collective well-being.

Related Topics

Chapter 42, “Transgender,” Jamie Lindemann Nelson

Chapter 44, “Body Integrity Identity Disorder (BIID) and the Matter of Ethics,” Nikki Sullivan

Notes

- 1 At 4’ 10.5”, I am not sure I agree. But I will grant the claim for the sake of argument.
- 2 In fact I am not sure why Daniels does not count the child whose shortness is genetic as having a pathological condition, by his own definition. Why is a statistically atypical and (by assumption) harmful gene structure any less pathological, on his definition, than a statistically atypical hormonal structure—especially given that the latter is probably genetically caused anyhow? The example seems to me to raise the first problem; I am not sure how Daniels can put meaningful boundaries around the notion of pathology. But this is a side point in the context of this second argument.
- 3 Many philosophers, including me, are suspicious of the idea of purely natural kinds. But I will grant their existence for the purposes of this chapter, since I am about to argue that health is *not* such a kind anyhow.
- 4 Health and various health conditions are kinds that have what Ian Hacking (1995, 1999) calls “looping effects”: Once we identify such kinds (cancer, schizophrenia, malnutrition . . .) and sort people into them, this will affect people’s self-conception, behavior, and treatment, and this in turn will change the character of the kind. Think, for example, about how the medicalization of drug and alcohol addiction has radically altered the institutional and cultural setting and meaning of addiction, along with the experienced identity and social life of many addicts.
- 5 “Trans*” is a relatively new notational term designed to designate not just male to female and female to male transgender folks, but anyone who does not identify with the sex they were assigned at birth, including those who identify as genderqueer, non-gendered, or any other variant. The asterisk is designed to mark that this is a covering term that can include those who identify as transgender, transsexual, transvestite, or any other variation, without the need for us to lock down these possibilities in advance.

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