Book review


In this thoughtfully assembled volume on philosophical issues in disability and disadvantage, editors Kimberley Brownlee and Adam Cureton have brought together an exciting mix of ‘established’ and ‘up and coming’ philosophers to address issues ranging from how to understand disability to whether and when to create children with disabilities. Showing rare selflessness, the editors have not included their own work in the volume, and have avoided a lengthy introduction, sticking largely to a summary of the topics addressed by the volume as a whole and a summary of the individual contributions. Yet some passing comments in the introduction are ripe for elaboration, such as the reflection that the ‘importance of issues of disability in moral and political philosophy’ struck the editors as they studied at Oxford as ‘people with the same rare visual impairment’ (p. 2). And later that, ‘we should be sensitive to the fact that certain views can express hurtful or wounding messages to those with disabilities, so we need to be mindful of how we assess and present our views about disability’ (p. 12). As I hope to make clear in this review, attention to these two issues — of experience with disability and of mindfulness to the impact of philosophical views and terminology — is of critical importance to philosophical work on disability.

From the very first contribution to the volume, by Guy Kahane and Julian Savulescu, the reader is pulled into controversies over how to understand, or even whether to use, the term ‘disability’. While Kahane and Savulescu argue for a revisionist understanding of the term, focused on reduction of welfare rather than either variation from the species norm constituting an impairment (the ‘medical model’) or lack of accommodation of physical and cognitive difference by social structures (the ‘social model’), other authors distance themselves from the very term ‘disability’. For instance, Anita Silvers discusses ‘outliers’ who are ‘situated at their society’s boundary-lines because they are regarded as so divergent or odd as to verge on being alien’ (p. 165). For Silvers, these outliers may be considered so on the basis of ‘perceived dissimilarities’ that could include, ‘[d]isparities of pigmentation, sex-related traits or behaviors, modes and levels of physical or cognitive functioning, origin or heritage, linguistic or religious practice, talent, and wealth’ among other considerations (p. 165).
But if how to understand ‘disability’ is controversial, one might have thought, at least, that the relationship between disability and disadvantage is straightforward. Indeed, Jeff McMahan suggests that it, ‘may be part of the concept of a disability that it is a misfortune’ (p. 245) and thus, it would seem, that the condition places an individual at a disadvantage relative to (relevant) others. But, of course, if we blow apart the term ‘disabled’ and think instead of Silvers’s ‘outliers’, then it would seem that extreme wealth or talent (certainly not disadvantages) would also place a person at a society’s ‘boundary-lines’.

Part of what is at issue in these discussions that take place across the contributions to this volume is who should count as disabled. Indeed, while pointing to radically different visions of why a person might fall under the relevant framework, both the welfarist model and the outlier model would expand the pool of those included (as ‘disabled’ or as ‘outliers’) quite dramatically beyond the traditional (medical) model of disability. McMahan, by contrast, would contract the group of persons with disabilities by leveraging the commonplace idea that disability is a misfortune in conjunction with the contentious claim that, for those individuals with ‘congenital’ and ‘radical’ cognitive limitation, this is a ‘feature of their individual nature’ rather than a misfortune (p. 244).

Given such profound disagreement over who counts as disabled, Richard Hull’s reflections, in the last essay of the volume, strike a chord. He writes, ‘[i]t clearly was necessary to appeal to what all people with disabilities had in common, in order to build a unified and powerful disability movement’ (p. 376). But, Hull wonders (citing Tom Shakespeare) whether, given the complexity and multidimensionality of impairment, ‘the notion of “disabled people” as a commonality [can] be sustained’ (p. 377). Are we all of us, and so none of us, disabled? Despite the conceptual questions raised in this volume over who should count as disabled, however, Jonathan Wolff helpfully reminds the reader that ‘anti-discrimination policy appears to need a clear and useful way of picking out a class of people for special protection, and, it may seem, the common sense view [of bodily or mental impairment] is essential’ (p. 127).

Assuming, then, that there is still some value to grouping together some persons as disabled, most contributors to this volume, to their credit, embrace neither a simple medical model, nor a simple social model, when it comes to explaining why a person is disabled. As Wolff puts it, generally speaking, disability ‘must lie in the intersection between an individual’s personal resources and external conditions’ (p. 125), thus disability is neither wholly intrinsic to the person nor wholly socially constructed. In going on to discuss the example of eyeglasses for vision impairment, Wolff points out that this highly successful intervention does not ‘remove’ the impairment but still, ‘can prevent impairment being a disability’ (p. 125). At the same time
‘[a] very wealthy paraplegic is still disabled, for although money can help with mobility it cannot currently restore it to the level enjoyed by others’ (p. 125).

Yet beyond recognizing that disability is neither wholly ‘in the person’ nor wholly ‘in society’ we might look more closely, as do Norman Daniels, Susannah Rose, and Ellen Daniels Zide (pp. 54–85), at the potentially differing perspectives of those with and without particular disabilities regarding the quality of life associated with that disability. Perhaps the person with paraplegia and the person who is fully ‘able-bodied’ agree that paraplegia is a disability (even given relative advantages of social and technological adaptation). But, do they agree about the degree to which one’s ‘quality’ of life is ‘lowered’ by the condition? Probably not. As Daniels, Rose, and Daniels Zide review, there is strong (though not univocal) evidence that persons with various different physical impairments rate their own quality of life significantly higher than how those who are not similarly impaired rate life with that disability or condition (pp. 62–3). The authors’ main concern is to point out, however, that when the impairment is caused by brain injury or is psychological, such as with depression, those with the ‘disability’ may actually be more likely to rate their own quality of life as lower than what is perceived by others.

Divergences between groups in rating quality of life with a particular condition are important because they seem to speak to the ways in which experience of disability may be essential to understanding some aspects of life with these conditions. However, as Frances Kamm notes in passing, for purposes of analyzing the cost effectiveness of various interventions, it is commonly members of the general public who are asked (via survey) to rate the quality of life with or without various conditions (p. 269). While Kamm does not address the issue, we might reasonably wonder why it makes sense to rely on those who have not experienced the impairment to judge the quality of a life lived with the impairment.

Daniels, Rose, and Daniels Zide review various reasons that have been offered for the divergence in quality of life ratings (pp. 64–8). Some of these suggestions, such as adaptation to disability and a ‘response shift’ in the background social comparison group, may seem to bolster the use of ratings from those without the disability in so far as the purpose of cost-effectiveness analysis is to develop social policies for resource allocation. For allocation to preventative measures, for example, it might seem important to take into account how much people want to avoid a condition, rather than how they would feel if they had adapted to the condition. But, of course, there should be a better way of taking those (reasonable) preferences into account than misrepresenting the quality of life experienced by those with the condition. Perhaps, then, the argument might be that people with disabilities may exhibit problematic adaptation, such as some ‘response shifts’, which can represent, ‘cognitive deficiencies such as denial of some of the realities of illness or newly suppressed recognition of the nature of full health’
(Paul Menzel et al. ‘The Role of Adaptation to Disability and Disease in Health State Valuation: A Preliminary Normative Analysis’, Social Science and Medicine, 55, 2002, p. 2150). But this suggestion begs the question of whether it is more likely that persons with disabilities will rate their quality of life on the basis of problematic coping mechanisms like denial, or whether those without the disability will misjudge the quality of life with the disability because of lack of understanding or prejudice.

What is at stake in this debate? Independently of outcomes, what is at stake is who speaks for persons with disabilities — who gets to tell their stories and represent their lives. But there is more afoot that is about outcomes. For cost-effectiveness analysis, which rests on a moral foundation of a limited scope utilitarianism (aiming to gain the most healthy life-years for the least cost), what is at stake is how resources should be allocated. In order to evaluate the relative ‘bang for the buck’ of different interventions, quality and quantity of life-years saved (or years lost to disability) are rolled together in ‘summary measures of health’. Importantly, however, in terms of allocation of resources, there is no simple better or worse for those with disabilities in choosing one set of ratings over another. If we imagine, for example, that those with paraplegia on average rate their quality of life as a .8 out of 1 (where ‘1’ is perfect health) while members of the general public rate it at .5 (using, for the sake of the example, Kamm’s hypothetical estimate), using the .8 rating would shift resource allocation beneficially for those with paraplegia in terms of health interventions for other conditions (or, especially controversially, for saving lives) but negatively in terms of allocation of resources to cure them of the condition (since, after all, life with paraplegia is not as bad as was thought).

Now, putting any lower value on treating those with disabilities or not saving lives of those with disabilities because of the ‘quality adjustment’ of life-years saved is precisely what Kamm addresses with her helpful, if somewhat complex, casuistical analysis. Generally speaking, however, while efforts have been made to ameliorate the problem by, for example, inclusion of societal values regarding allocation (Peter A. Ubel, Jeff Richardson, and Paul Menzel, ‘Societal Value, the Person Trade-Off, and the Dilemma of Whose Values to Measure for Cost-Effectiveness Analysis’, Health Economics, 9, 2000, pp. 127–36) or weighting life saving measures differently than other interventions (Erik Nord, ‘The Desirability of a Condition versus the Well Being and Worth of a Person’, Health Economics, 10, 2001, pp. 579–81), the problem of seeming discrimination against those with disabilities is one that continues to plague cost-effectiveness analysis’ use of summary measures of health. While cost-effectiveness analysis is part of the UK system of health care allocation, in the US context the concern about discrimination against persons with disabilities has been a thorn in the side of practical attempts to use the method from the George H. W. Bush Administration’s rejection of Oregon’s attempt to expand Medicaid twenty

While issues in cost-effectiveness analysis and disability play a minor role overall in this volume, other questions about what persons with disabilities ‘deserve’ are prominently featured. Several authors address questions of distributive justice and disability (see, especially, Lorella Terzi, Wolff, Christie Hartley, and Silvers). Somewhat more contentious, are questions of deservingness of moral and political equality, in particular for those with ‘profound’ or ‘severe’ cognitive limitations. While most authors addressing these issues argue for inclusion in different ways (see, especially, Hartley, Francis, and MacLean), McMahan, toward the end of his essay, connects up his argument about whether or not those with severe cognitive deficiency are ‘disabled’ with a provocative point regarding the relative ‘violability’ of ‘the cognitively limited’ (pp. 258–9).

It is important in the context of thinking about social, political, and moral community inclusion and ‘deservingness’ of persons with disabilities, to note that these questions are ones that disability scholars and researchers have moved beyond. Their shared assumption is of human equality and the same core features of quality of life for all human beings (Shalock et al., as above: 460–1) and their challenge is how to use quality of life measures to raise the well-being of persons with disabilities—cognitive, physical, or otherwise. A particularly curious aspect of the philosophical literature regarding appropriate moral community membership is the focus on questions of relative human versus non-human animal capacities. This vexing issue is addressed, at least in passing, by several contributors to the volume, though is prominently featured only in the article by McMahan.

What should be said about these aspects of the present volume and of the philosophical literature on disability generally? On the one hand, it is for philosophers to ask the unpopular and difficult questions, and we should not shy away from many of these. On the other hand, we must make sure to address these questions in ways that attend to our own personal and professional cultural biases as well as with a profound humility regarding our own limited experiential knowledge. Is it a special bias of philosophers, whose social and financial capital is bound to keen intellect, that lack of cognitive capacity should appear especially troubling? In her particularly thoughtful contribution to the volume, Hartley points to the important role that those
with cognitive difference can have in helping us to retain a sense of humility. The authors in this volume, for the most part, pay heed.

Department of Social Medicine and 
Department of Philosophy 
University of North Carolina at Chapel Hill 
CB# 7240, 348 MacNider Hall 
Chapel Hill, North Carolina 27599-7240 
USA 
rebecca_l_walker@med.unc.edu 
doi:10.1093/mind/fzs101