Special Section: Dissecting Bioethics

Dimensions of Disability

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This article attempts to clarify the concept of disability by explaining the ways in which it has been applied, and defined, by both philosophers and disability scholars. Conceptual approaches to disability can be divided into two main categories: the individualistic and the social approaches. In the individualistic framework, disability is seen as an individual condition that results in a disadvantaged position regarding civic, economic, and personal flourishing. This is the dominant view of disability in bioethics. According to the social approaches, disability is seen as a result of the oppressive material arrangements in existing societies, or as a corollary of the prevailing cultural values, ideas, attitudes, and language that produce and shape human reality. I argue that disability is essentially a normative concept that reflects the idea of what kind of beings humans ought to be, or, how society ought to be constructed to treat its members equally. In other words, the essential core of the concept of disability is ethical, and this implies that ethical examination is needed to provide a fuller picture of disability as a physical, psychological, and social phenomenon.

Seen from the viewpoint of moral philosophy, disabilities are intriguing entities. This applies especially to intellectual disabilities. Traditional ethical theories consist of assumptions and norms about what makes us distinctively human. For example, in philosophy the concept of a "moral being" denotes a being that merits moral rights and is capable of acting morally. It has been argued that only rational beings can be moral, which implies that nonhuman animals as well as some people with severe cognitive impairment, mental illness, or brain damage are "amoral" beings. Their behavior, even if harmful or otherwise undesirable, is not seen as immoral, but merely as a regrettable, unavoidable consequence of their not knowing better. In everyday morality and in moral philosophy (at least in the works of such classics as Plato, Aristotle, Kant, and Mill), rationality and practical reason are attributed to adult human beings whose intelligence is "normal."[1]

It can reasonably be argued that people with disabilities are, in the light of ethical theories, marginal human beings.[2] This leaves us with three alternatives. The first is to accept the tenets of Western moral philosophy and admit that people with disabilities *are* morally less human than others. The second alter-

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Thanks to Matti Häyry, Tuija Takala, and Tanja Vehkakoski for their useful comments. This paper was produced as a part of the project *Genes, Information, and Business*, financed in 2000–2003 by the Academy of Finland.

native is to reject altogether these ethical theories that marginalize, both socially and morally, people with impairments.

The third option is to question and revise, in the light of disability, these theories that are, after all, supposed to say something essential about all kinds of human life. Philosophical studies of humanity naturally include studies of human disability. Likewise, by examining marginal humanity we inevitably examine humanity in general because by defining what is marginal and abnormal we also define dichotomically typicality and normality; to define inferiority, is to define superiority. The definition of deviance and difference is thus always a dialogical process producing a dual reality.

The aim of this paper is to clarify the concept of disability by explaining the ways in which it has been applied, and defined, by both philosophers and disability scholars.

Individualistic Approaches to Disability[3]

In many traditional cultures and religions, disability has been seen as a sign of the moral flaws of an individual or her progenitors. This means that an infant's impairment is the result of her parents' moral offenses. If a person is impaired later in life, his impairment can be explained by his own moral failures. This view is called the *moral model of disability*. According to this position, disability is a disadvantageous state, usually a visible impairment, visited on an individual as retribution.[4]

In the modern era, impairments have been explained by scientific methods and reduced to an individual's physiological or mental deficiencies. This *medical model of disability* places the responsibility of the individual's deficits to her bad luck (e.g., accidents), to her inadequate health practices (e.g., smoking, bad diet), or to her genes. This position sees disability as the inevitable product of the individual's biological defects, illnesses, or characteristics. Disability is a personal tragedy that results from the individual's pathological condition.[5]

Another individualistic approach to disability, which I will take the liberty of calling the *intersubjective model of disability*, is the view that emphasizes cognitive interaction and affective experience as the basis of disablement. Disability is the product of personal experience and negotiation of social roles between individuals. This means that a person is disabled if he feels so, and it also means that the subjective experience of disablement is an elementary constituent of his self-understanding. The process is largely determined by how the individual positions himself in relation to other people, their identities, and characteristics.[6]

A distinguishing feature of the philosophical arguments concerning disability is that they are almost exclusively based on individualistic premises; disability is represented primarily as an unfortunate individual condition. At first, disability emerged in bioethics in the abortion debate in the late 1960s and the early 1970s. The arguments that set criteria to those beings that have the right to a continued existence, and what the proper indicators of humanhood are, have implications to disability as well. The moral justification of abortion has been largely based on the concept of "person." It has been argued that fetuses, and even infants, are not persons, hence not the sort of entities to which it is proper to ascribe full moral rights. The concept "person" has been defined in a manner that emphasizes mental faculties, which can be seen to result in a position where the personhood of some individuals with severe cognitive impairments is questionable.[7] The concept of personhood with its emphasis on mental faculties, combined with views that impairments are a bad thing for the individual in question, has formed a basis for normative judgments regarding the moral significance of disability. It has been argued, for example, that impairments can be relevant reasons for withdrawing life-saving medical treatment, terminating pregnancies, avoiding conception, and acquiring genetic information to prevent the birth of a disabled child.[8]

Disabilities have also been discussed in philosophical bioethics in the context of justice. Robert Veatch[9] and Allen Buchanan et al.[10] have applied, in a revised form, the egalitarian theory of John Rawls[11] in their examinations of the social and moral status of disabled people. They share the common belief that having mental or physical impairments is an unfortunate state of affairs. Disabled people have lost in the natural lottery, which means that the surrounding society is obliged to compensate for their misfortune. Thus, whatever the particular topic discussed is, disabilities are widely and mainly regarded as individual conditions that result in a disadvantaged position regarding civic, economic, and personal flourishing.

Social Approaches to Disability

According to many disability scholars, individualistic approaches (especially the medical model) are biased and lead to practices and social arrangements that oppress disabled people. Interventions are aimed solely at the “abnormal” individual, whereas the surrounding community is left intact. Resources are not directed to changing the environment but to, for example, medical treatments with the aim to “improve” the impaired individual. This leads to a social and moral marginalization of disabled people and gives permission to debar them from full participation in society.[12]

This criticism has been presented by a large number of theorists who take a social approach to defining disability. Some of them claim that disability is the result of oppressive material arrangements in society.[13] This position (developed mainly in the United Kingdom) is called the *social creationist view of disability*. In this perspective, it is essential to grasp the distinction between physical impairments and the social situation, called “disability,” of people with impairments. Impairment is defined as “lacking all or part of a limb, or having a defective limb, organism, or mechanism of the body,” whereas disability is “the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.”[14] The core idea of the social creationist view is that disabled people are an oppressed social group. Their inferior status is not a natural effect of their impairment, but it is produced by unjust social arrangements. Disability is seen as the material product of socioeconomic relations developed within a specific historical context. In this approach, the main attention is directed to the disabling barriers and material relations of power.[15]

In North America, theorists have developed the *social constructionist perspective to disability*, which sees disabilities as social constructs. This approach emphasizes the significance of ideas, attitudes, and language that, it is argued, produce and shape reality. Words do not merely or primarily represent reality but construct and create it. The concept of mental retardation, for example, exists in the minds of those who use it as a term to describe the cognitive states of other people. It is assumed to be a term expressing an objective, existing state of reality, whereas, in fact, it is a socially created category that primarily reflects the state of mind of those people who use the concept, not of those to whom the concept is applied. This view does not deny that there are differences, either physical or mental, between people, but it states that the nature and significance of these differences depend on how we view and interpret them.[16]

Another social approach to disability—the *postmodernist perspective*—is based on a critique of the hegemony of scientific knowledge, which is seen to work as the foundation justifying both epistemologically and morally the categories of special and ordinary needs. Science, in other words, justifies defining people as "normal" or "mentally retarded." Disability scholars who have assumed the postmodern approach question the validity of science and its hegemony in providing objective truths—there are no such things as objective truths in the first place.[17] Postmodernists emphasize the significance of language that constructs reality. The present vocabulary of, for example, mental retardation is seen as demeaning and oppressive to those people who have been labeled as mentally retarded. Distinctions such as ability versus disability that are based on "scientific" knowledge should be deconstructed and replaced by a language that does not classify some people as "other" (that is, deviating from "normal" and "full" humanity). This could be achieved through an open dialogue where especially those voices that do not speak the language of science (i.e., individuals with disabilities and their loved ones) were taken into account.[18]

It has been argued that some tenets of the social approach to disability have become fixed truths that ought not to be challenged.[19] The social views of disability originally challenged some traditional individualistic assumptions and practices regarding disability—they brought balance to discussions on disability by providing differing views. Soon, however, the social approach (especially the social creationist view in the United Kingdom) was no longer a competing view; it became *the* view that one ought to adopt to be morally and politically among the "good ones." This process has led the social view on disablement to contradict one of its original ideas: to respect the variety of individual experiences and voices. To announce that one idea is the highest guiding principle, and others are oppressive and wrong, potentially gives rise to other forms of oppression. A monopolistic view on disability also denies the variety of experiences of disablement—many people do suffer due to their impairments and not all disabled people view themselves as oppressed. To deny the significance of these voices, or to silence them, would in fact be a form of objectification and oppression.

Toward an Ethical Model of Disability?

Disability is essentially a social phenomenon and concept. It is construed in particular social contexts, and they determine the meaning it carries. Disability is also a normative concept that reflects the ideas concerning what kind of beings humans ought to be, both mentally and physically, and how societies ought to be arranged to ensure the equal treatment of their members. The term "disability" implies that individuals with disabilities lack essential human abilities or possibilities to qualify as persons (in a morally significant sense) or to live a good life. Having a “disability” implies an undesirable state of functioning or being of an individual.

Physical and mental abilities are essential constituents of humanity, not merely because these abilities differentiate us from most nonhuman animals as individuals but because they make possible the communal and relational aspects of human life. The concept of *dis*ability implies that a disabled person lacks a certain ability, or possibility, that could contribute to her personal well-being and enable her to be a contributing member of society. Abilities and possibilities are considered to be good and useful, whereas *dis*abilities may be impediments to human flourishing.

Sociological or psychological research, for example, can clarify how the creation and definition of disabilities take place, but the essential core of the concept of disability is ethical. The tenets of the traditional individual approach to disability imply that disability can be reduced to an individual’s insufficient abilities. This inevitably places the disabled individual into an unfortunate, and even tragic, position. In the social approaches to disability, impairment and disability are not linked together as strongly as in the individual approach. Instead, it is emphasized that these two phenomena are distinct. Proponents of the social views do not necessarily find that impairments are undesirable conditions as such. Disability, however, is seen as an undesirable state of functioning, or an undesirable phenomenon, arising primarily or at least in part from unjust social arrangements. Thus, all individualistic and social approaches to disability contain a strong normative dimension that implies what is good or bad for an individual and what is right or wrong with regard to social arrangements.

The crucial point, then, is to examine the relevance and soundness of the norms that cause us to define certain conditions and ways of functioning as disabilities. The fundamental question is: What individual conditions or ways of functioning can, on sound normative grounds, be considered as disabilities? That is, can we define plausible criteria for a morally desirable way of functioning and being a human being? To develop an account that attempts to answer these questions would have to be based on a view of good human functioning and a conception of being human. In the words of Martha Nussbaum:

> What are the features of our common humanity, features that lead us to recognize certain others, however distant their location and their forms of life, as humans and, on the other hand, to decide that certain other beings who resemble us superficially could not possibly be human? (p. 219)[20]

Given that society plays an essential role in the creation and construction of disability, the questions of definition cannot be detached from the issue of how a just society ought to be arranged.

In other words, what is the core of humanity? Which individual conditions can compromise the achievement of central elements in human existence and well-being? If these questions are found relevant, there are at least four alternative ways to construct accounts giving answers to them: (1) a universal, objective theory of humanness that can distinguish disabled people from the nondisabled; (2) a subjectivist theory of disability that would make an individual’s personal experience the central, and the only relevant, criterion—that is, if an individual feels or thinks that she is disabled, then she *is* disabled; (3) a communitarian theory of disability in which disability would be defined according to prevailing cultural traditions and communal practices; and (4) an account that combines the three foregoing alternatives. This last account could include some universal norms, but it would also consider subjective experiences and interests, as well as the social and cultural factors that influence the creation and construction of disabilities.

To conclude, I suggest that a fruitful way to conceptualize disability from an ethical viewpoint would be to examine the question: Are there individual conditions that in themselves prevent individuals from living a good life, or which in themselves constitute a significant threat to human well-being? This question reflects the following idea. If the unfortunateness of some condition actually results from communal values and social arrangements, that particular condition is a *contingent* disability—it has been determined and created by accidental and arbitrary factors. If this is the case, disability can be removed by social arrangements as well. Society has produced injustice and is therefore obliged to abolish the structures, practices, and values that cause and sustain people's disablement and prevent the consideration of different dimensions of the human variety. The possibility of constructing an "ethical model of disability" based on such premises is an issue that merits further examination.

Notes

1. Sapontzis SF. Are animals moral beings? *American Philosophical Quarterly* 1980;17:45–52.
2. See: Silvers A. Formal justice. In: Silvers A, Wasserman D, Mahowald MB, eds. *Disability, Difference, Discrimination: Perspectives on Justice in Bioethics and Public Policy*. Lanham, Md.: Rowman and Littlefield; 1998:1–145, at 3.
3. It should be noted that the division put forward here regarding different approaches to disability resembles that of presented by many other disability scholars. See note 2, Silvers 1998; see also: Hahn H. The politics of physical differences: disability and discrimination. *Journal of Social Issues* 1988;44:39–47; Priestley M. Constructions and creations: idealism, materialism, and disability theory. *Disability and Society* 1998;13:75–94; Rioux MH. Disability: the place of judgement in a world of fact. *Journal of Intellectual Disability Research* 1997;41:102–11.
4. See note 2, Silvers 1998:56–9.
5. See note 2, Silvers 1998; see note 3, Priestley 1998; see also: Oliver M. *The Politics of Disablement*. London: Macmillan; 1990; Oliver M. *Understanding Disability: From Theory to Practice*. London: Macmillan; 1996.
6. See note 3, Priestley 1998; see also: French S. Disability, impairment, or something in between? In: Swain J, Finkelstein V, French S, Oliver M, eds. *Disabling Barriers—Enabling Environments*. London: Sage; 1993:17–25; Morris J. *Pride against Prejudice*. London: Women's Press; 1991.
7. Fletcher J. Indicators of humanhood: a tentative profile of man. *Hastings Center Report* 1972;2(5):1–4; Tooley M. Abortion and infanticide. *Philosophy and Public Affairs* 1972;2:37–65; Tooley M. *Abortion and Infanticide*. Oxford: Clarendon Press; 1983; Warren MA. On the moral and legal status of abortion. *Monist* 1973;57:43–61.
8. Buchanan A, Brock DW, Daniels N, Wikler D. *From Chance to Choice: Genetics and Justice*. New York: Cambridge University Press; 2000; Davis DS. Genetic dilemmas and the child's right to an open future. *Hastings Center Report* 1997;27:7–15; Glover J. *Causing Death and Saving Lives*. Baltimore, Md.: Penguin; 1977; Harris J. Is there a coherent social conception of disability? *Journal of Medical Ethics* 2000;26:95–100; Hudson J. What kinds of people should we create? *Journal of Applied Philosophy* 2000;17:131–43; Kuhse H, Singer P. *Should the Baby Live? The Problem of Handicapped Infants*. New York: Oxford University Press; 1985.
9. Veatch RM. *The Foundations of Justice: Why the Retarded and the Rest of Us Have Claims to Equality*. New York: Oxford University Press; 1986.
10. See note 8, Buchanan et al. 2000:61–103, 258–303.

11. Rawls J. *A Theory of Justice*. New York: Oxford University Press; 1972.
12. See note 5, Oliver 1990; see note 2, Silvers 1998.
13. See note 5, Oliver 1990; Oliver 1996; see also: Barnes C. Theories of disability and the origins of the oppression of disabled people in western society. In: Barton L, ed. *Disability and Society: Emerging Issues and Insights*. London: Longman; 1996:43–60.
14. See note 5, Oliver 1996:22.
15. See note 3, Priestley 1998; see also: Shakespeare T, Watson N. The social model of disability: an outdated ideology? *Research in Social Science and Disability* 2001;2:9–28.
16. Bogdan R, Taylor SJ. *The Social Meaning of Mental Retardation: Two Life Stories*. New York: Teachers College Press; 1994; Linton S. *Claiming Disability: Knowledge and Identity*. New York: New York University Press; 1998; Taylor S. Disability studies and mental retardation. *Disability Studies Quarterly* 1996;16(3):4–13; Wendell S. *The Rejected Body: Feminist Philosophical Reflections on Disability*. London: Routledge; 1996.
17. Danforth S. On what basis hope? modern progress and postmodern possibilities. *Mental Retardation* 1997a;35:93–106; Danforth S. Power and language in research texts: a rejoinder to Kleinert and Biklen. *Mental Retardation* 1997b;35:391–7; Danforth S. What can the field of developmental disabilities learn from Michel Foucault? *Mental Retardation* 2000;38:364–9; Danforth S, Rhodes WC. Deconstructing disability: a philosophy for inclusion. *Remedial and Special Education* 1997;18:357–66; Skrtic TM. *Behind Special Education: A Critical Analysis of Professional Culture and School Organization*. Denver: Love Publishing; 1991.
18. See note 17, Danforth 1997a; Danforth 2000.
19. See note 15, Shakespeare, Watson 2001; see note 6, French 1993; Morris 1991.
20. Nussbaum M. Aristotelian social democracy. In: Douglas RB, Mara G, Richardson HS, eds. *Liberalism and the Good*. London: Routledge, 1990:203–52.