

PART I

Disability: Definitions and Theories

Introduction to Part I

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The chapters in Part I of this volume, “Disability: Definitions and Theories,” might just as easily be characterized as “The Perils of ‘Normal.’” Using philosophical methods, each of the chapters seeks to undermine assumptions made by those without disabilities about the moral lives of those *with* disabilities.

In “Disability, Health, and Normal Function,” Elizabeth Barnes takes issue with the notion of “normal function” at the heart of naturalistic theories of health that one finds in some of the key work in the area, that of Christopher Boorse, Daniel Hausman, Norman Daniels, etc. Such views, to generalize a bit, endorse “a biological norm of species-typical functioning” and treat “diseases/ illnesses/ disabilities [as] departures from this species norm.” While also briefly discussing more external critiques of this kind of approach, Barnes’ main critique is an internal one: that such theories conceive of pathology as that which reduces “the ability to survive and reproduce,” but many of the things that are conventionally viewed as disabilities do not cause such reductions. Barnes attempts several charitable reconstructions of the normal function view – including tying it to benchmark environments or natural selection – but ultimately finds it remains problematic. The deeper problem with this view is that people with disabilities can function well without functioning normally (in the sense of species-typical functioning).

Ani B. Satz’s “Healthcare as Eugenics” offers a different line of attack on the same set of theories. In harmony with Barnes, Satz understands these theories to “assume that atypical functioning is undesired, less effective, and to be avoided,” that is, that “typical or normal methods of functioning (such as walking) are valued over other forms of functioning (such as wheeling), often regardless of comparative effectiveness.” But Satz makes a provocative and confrontational critique: health care institutions adopting this viewpoint are effectuating a form of eugenics. She reviews the myriad ways “health care delivery and funding privilege and promote typical methods of human functioning over equally or more effective atypical methods of functioning, thereby promoting certain human traits” and concludes that “because the government extensively funds health-care, the government at least tacitly supports these choices.”

In “Epistemic Injustice, Disability Stigma, and Public Health Law,” Daniel Goldberg uses a stream of philosophical thought associated with Miranda Fricker of “epistemic injustice,” the idea of being wronged in one’s capacity as a knower, to consider the way public health stigmatizes disability. Following this line of work, he distinguishes testimonial epistemic injustice – in which prejudice downgrades the speaker’s credibility – and hermeneutic epistemic injustice – in which prejudice obscures a significant area of social experience from collective understanding. He finds both present in the case of disability. For example, the testimonial epistemic injustice of making assumptions about the abilities of those with intellectual disabilities and the hermeneutic epistemic injustice of over-attention to the medical model of disability over the social model’s recognition that many of the injuries experienced by people with disabilities come from the underlying social structure. Among other insights, he develops a basic feedback loop model in “which both dimensions of epistemic injustice (testimonial and hermeneutical) reflect and feed disability stigma.”

In their own way, each of the chapters interrogates the idea of “normal.” At one level, the critique is that the concept’s content is deeply contested terrain. At another, it is the idea that the concept, whatever the merits of its content, has been “weaponized” as a way of deciding whose voices carry authorities and whose do not. The strongest claim is that the concept is not just wrong in its reference set or wrong in its stigmatizing effects, but ultimately represents an attempt to eliminate the “other” from existence. These three chapters will certainly enlighten and provoke even those deeply enmeshed in these debates.

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Disability, Health, and Normal Function

*Elizabeth Barnes*¹

In philosophical discussions of health, no single idea has been more influential than the concept of “normal function.” Naturalistic theories of health, such as those defended by Christopher Boorse and Daniel Hausman, take normal function to be the central concept via which we should define and understand health.² Proponents of such views argue that health is a purely naturalistic (rather than normative) concept that can be understood without reference to values or preferences. There is a biological norm of species-typical functioning, according to such views, and diseases, illnesses, and disabilities are departures from this species norm.

But the influence of the idea of normal function extends well beyond purely naturalistic theories of health. Jerome Wakefield, for example, argues that disease has an inherently evaluative component, but that abnormal function is a necessary (though not sufficient) condition for disease.³ Norman Daniels argues for an incorporation of the idea of normal function into an account of health care resource distribution.⁴ And Tom Shakespeare argues that while it cannot be used to characterize disability, a Boorsian theory of normal function is how we should

¹ Many thanks to Ross Cameron, Jason Turner, Robbie Williams, and Liam Kofi Bright for helpful discussion.

² See generally Christopher Boorse, *Health as a Theoretical Concept*, 44 *Phil. Sci.* 542 (1977) (hereinafter “Boorse, Health as a Theoretical Concept”); Christopher Boorse, *A Second Rebuttal on Health*, 39 *J. of Med. & Phil.* 683 (2014) (hereinafter “Boorse, A Second Rebuttal on Health”). See also Daniel M. Hausman, *Health, Naturalism, and Functional Efficiency*, 79 *Phil. Sci.* 519 (2012) (hereinafter “Hausman, Health, Naturalism, and Functional Efficiency”); Daniel M. Hausman, *Health and Functional Efficiency*, 39 *J. Med. & Phil.* 634 (2014) [hereinafter “Hausman, Health and Functional Efficiency”].

³ See generally Jerome C. Wakefield, *Disorder as Harmful Dysfunction: A Conceptual Critique of DSM-III-R’s Definition of Mental Disorder*, 99 *Psychol. Rev.* 232 (1992) (hereinafter “Wakefield, Disorder as harmful dysfunction”); Jerome C. Wakefield, *The Biostatistical Theory Versus the Harmful Dysfunction Analysis, Part 1: Is Part-Dysfunction a Sufficient Condition for Medical Disorder?*, 39 *J. Med. & Phil.* 648 (2014) (hereinafter “Wakefield, The Biostatistical Theory Versus the Harmful Dysfunction Analysis”).

⁴ See generally Norman Daniels, *Just Health Care* (1985); Norman Daniels, *Just Health: Meeting Health Needs Fairly* (2007).

understand the notion of “impairment” that underwrites many contemporary definitions of disability.⁵

In gaining this sort of influence, a broadly Boorsian view of normal function has not lacked for criticism. But, in what follows, I want to press a particular line of criticism that I think deserves more attention. This line of criticism becomes especially salient, I think, when we look at the rich and thriving lives led by many disabled people. It is surely correct to say that many (perhaps all) physical disabilities involve “pathology” in the biomedical sense of the term. Regardless of whether you think that achondroplasia, spinal cord injury, absence of a limb, etc. automatically reduce your quality of life or have a directly negative impact on your well-being, these are all conditions for which you could legitimately seek medical intervention and assistance, and which could legitimately be said to affect your health in some way. This doesn’t make them bad in the normative sense, it doesn’t mean that “cures” are obviously the best thing, and it doesn’t entail that disabled people are always less healthy than their nondisabled peers. And it also, of course, doesn’t mean that disability can be fully explained by or reduced to biomedical pathology. But whatever the best account of “pathology” ultimately is, it seems clear that most physical disabilities involve pathology.⁶

And yet, it’s also clear that, for many disabilities, people live long and full lives with them. The standard normal function account, however, relies on the idea that negative departures from normal function – which are coextensive with pathology – reduce the ability to survive and reproduce. Normal function accounts, perhaps rightly, take many disabilities to be paradigm cases of pathology. And yet people with these disabilities often live perfectly normal lifespans and have children without problems. And so, to capture what are by its own rights paradigm cases of pathology, the normal function account must have some way of specifying how a functional *ability* can be reduced even when its actual practice does not seem to be reduced in any way. Call this the counterfactual problem. In what follows, I will argue that normal function accounts do not have a good answer to the counterfactual problem.

I. SPECIES-TYPICAL FUNCTIONING

Let’s start by looking at by far the most well-known normal function account of health: the “biostatistical theory” that originates from the work of Christopher Boorse.⁷ Though the details of the account have evolved over time,⁸ the basic picture has remained relatively constant since Boorse first proposed it over forty

⁵ Tom Shakespeare, *Disability Rights and Wrongs Revisited* (2014).

⁶ This point is politically as well as theoretically important. Access to health care and health-related interventions are especially important for disabled people, and a key part of the disability rights platform. Lack of access to health care is particularly disadvantageous to disabled people at least in part because disabilities often or typically involve some biomedical pathology.

⁷ See Boorse, *Health as a Theoretical Concept*, *supra* note 1 (for the seminal presentation).

⁸ See Boorse, *A Second Rebuttal on Health*, *supra* note 1 (for a detailed discussion).

years ago. And while other defenders of normal function accounts depart from Boorse in various ways, this has largely been a matter of quibbling with details.

For Boorse, normal function is defined in terms of statistical typicality. An organism functions normally if it functions in a way that is statistically typical for comparison classes of its particular species matched for age and sex.⁹ In this context, the functioning of a part or process is the ability of that part or process to accomplish its basic biological goals or purposes (e.g., the function of the kidneys is to filter waste, the function of the cardiovascular system is to circulate blood, etc.). Boorse then construes the function of the entire organism – that is, its basic biological goals or purposes – as survival and reproduction. And so, an organism is functioning normally if it is able to accomplish its basic biological goals of survival and reproduction at a level that is statistically typical for members of its species matched for age and sex.

The normal function of an organism can be understood, according to Boorse, in terms of the normal function of its parts and processes. A part or process is functioning normally if it is making a species-typical contribution to the organism's ability to survive and reproduce. An organism is functioning normally if all its parts function normally.¹⁰ Likewise, an organism is functioning abnormally if one or more of its parts or processes is making a lower than typical contribution to its ability to survive and reproduce.¹¹

It's important to emphasize that not all departures from normal function are pathology. One way to function abnormally is to function unusually well. Boorse construes pathology as *negative* departures from normal function – departures from species-typical function that hinder the organism's ability to survive and reproduce.¹² For a part or process to be pathological, it must interfere with an organism in the

⁹ The comparison class that determines statistical typicality has to be matched for both age and sex for the model to stand a chance of giving a workable account of “normal” function. Absence of menstrual cycles, for example, is abnormal in a 25-year-old female (assuming she isn't pregnant), but normal in a 25-year-old male and in a 65-year-old female.

¹⁰ Boorse doesn't specify how we determine which things count as the parts of an organism, and this might turn out to be a fairly complicated question. Parasites and harmful bacteria that live in our intestines are, I take it, not our parts in Boorse's sense, given that their normal function is inversely correlated with ours. But our normal function does require the normal function of lots of intestinal bacteria, so we can't simply say that parasites and harmful bacteria aren't our parts because they are in some sense separate organisms – at least if we're going to have a view according to which the functioning of the organism is determined by the functioning of its parts. (And counting things as our parts just in case their functioning makes a positive contribution to our functioning looks circular.) More strongly, it's just not at all obvious that the functioning of complex organisms like humans is reducible to the functioning of their individual parts. Current microbiome research suggests we have something like an ecosystem in our digestive tracts – a system which we depend on for health, but which isn't (obviously) reducible to the individual bacteria that it contains.

¹¹ This claim will clearly need a bit of modification, however, since you can function abnormally by missing a part. We'll return to the issue of what is meant by a part or process making a lower contribution to survival and reproduction.

¹² There's some lack of clarity in the various presentations of Boorse's account over whether we should read the claim about goals as a disjunction (“survival or reproduction”) or a conjunction (“survival and

sense that its contribution to the organism's survival and reproduction falls below the species-typical norm.

Boorse emphasizes that the goals of survival and reproduction are to be understood in evolutionary terms – they are the “goals” of an organism trying to pass on its DNA. So, the physical organism that is your body can be said to have the goal of reproduction, according to Boorse, even if you spend a lot of effort trying to avoid reproduction. States that interfere with this goal count as pathological in Boorse's sense even if they are desired and acquired by medical intervention (e.g., tubal ligation or vasectomy). And what matters for an evaluation of health or pathology is an organism's ability to meet these goals, which might come apart from whether the goals are actually attained. So, for example, you don't count as diseased if you simply remain celibate and never reproduce; in such a scenario, you could still have the *ability* to reproduce, and ability to reproduce – rather than actual reproduction – is what matters to a normal function analysis.

To put it succinctly, for Boorse, health is the absence of pathology. Pathology is a negative departure from normal function. And negative departures from normal function are departures from species, age, and sex-typical function that reduce the ability to survive and/or reproduce.

There are, of course, many well-rehearsed objections to this view. Some object to the very idea that organisms can be said to have “functional goals” as Boorse describes them – at least in any sense that's naturalistic.¹³ Others worry that the account, as stated, can't give a workable definition of pathology, even if we grant that the idea of “normal function” is naturalistically plausible. One serious problem, for example, is the presence of common pathology – especially given that Boorse's analysis must incorporate statistical normalcy for reference classes matched for both age and sex.¹⁴ This creates problems when we consider health conditions that are incredibly common in aging populations. Almost half of adults age sixty-five or older, for example, have been diagnosed with osteoarthritis, and a substantial percentage of adults over forty have been diagnosed as well.¹⁵ Given that statistical

reproduction”). The conjunctive reading has been objected to, since ostensibly some things which enhance your chances at reproducing might limit your chances at surviving. In light of this, Boorse explicitly revises to the disjunctive reading. See Boorse, *A Second Rebuttal on Health*, *supra* note 1. But the disjunctive reading is arguably too expansive. For example, there are many things that might detract from an organism's ability to reproduce that aren't pathological (same-sex attraction, preference for nonpenetrative sex, and so on).

¹³ See Elliot Sober, *The Nature of Selection* (1984). See also Ron Amundson, *Against Normal Function*, 31 *Studies in Hist. & Phil. of Sci. Part C: Studies in Hist. & Phil. of Biological & Biomedical Sci.* 33 (2000).

¹⁴ See, for example, Rachel Cooper, *Disease*, 33 *Studies in Hist. & Phil. of Sci. Part C: Studies in Hist. & Phil. of Biological & Biomedical Sci.* 263 (2002); Peter H. Schwartz, *Defining Dysfunction: Natural Selection, Design, and Drawing a Line*, 74 *Phil. of Sci.* 364 (2007) (for discussion).

¹⁵ And some studies suggest that doctor-diagnosed arthritis substantially underestimates the frequency of painful and limiting arthritis. Arthritis Foundation, *Arthritis by the Numbers: Book of Trusted Facts & Figures* (2018), available at www.arthritis.org/Documents/Sections/About-Arthritis/arthritis-facts-stats-figures.pdf.

atypicality for comparison classes matched for age and sex is a necessary condition for pathology, it doesn't look like Boorse's model can consider arthritis in older adults pathology, even though it's a significant health problem.¹⁶

In what follows, however, I want to present a different angle of criticism to normal function accounts. By specifically focusing on cases of disability, I'm going to argue that the normal function account can't adequately describe a notion of "ability" – as it pertains to the ability to survive and reproduce – that is sufficient to ground a theory of pathology.

II. THE BASIC PROBLEM

Looking at normal function accounts through the lens of disability highlights a unique problem for such accounts – one which has received very little discussion amid all the wide-ranging debates over normal function and health. Defenders of normal function-based views – including Boorse, Wakefield, and Hausman – take disabilities as paradigm cases of negative departures from normal function. And yet, to state the obvious, there are many, many disabilities which do not, in a modern industrialized context, prevent the individuals that have them from having children or living a normal lifespan. Disabilities such as these allow us to press specifically on what is meant by ability in the context of normal function accounts of health.

Let's begin with Boorse's view. Boorse insists that it is the actual, current contribution to survival and reproduction that matters when assessing function.¹⁷ This is, he thinks, essential to the medical understanding of pathology, and it is the medical understanding of pathology (and, correspondingly, health) which he takes himself to be theorizing. Now consider deafness as an example. Deafness is something Boorse wants to count as a paradigm example of negative departure from normal function – that is, a statistically atypical type of functioning which impedes a person's ability to survive and reproduce. To make clear what should be obvious, however, Deaf people can live perfectly long lives and can have children without difficulty. (That is, deafness does not by itself affect life expectancy and doesn't have any impact on fertility.¹⁸) So how are we to understand the claim that deafness

¹⁶ What's more, it doesn't look like a viable option for Boorse to simply say that common health problems like arthritis are not really pathology, since he adamantly maintains that the "target concept" of his analysis is the understanding of pathology employed in medical practice, and medical practice certainly understands arthritis and other common ailments as pathology. Boorse discusses the possibility of making age-comparison classes less fine-grained, and so having "adult" simply be the comparison class – but grants that this removes the possibility of distinguishing normal aging (including menopause, graying hair, etc.) from age-related pathology such as arthritis. See Boorse, *A Second Rebuttal on Health*, *supra* note 1.

¹⁷ He's not, for example, considering the contribution to survival and reproduction traits may have made when they were selected and passed on during an evolutionary process that occurred millions of years ago.

¹⁸ There is correlation between deafness and lower life expectancy in some populations, but these correlations appear to be mitigated by two factors: the cause of deafness and its socioeconomic impact. So, for example, infectious disease is a major cause of deafness internationally, but in these cases it is

negatively impacts the ability to survive and reproduce, given these basic facts about deafness? Call this the “counterfactual problem.”

I’m going to assume that proponents of normal function accounts are aware that deafness – alongside many other disabilities – doesn’t detract from lifespan or fertility, at least in a modern industrialized context. We are left with the puzzling question of how to understand the contention that, on a normal function account, disabilities like deafness are paradigm instances of pathology. Clearly, deafness does not *actually* interfere with survival or reproduction for many Deaf people. So, there must be a substantial amount built into “ability.” For the account to deliver the intended results, the thought must be that something like deafness can have a negative impact on an individual’s ability to survive and reproduce without actually shortening their lifespan or preventing reproduction. This is an odd reading of ability, to be sure, but let’s see if we can make sense of it.

III. FUNCTIONAL EFFICIENCY

It’s true, of course, that, in cases of deafness a person’s auditory system does not function in a way that’s statistically typical. Perhaps the basic thought is that, although their overall survival and reproductive abilities are not statistically atypical, their auditory system’s *contribution* to those abilities is. As Boorse says, the “normal function of a part or process within members of the reference class is a statistically typical contribution by it to their individual survival [or] reproduction.”¹⁹ By focusing on the contribution to survival and reproduction of a particular part or process, perhaps we can understand deafness as pathology in terms of the abnormal function of that part or process (the auditory system or the process of hearing), without needing to appeal to an actual reduction in lifespan or fertility.

But this strategy alone is insufficient. Recall that for something to be pathological, it can’t merely be atypical. There might be lots of ways in which a person’s hearing could atypically contribute to their overall function without being pathological in Boorse’s sense – including by being especially sensitive or acute. This is precisely why normal function accounts define pathological function – as opposed to merely abnormal function – as something which detracts from survival and reproduction. So even if deafness means that a part or process makes an atypical contribution to an organ’s overall function, it doesn’t follow – by the standards of Boorse’s own model –

the infectious diseases and not the deafness that are causing shorter life expectancy. Similarly, deafness is often associated with poverty, and poverty is frequently associated with lower life expectancy, but again it seems that it is the health impact of poverty, and not deafness, that causes the reduction in life expectancy. A major UK study comparing Deaf and hearing populations found that Deaf people often have poorer health outcomes, but for health factors such as blood pressure and diabetes, which are medically unrelated to deafness. They did not find evidence of variation in life expectancy. See Emond, Alan et al., *The Current Health of the Signing Deaf Community in the UK Compared with the General Population: A Cross-Sectional Study*, 5 *BMJ Open* e006668 (2015).

¹⁹ Boorse, A Second Rebuttal on Health, *supra* note 1, at 684.

that it's pathological. For that, we need to be able to say that there's some way in which deafness detracts from the individual's ability to survive or reproduce.

Here both Boorse²⁰ and, especially, Hausman²¹ put a great deal of emphasis on the idea of "functional efficiency." Individual parts and processes have functional goals, which they can accomplish more or less efficiently; if a part or process falls below the species-typical norm for achieving its end goal, it is pathological.²² We can then say that deafness is pathological because the functional goal of the auditory system is hearing, and Deaf people function less efficiently with respect to that process, regardless of their overall lifespan or fertility.

But this is too quick. The human species is full of examples of "normal anatomical variation" – missing muscles, extra muscles, extra nerve branches, extra bone, etc. – which cause body parts to function somewhat differently but are not considered pathology.²³ Likewise, a process in the human body can be abnormal without being pathological – variation in the length or regularity of the menstrual cycle, for example, is a relatively common abnormality in women and is not by itself pathology.²⁴ And humans can function far below the typical level of functional efficiency for a particular part or process without thereby being considered to have pathology. The most straightforward example of this is missing anatomy. The palmaris longis tendon in the wrist is completely absent in a significant subset of people, and obviously for these people that part does not function at typical efficiency or meet its functional goals (movement of the wrist). But absence of the palmaris longis is considered a normal anatomical variant and is not pathological.²⁵

Cases like these are precisely what push Boorse toward the emphasis on overall goals of survival and reproduction. In characterizing pathology, we need

²⁰ See generally *id.*

²¹ See Hausman, Health, Naturalism, and Functional Efficiency, *supra* note 1; Hausman, Health and Functional Efficiency, *supra* note 1.

²² Boorse uses the example of the heart's pumping blood versus the sound it makes when doing so. If a heart pumps blood at a lower rate than is normal for the species, then it is pathological, because pumping blood is the functional goal of the heart; but if it pumps blood a bit more quietly than is normal that is not pathology, because the sound a heart makes when beating is not its functional goal – the sound a heart makes plays no role in the organism's survival and reproduction. See Boorse, A Second Rebuttal on Health, *supra* note 1.

²³ See, for example, Ralf Tunn et al., *Anatomic Variations in the Levator Ani Muscle, Endopelvic Fascia, and Urethra in Nulliparas Evaluated by Magnetic Resonance Imaging*, 188 *Am. J. of Obstetrics & Gynecology* 116 (2003); Richard Bergland et al., *Anatomical Variations in the Pituitary Gland and Adjacent Structures in 225 Human Autopsy Cases*, 28 *J. of Neurosurgery* 93 (1968).

²⁴ Note that if we consider the function of menstruation to be the shedding of the uterine lining, then an unusually long menstrual cycle would be subnormal function (although clearly not pathology in anything like the medical sense of the term). Yet a longer menstrual cycle can be advantageous in other ways, given that the woman loses blood less often. Functional efficiency is hard to objectively quantify here. Kirstine Münster, Lone Schmidt, & Peter Helm, *Length and Variation in the Menstrual Cycle: A Cross-Sectional Study from a Danish Count*, 99 *BJOG: An Int'l J. of Obstetrics & Gynecology* 422 (1992).

²⁵ See, for example, N. W. Thompson et al., *Absence of the Palmaris Longus Muscle: A Population Study*, 70 *Ulster Med. J.* 22 (2001).