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Naturalism and the social model of disability: allied or antithetical?

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ABSTRACT

The question of how disability should be defined is fraught with political, ethical and philosophical complexities. The social model of disability, which posits that disability is socially and politically constructed and is characterised by systemic barriers, has enjoyed broad acceptance that is exemplified by the slow but steady progress in securing civil rights for persons with disabilities. Yet, there remains a palpable tension between disability studies scholars and activists and bioethicists. While philosophers and bioethicists should heed the theories developed from the standpoint of persons with disabilities, disability activists should acknowledge the possibility that philosophical theories about the basic reality of disease, illness, health, function and impairment offer a more steady foundation for social or political critiques of disability. I argue that naturalistic theories of function and dysfunction provide a valuable starting point to clarify questions about the broader concept of disability. A naturalist theory of function may serve as the core of the concept of disability and provide disability scholars and bioethicists alike a stronger set of arguments in analysing real or potential instances of disability.

The question of how disability should be defined is fraught with political, ethical and philosophical complexities. Nonetheless, it seems safe to say that the social model of disability, which posits that disability is socially and politically constructed and is characterised by systemic barriers, has enjoyed broad acceptance that is exemplified by the slow but steady progress in securing civil rights for persons with disabilities. The social model, as Amundson, Shakespeare and others point out, was created by disability rights political activists and not by philosophers or bioethicists. And there remains a palpable tension between disability studies scholars and activists and bioethicists; at times, the former may accuse the latter of ableist bias, and the latter may argue the former are irrational or illogical.³ While philosophers and bioethicists should heed the theories developed from the standpoint of persons with disabilities (a disciplinary distinction that is not mutually exclusive), disability activists should reciprocally acknowledge the possibility that philosophical theories about the basic reality of disease, illness, health, function and impairment might offer a more steady foundation for social or political critiques of disability.

In this brief paper, I wish to argue that, notwithstanding their limitations and if understood correctly, naturalistic theories of function and dysfunction provide a valuable starting point to clarify questions about the broader concept of disability. I concede that a robust concept of disability should be contextual and moderately normative. However, recognition that a naturalist theory of function may serve as the core of the concept of disability can provide disability scholars and bioethicists alike a stronger set of arguments in analysing real or potential instances of disability.

It would seem such a tack—to turn towards a naturalistic argument—is somewhat naive given the vast amount of critical literature attacking such theories of health, disease and illness. This is because, as I mentioned, the social model of disability has prevailed in providing a powerful account of the day-to-day experiences of persons with disabilities. Indeed, one crucial aspect of the concept of disability should be based on critical analysis of social and political power structures insofar as those structures impose an unjust burden on disabled individuals.5 However, theories based solely on an aggregate of personal experiences—while valuable empirically may not be as normatively powerful as those with a more unified ethical substratum. Regrettably, particular foundational concepts and distinctions characterising disability—despite being substantially described by philosophers, activists and clinicians are often ignored, repudiated as overly reductionistic or deemed superfluous.6

I wish to therefore address the specific question of whether or not a naturalistic concept of function is itself useful, and if so, whether it would be to some pragmatic advantage of activists and allies to employ this concept towards their philosophical and political ends. I believe it is and I argue that this version of naturalism in nosology, if understood correctly, can be used to anchor our larger ontology of disability. Naturalism provides the conceptual resources to first recognise instances of dysfunction, second, to evaluate dysfunctions as potential impairments, and third—after accounting for social values and structures—to recognise constellations of dysfunction and impairment as instances of disability. Therefore, what I am hoping to do is to clarify the most basic concept of function, so that we can use more precise language when debating the derivative definition disability.





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ⁱI resist using the term 'medical model' to describe the antithesis of the social model. Medicine is a normative human enterprise, complete with professional standards, internal morals, and far reach into economics, education and other areas of life. The term 'naturalism' narrows the scope of my account.



Theoretical ethics

In aiming towards a clearer concept of function, I will focus on Boorse's biostatisical theory. But my approach will also complement and resonate with earlier naturalist theories that have called for clarity about the basic concepts of medicine and with allied theories that define disability in biostatistical terms. For example, as early as 1959, JG Scadding argued that the term 'disease' was in general use without precise definition or critical examination, encompassing signs, symptoms and entire complexes of abnormal phenomena. Likewise, Nordenfelt's theory of action generation relies on a precise understanding of objective biological function in order to determine the points along the causal chain from basic to complex actions. In this way, it is congruent with naturalism.

Let me first mention a few of the characteristic points of contention in the debate surrounding the objectivity of function and suggest that many of the objections miss the point.

DYSFUNCTION AS EMPIRICAL

Let us begin with an example: large atrial septal defects (ASDs) are holes in the heart that occur when the fetal foramen ovale fails to close completely. These can occur across a range of severity; some require surgery and some ASDs are more or less harmless. Since we know that the majority of adult hearts do not have holes across their septa, we can say that it is (1) atypical of species with four chambered hearts to have holes across the atrial septa in adulthood and (2) that in cases where there exists a septum, the efficiency of the heart is compromised, which may lead to problems at the level of organ systems and the individual as a whole. It is true that adults with ASDs can live their whole life without knowing of the ASD. Yet this possibility does not mean that the ASD is not a dysfunction.

The key here is to take account of the dysfunction as real and potential cause of impairment by first noticing that there is a deviation in what is empirically determined to be the statistically normal form and function of the heart. This again is meant as a statistical measurement and not a value judgment. Once we determine that ASDs are atypical and that they increase the risk of other problems, we can confidently say they represent a dysfunction. I have not implicated in any way social or political values in this appraisal of function, any more than a chemist might in her observations of tracings on a mass spectrometer printout that describes the structure of a molecule.

This description of function reflects one that would probably be offered by Christopher Boorse, who offers the most widely cited naturalistic theory of health, disease and illness. ¹⁰ His account rests on the concept of species typical function—which is meant as an empirical and descriptive accounting of the range of form and function of an individual's parts: their physiologies, physical organs, tissues, cells and genes perhaps. Mental dysfunction is similarly appraised as those psychological states that are atypical and harmful to the survival and flourishing of the organism. Catatonic schizophrenia is a clear example. ¹¹

For Boorse, organismic dysfunction or gross impairment are value-free, empirical realities in cases of disability. Also strong objections have been raised against Boorse's biostatistical theory. But do these objections hit their target or do they rely on straw men representations of Boorsian naturalism?

One well-developed and persistent objection comes by way of Bill Fulford who claims that Boorse's concept of function is covertly normative. Fulford develops this objection first by highlighting Boorse's use of what he calls 'evaluative' terminology in discussing instances of dysfunction and disease. Fulford essentially argues that the term 'dysfunction' cannot be employed descriptively—particularly in the context of medicine—without

it betraying a value judgment about that which is deemed 'dysfunctional. 12 Without delving too deeply into the particulars of the philosophy of language here, Fulford might be on to something about the difficulty of abstracting a concept like biological function away from its medical context (at least in nosological theories) without keeping the residue of certain evaluative elements created by the original context. Engelhardt has argued this point in a similar fashion. 13

Fulford's second objection is related to his first and aims at the heart of Boorse's concept of function by taking issue with the broader attempt by philosophers of biology to disentangle function and teleology in a meaningful way. Fulford claims that any account of function that takes teleology seriously must in some way be evaluative. But for both of these objections, Boorse supplies reasonable and, in my opinion, compelling rejoinders. First, Boorse answers Fulford's linguistic attack by showing that his use of words to describe states are not evaluative and Fulford seems to be excessively reading norms into Boorse's statements. Fulford, as Boorse notes, accuses him of using an oddly expansive list of evaluative terms. To wit, according to Boorse, Fulford even claims his use of the word 'kidney' is value-laden.¹⁴

One of the potentially stronger objections to Boorse's theory of dysfunction-as-disease is the popular claim the Boorse conflates 'difference' with 'dysfunction'. One strain of this claim turns on the basic evolutionary fact that difference is good; after all without a range of differences a species is in evolutionary peril. Another strain of this objection analogises between Boorse's concept of normal function and the reification of race, which was historically legitimised by what we now know to be pseudoscience in pursuit of more insidious economic and social goals. Boorse would argue his opponents should not misconstrue his definition of dysfunction as being synonymous with a folk definition of 'difference.' In fact, his concept of function allows for an infinite array of differences. It is only those very specific differences that undermine the ability of the organ or system to achieve the individual's larger goals of survival and reproduction that are salient to Boorse.

These are just a couple of the dozens of points of debate between Boorse and his critics. Nonetheless, despite Boorse's many replies and clarifications, this same set of objections has appeared and reappeared in the literature since the 1970s. For example, Bolton in 2008 reiterated the claim about difference-dysfunction conflation as being one of the more devastating objections to Boorse's concept of function. This objection, Bolton claims, is even more potent today because it has been amplified by those in the disabled community:

Whatever may have been the attraction of Boorse's analysis several decades ago, as a response to the 1960s controversies, it is particularly problematic now in its proposal that mere statistical difference from some population norm constitutes disease or some mental equivalent. It invites the protest from individuals with such conditions—now that they have a voice—that difference is being pathologized and hence disqualified. ¹⁵

Bolton's confidence in this objection might be well placed in a certain political sense, but I think it misses the mark in refuting Boorse's actual theory. Simply because Boorse's argument is now considered to be politically distasteful does not, in fact, make it theoretically unsound.

And so, my point in presenting these thumbnails of objections to Boorse's concept of function is simply to provide enough background to claim that, while Boorse has been subjected to withering criticism over the past four decades, his concept of biological function stands up well to those attacks, particularly because most objections turn on misunderstandings of his position. Boorse's core concept of species typical function seems to be about as objective as it gets when talking about any scientific concept. He himself admits scientific concepts will always be impregnated with a certain amount of 'value' brought to their investigation by the human investigator.

Does this mean that laws, theories or concepts like gravity, quantum mechanics or ideal gasses should be under suspicion as normatively biased social constructions? And is the positivistic standard impossibly high for concepts related to human health, disease and illness? Perhaps the level of 'value-ladenness' found in the theories of particle physics or chemistry instil in us less worry because theoretical constructions in the physical sciences seem more 'objective' in the positivistic sense, and because these theories do not have a direct impact on the daily life of those with chronic illnesses or disabilities. The values that are used to prioritise research initiatives, for example, in particle physics are not as personal as those that influence research on assisted reproduction or mental illness.

To be clear then: naturalism on disability should not be taken as an assault on diversity. It is meant as an empirical appraisal of the unique capabilities across individuals—not of individuals—and across a spectrum of specific human capacities. Granted, naturalistic assessments of function can be worrisome because they sometimes justify misapplication; assessments must be done with caution.

A NATURALIST-SOCIAL MODEL HYBRID

Consequently, it seems possible that we can ground our concept of disability in core cases of dysfunction and then show that these facts are clearly distinguishable from normative claims about disability. Similar to Boorse's and Wakefield's respective concepts of illness and mental disorder, I believe disability to also be a two-part concept. ¹⁶ Disability involves first a deviation in species typical functioning and then a social evaluation of harm. Indeed, WHO's constitution implicitly accounts for biological function and social context, while WHO's International Classification of Functioning, Disability and Health framework does so explicitly. ¹⁷ Similarly, the Americans with Disabilities Act defines disability in terms of an impairment that limits major life activities. Although some naturalists might argue that these definitions are overly broad, I won't address this debate here.

The next question is whether—after getting function right—this concept may be used to achieve the political goals of persons with disabilities and their allies. This is to say, can a naturalistic concept of function work alongside social models of disability? I think it can. In debates about the social and political dimensions of disability claims about biological facts are often commingled with ethical claims. The possibilities of naturalism come to light when we recognise its theoretical usefulness in developing arguments to defend the rights of persons with disabilities.

Though it is highly unlikely that an unabashed naturalist like Boorse would defend the social model of the concept of disability as philosophically coherent, he is certainly not naive about the social dimensions of disability. He has argued that disability is an explicitly normative construct, the definition of which varies according to specific contexts, needs and goals of the person affected. He writes: "...of two medically identical people only one may be disabled. The same elbow tendinitis may disable a pitcher but not a soccer player... Second, a paradigm of disability in one context may not be a disability at all in

another. Blindness and psychosis are core cases of disability in many contexts, but neither justifies special parking rights: patients with schizophrenia can park anywhere, while blind people cannot park at all." 18

It therefore seems a key point of confusion in the debate between naturalists and social model advocates is the result of sloppiness—or misinterpretations—of fact and value claims. In both camps, it seems, the is-ought distinction collapses around haphazard statements related to function, impairment, disability and social worth. Activists and allies conflate the concepts of impairment and dysfunction with social barriers that cause disability and unnecessarily complicate some rather straightforward ethical claims. For example: that it is possible to assess an organ as objectively dysfunctional—such as in the case of ASDs (an opening where there should be a closure) or duodenal atresia (a closure where there should be an opening).

We should note here that social model advocates often implicitly accept a naturalistic concept of dysfunction; they recognise certain dysfunctions as such, particularly when they are incompatible with life. Cases involving babies diagnosed with Down syndrome and duodenal atresia illustrate this point. In the cases of Baby Doe and the Johns Hopkins Baby, duodenal atresia was left untreated. Yet a key argument deployed by disability rights advocates was that such a dysfunction ought to have been fixed. Thus, the concept of an objective biological dysfunction is used quite readily even by proponents of the social model.

ACHIEVING SHARED GOALS

An accurate understanding of the naturalist concept of function provides a promising theoretical strategy for developing just policies and enlightened attitudes about disability because, if we get function right, we can more clearly see cases where ableism is occurring and where value claims may be smuggled in the cargo of 'brute facts'—a term Vehmas and Mäkelä adapt from Searle.ⁱⁱ By accepting there exists a distinction between brute facts and evaluative claims, arguments that disability emerges from social values will be strengthened. We will see more clearly where the definition of disability is being haphazardly applied or misapplied. We can thus draw finer distinctions between normatively constructed social structures that create disabilities on the one hand and immutable facts on the other. Vehmas and Mäkelä offer a related point with regard to the concept of impairment:

Medicine has traditionally recognised one-sidedly the brute level of impairments whereas disability studies has concentrated merely on the institutional level and ignored, chiefly for political reasons, the biological facts related to disablement. The medical community has now acknowledged...the nature of disability as a social phenomenon. However, for disability studies the recognition of impairment, its nature and effects on people's lives, still seems to be a nut too hard to crack. The close relationship of the brute (biological) level with the institutional (social) level is something which the disability studies perspective should finally recognise, accept, and deal with.¹⁹

Likewise, the goal of this paper has been to bridge the gap between naturalists and social model advocates with regard to biological function, by clarifying the concept once more.

ⁱⁱWe should note that although Searle argues that biological functions are technically not brute facts (like mountains or rivers) and are observer-relative, they remain objective in the sense that they are predicated on the value of survival of an organism.

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Accordingly, a naturalistic understanding of function provides the necessary conceptual anchor for a more coherent concept of disability, without which we will continue to be buffeted about by conceptual ambiguity in the seas of social and political values.

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REFERENCES

- 1 Amundson R. Disability, ideology, and quality of life: bias in biomedical ethics. In: Wasserman D, Bickenback J, Wachbroit R, eds. Quality of life and human difference. Cambridge, UK: Cambridge University Press, 2005:101–25.
- 2 Shakespeare T, Watson N. Defending the social model. *Disabil Soc* 1997;12 (2):293–300.
- 3 Kuczewski M. Disability: an agenda for bioethics. Am J Bioeth 2001;1(3):36-44.
- 4 Drake S. Euthanasia is out of control in The Netherlands. *Hastings Cent Rep* 2005;35(3):c3.
- 5 Hull R. Disability and freedom. In: Kristiansen K, Vehmas S, Shakespeare T, eds. Arguing about disability: philosophical perspectives. New York, NY: Routledge, 2009:93–104.

- 6 Edwards S. Dismantling the disability/handicap distinction. J Med Philos 1997: 22:589–606
- 7 Nordenfelt L. The importance of a disability/handicap distinction. J Med Philos 1997:22:607–22.
- 8 Scadding JG. Meaning of diagnostic terms in broncho-pulmonary disease. Br Med J 1963;2(5370):1425–30.
- Nordenfelt L. On disabilities and their classification. Linköping: University of Linköping, 1997.
- Boorse C. Health as a theoretical concept. *Philos Sci* 1977;44(4):542–73; Boorse C. On the distinction between disease and illness. *Philos Pub Aff* 1975;5 (1):49–68; Boorse C. A rebuttal on health. In: Humber JM, Almeder EF. What is disease?. Totowa, NJ: Humana Press, 1997:3–134.
- Boorse C. What a theory of mental health should be. J Theory Soc Behav 1976;6 (1):61–84.
- Fulford KWM. Moral theory and medical practice. New York: Cambridge University Press, 1989; Fulford KWM. What is (mental) disease? an open letter to Christopher Boorse. J Med Ethics 2001;27:80–5.
- 13 Engelhardt HT. The foundations of bioethics. 2nd edn. New York: Oxford University Press 1996
- Boorse C. A rebuttal on health. In: Humber JM, Almeder RF, eds. What is disease? 3–134. Totowa, NJ: Humana Press, 1997:20.
- Bolton D. What is mental disorder? an essay in philosophy, science, and values. New York: Oxford University Press, 2008:115.
- 16 Wakefield J. The concept of mental disorder: on the boundary between biological facts and social values. Am Psychol 1992;47(3):373–88.
- World Health Organization. International classification of functioning. Disability and Health (ICF), 2007:191.
- 18 Boorse C. Disability and medical theory in philosophical reflections on disability. Vol 104. Ralston DC, Ho J, 2010:169–82.
- 19 Vehmas S, Mäkelä P. A realist account of the ontology of impairment. *J Med Ethics* 2008:34:93–5.