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Introduction

Rethinking the Good Human Life in Light of Disability

Historically, philosophers have not been greatly interested in disability. Although disability has always been a part of the human experience and therefore a universal feature of humanity, the major figures in the history of philosophy, if they mentioned disability at all, usually spoke of it as the exceptional case or the special issue that, for the purposes of ethical, political, or social theory, could be safely ignored. In the past few decades this has changed dramatically, and ethical and political philosophers in particular have begun to integrate disability issues into their work. Although not the leaders in this trend, bioethicists have perhaps been among the most prominent voices addressing disability.

Much to the chagrin of disability scholars and activists, however, initially this focus was almost entirely negative: having a disability was assumed to be a justification for euthanasia, evidence of disability was grounds for selective abortion, and political theorists looked only at what justice required the state to do by way of compensation for the undeserved misfortunes people with disabilities had to endure. For their part, bioethicists seemed more concerned about justifying the morality of eliminating people with disabilities than with improving their lives (Parens and Asch, 2001). This was ironic because both bioethics and disability scholarship grew out of a rejection of the paternalistic assumptions of the medical community and both expressed themselves ethically in terms of basic human values of autonomy, self-determination, and respect for persons (Asch, 2001).

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As the focus of bioethics has shifted in recent years to issues of social justice, philosophers are taking more seriously the importance of accessibility, inclusion, and equality in health care and social policy generally, and the synergy between disability scholarship and bioethics has accordingly been strengthened. Ethical and political philosophers also take great care to integrate disability into their conceptions of equality and systematic political theorizing. This is unquestionably a positive development for both philosophy and disability scholarship. Still, the bulk of this new literature continues to address very specific social and ethical issues, overlooking what philosophers traditionally understood as the fundamental philosophical questions.

This volume seeks to expand and strengthen the links between philosophy and disability scholarship by focusing on what, by any standard, is one of the oldest philosophical issues: What constitutes the good human life? This question is both one of the oldest and one of the most modern of philosophical topics. All classical philosophical traditions have offered approaches, methods, and systematic answers to it. Modern philosophers, at least since the twentieth century, have pursued a variety of methodologies and tactics to address the good life, if not directly then at least obliquely by focusing on moral and political debates that a conception of the good life would inevitably inform. Questions about moral obligations to oneself and the role and proper scope of the obligations of the state to its citizens, and about the proper distribution of subjective happiness and objective resources, invariably shed light on what, as philosopher Derek Parfit put it, “makes life go well” (1984). Philosophical positions in this domain have shaped ethical theory and political ideology, but also, and perhaps more than at any other time in history, have directly affected law, social policy, and our understanding of the content and significance of human rights.

Disability studies scholarship, at least relative to philosophy, is very much in its infancy. But this scholarship is rapidly growing, in part because of its robustly interdisciplinary methodologies that span the natural and social sciences and the humanities (Cureton and Brownlee,

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2009; Roulstone, Thomas, and Watson, 2012). Born out of a worldwide political movement and invigorated by the successes of that movement, disability studies has continued to pursue, if not an overtly political, then a politically informed research agenda. The fundamental philosophical question of the good human life has not, at least in that abstract formulation, been the direct focus of disability scholarship; instead, disability scholars have found themselves responding to claims and assumptions that impairments per se undermine the prospects of living a good human life. They have taken up that challenge, but only piecemeal and defensively.

Against those bioethicists who, impressed by new reproductive technologies offering the prospect of "preventing disability" by prenatal diagnosis and selective abortion (cf. Buchanan et al., 2000), disability scholars have also had to adopt a defensive posture by arguing that disability is a complex and interactive phenomenon and as such the disadvantages of having a disability cannot be traced to the underlying impairments alone, but to stigma, discrimination, lack of accommodation, and other social factors (Amundson, 1992; Bickenbach, 1993; Silvers, Wasserman, and Mahowald, 1998; Wasserman, 2001). In particular, they have argued that public health practices of prevention, although unobjectionable on their face, also send the clear message that individuals living with preventable impairments have lives not worth living (Asch, 2001). They insist that the prejudice that often occurs during a life with an impairment is itself a discriminatory stance toward disabled people and their lives.

Political philosophers typically address the impact of disability on the good life from the perspective of the implications of disability on distributive justice generally, and the demands of social and political equality specifically. Confronting the hard fact that the combination of increased longevity and medical improvement more or less guarantees an ever-increasing prevalence of persons with disabilities and chronic health conditions (WHO, 2001, 2011), the naive view that political theory can ignore disability as a social justice outlier has been

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recognized as utterly untenable. Political philosophers have debated the consequences of viewing physical and mental impairments as potential decrements in well-being, including the appropriate response by a just society. At this juncture, competing understandings of what disability is direct the discussion: if understood as a purely biological phenomenon only partially within human control, then the situation of persons with disabilities points to some form of charity or social transfers grounded in social solidarity. If understood as entirely or in part a disadvantage created by stigma, discrimination, and lack of accommodation, then a case is made for a human rights–based and antidiscrimination social response. Perhaps the most salient contribution of disability studies to political philosophy has been the insistence that only the latter human rights approach to disability is tenable.

Philosophically, the question of what makes for a good human life arguably presupposes the question of what constitutes a human life of moral value, conceptualized as the grounds of personhood. This in turn raises the question of whether human beings are essentially or merely contingently moral persons, that is, whether some nonhuman animals may qualify as persons, while some human beings with impairments may not qualify. Can some members of *homo sapiens*, in short, have impairments of such kind or severity that they are not persons in the required sense, that is, entities with fundamental moral worth? An engrained philosophical tradition insists that as human moral worth is grounded on rationality – and its preconditions, cognition and consciousness – profound intellectual or cognitive impairments might wholly undermine moral worth, and so the possibility of living the good human life. Against this prejudice, some philosophers have tried to untether moral worth from an overly rational or cerebral conception of humanity to redeem the value of living with severe intellectual impairment. Suggestions of participation in human community, connectedness with others, and membership in the human form of life have been suggested as alternative ways of grounding human worth and the basis for the good human life (Kittay, 2005, 2009; Kittay and Carlson, 2009).

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Other than alternative ways of understanding or modeling disability, the fact that there are competing conceptualizations of the good life further muddies the waters. As might be expected, philosophical approaches to human well-being or the good human life has a long and complex pedigree. Derek Parfit's taxonomy of philosophical positions, although itself controversial, is a good place to start (1984): philosophers have either adopted a purely subjective approach to the good life, with accounts grounded in hedonism, preferences, or desire satisfaction, or have looked toward objective accounts, which Parfit called "objective list accounts," in which efforts are made to identify necessary conditions of the good life. Mooted constituent components of the good life range from Aristotle's "eudemonia" – the good that is constituent of the essence of humanity – to John Rawls's more pragmatic "primary social goods" (1971) and Amaryta Sen's capabilities or opportunism for securing what one wishes to do or be (2009). T. M. Scanlon has helpfully labeled these accounts as "experiential theories," "desire theories," and "substantive-good theories" (1998), or more simply, subjective and objective theories of well-being.

Subjectively, the relationship between impairments and well-being is not straightforward, because of either psychological processes of adaptation to impairment or other fundamental shifts in how an individual deals with his or her impairments so that what was originally viewed as a detriment to the good life is subsequently viewed neutrally, or even positively. Thus, if the good life is understood exclusively in terms of what is called *subjective well-being* (SWB), *happiness*, or *positive life satisfaction*, then we should expect that the experience of living with an impairment, even a serious one, will not necessarily reduce or eliminate the goodness of living, at least as it is experienced by that individual. Objectively speaking, however, it seems more intuitive to think of impairments, at least prima facie, as decrements to the good life, although, as the chapters in this collection argue, this inference too is suspect for many reasons: when an impairment such as blindness or

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lower body paralysis is so thoroughly internalized as to form part of one's identity, it seems insensitive and factually incorrect to continue to insist the impairment is both an objective harm and an essential detriment to that individual's good life.

In the health and social science literature on what makes a life good, which is most often couched in terms of "quality of life," a similar distinction is drawn between objective and subjective quality of life, the former broken down into domains of good things in life, about which there is general consensus. Because of parallel developments from different disciplines, and the general lack of awareness of what is happening outside the researcher's own discipline, significant overlap occurs between the quality of life and well-being discussions, causing considerable confusion in terminology. Until fairly recently, the quality of life work took the lead on developing empirical measurement instruments, which soon became widely used in medicine and rehabilitation as therapeutic outcome measures. Here too the same challenge comes to the fore: What do we make of the considerable evidence that people with severe disabilities, who rank low on objective lists of the good life, report high levels of subjective quality of life? Only fairly recently has the well-being literature followed the trends in quality of life instrumentation and moved from theory to empirical research (Kahneman, Diener, and Schwartz, 1999).

One of the most challenging issues in the growing debate about the effect of impairments on well-being or quality of life is whether it is possible to reconcile two apparently diametrically opposed propositions: first, that the prevention of impairments through public health and safety measures is not merely desirable but a genuine social responsibility; second, that strong self-report evidence demonstrates that people with those impairments live good and valuable lives. The disability community may, in its rush to deny that disability is an utter tragedy that can only ruin one's life, feel compelled to oversteer to say that disability is "just a difference" and the disadvantages a person may experience are entirely the result of social prejudice. More cautious writers point out that impairments are real phenomena, and not infrequently painful and choice limiting, so that even if all social and physical barriers were removed, though the life of a disabled individual would thereby be made easier, disadvantages may nonetheless remain.

Interestingly, a parallel strategic problem has been identified as a political challenge for the disability community at large. Often called the "dilemma of difference" (Minow, 1990), it involves the fact that should people with disabilities and their political advocates concede that impairments, on their own, can have adverse effects on the good life, then they are in effect agreeing with common perceptions that a life with impairments is not worth living. On the other hand, if these advocates insist that impairments have no essential deleterious effect on the good life, if they are, once again, mere "differences," then the advocates seriously jeopardize the case they have to make to the state that positive social response is essential to meet the health and other practical needs impairments create, without which full social inclusion and participation would be impossible.

The central question of this book is, therefore, whether, in any conception of the good human life, disability is an alternative way of living that can be as valuable as any other or whether disability is intrinsically associated with deficiency or defect in the value of life, one that must be tolerated or socially compensated and accommodated. As will become apparent in the chapters included in this volume, this question can be addressed from a variety of perspectives and philosophical methodologies. Despite the diversity of approaches and conclusions, however, all of these chapters share the conviction that disability is a fundamental feature of human existence – neither an outlier to nor an anomaly of the human condition – and that it is well within our grasp to understand the significance of the immense variety of human lives and conditions, and through that understanding to secure the preconditions for achieving the common dignity of all individuals.

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THE CHAPTERS

The volume starts with two chapters that focus on the relationship between intellectual impairment or cognitive disability and the good human life. Benjamin L. Curtis and Simo Vehmas discuss the moral significance of severe intellectual impairment and set out to explore how particular mental characteristics are thought to determine an individual's moral status. In particular, they ask why some philosophers argue that people with severe intellectual disabilities have comparable psychological and emotional capacities to animals. They compare two opposing camps on this issue: the "intrinsic property camp," represented by philosopher Jeff McMahan, and the "special relations camp" associated with the work of Eva Feder Kittay. They conclude by motivating and describing their "hybrid view" of the relationship between intellectual capacity and moral status, a view that sets the benchmark of moral worth at consciousness, which, they argue, is an essential precondition for entering into a relationship with the human community. Barbara Schmitz takes up this issue of the moral status of cognitively disabled people, but turns instead to the important Wittgensteinian notion of the "human form of life" as her benchmark. On this view, a truly human life is made up of a multiplicity and plurality of practices, rather than a single, putatively essential human capacity or characteristic. Cognitively disabled individuals, she argues, must not be viewed, by philosophers or anyone else, as "something else," but, in light of what they have and experience in common with everyone else, as full members of the human community with equal intrinsic moral worth.

As noted earlier, the assumption, shared by philosophers and the lay alike, that all serious or severe impairments are always and indeed necessarily harmful to the good human life, dramatically conflicts with a reliable body of evidence that people with disabilities themselves positively rate their well-being. This clash, sometimes called the "disability paradox" (Albrecht and Devlieger, 1999), is addressed by Thomas

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Schramme in his contribution. He argues there is nothing contradictory about a person with a disability agreeing that having a disability is comparatively worse than not having one, while insisting that, from his or her perspective, it does not adversely affect well-being or the prospects of living a good human life. Because well-being is closely related to one's identity, he argues, it is not unexpected that once a disability has been internalized, its absolute, objective harmfulness will decrease or even disappear. Tom Shakespeare addresses the same perplexity, but in a form more relevant to public policy. He asks how we can reconcile the evidence that many people with disabilities assess their lives positively with the view that prevention of health conditions and impairments is a desirable social aim. He shows that while there are no good reasons for discounting the views of persons with disabilities, it is also naive to deny that impairments limit people's lives and choices, and in a sense are true harms. Because of this, social and public health prevention programs are fully justified, as long as they do not mistakenly reinforce the misperception that disability is a tragedy, that disabled people are useless, or that the prospect of living a good life is forever closed to them.

Halvor Hanisch also addresses this debate, but from a different methodological perspective that takes the discussion in a very different direction. He argues that, ultimately, the question of the impact of disability on the good life depends on what he calls the "recognition of life with a disability" by both the disabled individual and the surrounding community. Integrating the accounts of recognition in the writing of French cultural theorist and psychoanalyst Julia Kristeva and Canadian political philosopher Charles Taylor, Hanisch notes that, in the end, an appreciation of the fact that life with a disability can be a good life crucially depends on resolving the apparent conflict between an acknowledgment of commonality in universal dignity and the recognition of difference, or in other words, the recognition of the goodness in living a fundamentally different kind of human life.

The contribution of David Wasserman and Adrienne Asch takes as given that disabilities need not have a substantially adverse impact on well-being – on any subjective, objective, or hybrid account of that notion – and goes on to explore more deeply the subtle issues that remain and that must be taken into account in the relationship between disability and well-being. They argue it is important to distinguish in this regard between impairments that consist of the loss rather than the absence of a function, between impairments that involve pain, progressive functional decline, and reduced life expectancy and those that do not, and, finally, the different impacts on living caused by the impairments themselves and those that result from social and environmental exclusion. After factoring out the clearly detrimental aspects of disabilities, they try to distill the remaining residue of disadvantage that might account for the intuition that, as a general matter, prevention of impairment is always justified as a social goal.

The relationship between disability and well-being has recently reemerged as a social concern with the advent of the so-called well-being agenda in countries such as the United Kingdom. Jerome E. Bickenbach explores the recent social policy phenomenon of assessing policy in terms of well-being population outcomes, rather than economic or other social indicators. In particular, he scrutinizes the growing disquiet with the agenda voiced by disability advocates who discern in it the potential for identifying the responsibility for unhappiness in the individual, thereby ignoring the impact of external social factors such as discrimination and oppression and legitimatizing a particularly strong version of paternalism. While agreeing that these are potential worries, he warns against overstating the problem by relying on *disability exceptionalism*, namely the view that living with a severe impairment may well be preferable in terms of well-being than living without it.

In many health and allied health disciplines, the standard and widely used tool for assessing how well life is going for a patient is the quality of life questionnaire. Hans Reinders takes up the issue of the validity of quality of life assessment of disabled individuals by considering the story of Sam, a severely handicapped boy who managed not only to survive but, from his own perspective, to lead a high-quality life, despite