

Quality of Life and Human Difference

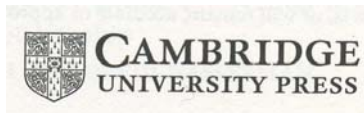
Genetic Testing, Healthcare,
and Disability

Edited by

DAVID WASSERMAN
University of Maryland

JEROME BICKERBACH
Queen's University

ROBERT WACHBROIT
University of Maryland



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Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics

Ron Amundson, University of Hawaii at Hilo

The central philosophical concepts regarding disability were constructed not by philosophers but by disability rights activists. Only recently have these concepts received attention in the philosophical literature. This paper will argue that an important discussion in biomedical ethics is biased against the civil rights interests of people with disabilities because of the failure of philosophers to come to terms with the disability rights movement. Quality of life is conceived in a way that directly conflicts with the Social Model of disability, and the conflict is deeply rooted in biomedical ethical discussion. One particular application will be discussed: the reduction of health care for disabled people because of their alleged low quality of life.

1. Two Models.

A defining characteristic of the disability rights movement is a particular explanation of the disadvantages experienced by disabled people. Disadvantages are explained as effects not of biomedical conditions of individuals, but rather of the socially created environment that is shared by disabled and nondisabled people. This environment (it is said) is so constructed that nondisabled people are privileged and disabled people penalized. Disability is a social problem that involves the discriminatory barriers that bar some people but not others from the goods that society has to offer. For this reason the view is often called the Social Model of disability. It contrasts with the traditional view, sometimes termed the Medical Model, according to which disability is a problem of individuals whose biomedical states disadvantage them. On the Medical Model, disadvantages are natural and inevitable outcomes of simple biomedical facts. Reductions of these natural disadvantages can be accomplished

only by individual cures (changing the biomedical facts) or by charitable donations intended to compensate the victims of disability for their inevitable and pitiable conditions. The Social Model depicts disability as a problem experienced by a class of people that is caused by social organization and that can be remedied by social change. The Medical Model is an individualistic rather than a social theory. Disabilities are properties of individuals, and remedies (e.g. cures, rehabilitations, or charitable donations) are meted out one individual at a time.

The 1990 Americans with Disabilities Act is an outgrowth of the disability rights movement and the Social Model of disability. Patterned after earlier civil rights laws, it treats discrimination as a cause of disadvantage, and mandates equal treatment (often in the form of equally accessible environments) as its solution. The ADA has given very wide publicity to the problem of disability. But the Social Model that underpins the ADA has not been as widely understood or accepted, and many people who accept the goals of the ADA still tacitly assume the Medical Model of disability. This paper will examine one of the manifestations of the Medical Model in contemporary biomedical ethics. It will do so from the perspective of the Social Model. The concept of quality of life (QOL) is entwined in many issues of biomedical ethics. I will try to show that prominent discussions of the QOL of disabled people reveal an unjustified and unexamined commitment to the Medical Model of disability, and for that reason a bias against the interests of disabled people. This not a simple factual error, of course. The treatment of QOL is embedded within a well-articulated framework of literature involving prominent ethicists and other philosophers. The sophistication in philosophical ethics of any one of these people far exceeds my own. I am a philosopher and historian of biology, a disabled person, and a disability activist. I come to this discussion as an activist, representing a perspective that I consider poorly understood among biomedical ethicists.

The reader may consider the Social and Medical Models to present a false dichotomy, each attending to only one aspect of disability. This may be true, but I will make no attempt to work a conciliation here. Academic attention to the problem of disability is barely a decade old. The hopes for a global theory of disability are even dimmer than the hopes for global theories of race or gender. The disability rights movement, like the civil rights movements for women and for “racial” minorities, will require significant retooling of our conceptual categories. A decade is not enough.¹

The Medical and Social Models of disability are ideological, as explanations of social disadvantage often are.² My claim that they are ideological amounts to the following: Each Model presents an account of the causal relations that hold between disability and other phenomena. The causal accounts look at first like other causal explanations – like the gravitational explanation of the tides, for example. The causal accounts involve or entail the identification of various phenomena as *natural* or *unnatural*, and as *inevitable* or *contingent and changeable*. On closer inspection it can be discovered that the contrasting causal accounts of the same phenomenon (here disability) serve and harm the interests of different groups of people. A causal account that depicts a social phenomenon as natural and inevitable (or changeable only at great cost) works to the advantage of the people who benefit from the phenomenon, and to the harm of the people who are hurt by the phenomenon. When the same phenomenon is depicted as artificial and changeable, the reformist interests of those harmed by the phenomenon are served. My goal in this paper is not to argue for the correctness of the Social Model. Rather, I will show that important bioethical discussions presuppose its falseness, and assume the correctness of the Medical Model. This unexamined assumption produces a bias within the practice of biomedical ethics against the goals of the disability rights movement.

2. Disability and QOL: The Standard View.

The Standard View is that disabilities have very strong negative impacts on the qualities of life of the individuals that have them. This view is widely held by nondisabled people, both in popular and in academic culture. The Standard View is confronted by a fact that I will term its Anomaly: when asked about the quality of their own lives disabled people report a quality only slightly lower than that reported by nondisabled people, and much higher than that projected by nondisabled people. Both the Standard View and its Anomaly have been robustly demonstrated in a number of studies. Disabled and nondisabled people have very different assessments of the quality of disabled people's lives.

Many factors are commonly assumed to lower one's QOL. Poverty, the loss or the lack of loving relationships, thwarted ambitions and frustrated hopes are all assumed to reduce QOL. Some of these are contingently related to disability, as they are to other causes. But disability itself holds a privileged position in the catalog of QOL-reducers. The life-badness that is assumed to follow from disability goes beyond the

badness that comes from the partial and contingent associations that disability has with loss of love, loss of income, etc., etc. In other words, disability is conceived to have a *surplus badness*, over and above its specific and identifiable affects. It is assumed to be categorically bad, bad beyond its contingent effects, bad to the bone, butt-ugly bad. I will argue that the surplus badness attributed to disability comes not from a rational appreciation of the consequences of disability itself, but from the stigma that disability carries both in popular and in academic culture. In other words, the Standard View is an *expression* of the stigma of disability. It is not (as it presents itself) an estimate of the objective consequences of impairments.

I am interested in the Standard View for three reasons, two of them specific and one generic. The first reason is that the Standard View generally devalues the lives of disabled people. It enforces the “pity” aspects of the Medical Model that disability rights advocates find so objectionable, and thereby obscures the civil rights basis of the disability rights movement. The second reason is that under certain theories of health care rationing, the supposed low QOL of disabled people can imply that they have less claim on health care than nondisabled people do. This is a concrete example of harm that the Standard View can cause. The third, generic, reason is that the Standard View is well integrated within the literature of biomedical ethics. Its flaws are reflected in a wide range of philosophical discussions of disability.

But isn't the Standard View refuted by its Anomaly? Hardly anyone thinks so. Disabilities are so stigmatized that reports to the contrary from the stigmatized group itself are almost universally discredited or ignored. The comedian Jerry Lewis represents the Muscular Dystrophy Association in its charitable appeals. For over a decade he has been strongly condemned by disability activists for his demeaning depiction of disabled people as pitiable wretches and partial people, in desperate need only of charity and cures. In response to activists' claims that they don't want pity, Lewis recently replied “If you're paraplegic and in a wheelchair and you don't want pity, stay in your house!” (CBS Morning Show, 2001).

Some scholars are more thoughtful than Mr. Lewis about the Anomaly. But they are no less resistant to modifying the Standard View in light of it. This is, I believe, because of the View's close integration with other important concepts within the literature. In Sections 3, 4, and 5 I will discuss and critique a constellation of views and concepts that forms the academic context for the Standard View. Sections 6 and 7

will then discuss and critique how the Standard View itself is defended. Sections 8 and 9 examine the use of the Standard View to justify health care priority penalization for disabled people. Section 10 discusses the Anomaly itself (actual reports from disabled people, at last). It also suggests a way in which a low assessment of the QOL of disabled people might be empirically grounded.

3. The Links: Normality, Opportunity, and QOL

Within current biomedical thinking, the Standard View of QOL and disability is tied into a well-articulated set of views involving the notions of biological normality and the importance of a wide opportunity range for quality of life. The area includes important work by Christopher Boorse, Norman Daniels, and Dan Brock. The work is founded on Boorse's concept of what he calls "species typical function." Despite the statistical sounding term "typical," Boorse's concept is of the *normal* functioning of members of a species (not just the most common or usual function). Boorse claims that the distinction between normal and abnormal function is an empirically grounded implication of biomedical science, not a prejudice of human observers. In effect, normal and abnormal function are distinct natural kinds. Impairments (the biological aspects of disabilities) are objectively and scientifically defined as species-abnormal functionings (Boorse 1977).

Boorse's claim is empirical, not normative. Nevertheless it is very widely cited in the normative literature. His apparently moderate claim about biology supports normative consequences in the work of Norman Daniels, Dan Brock, and others. Daniels uses Boorsian normality to explain the moral importance of health care. On Daniels's view, the importance of health care is to maintain normal function, i.e. to avoid disease and impairment. Normality is important because of its essential connection to opportunity. Species abnormal function reduces the "normal" opportunity range, while health care maintains and restores species normal functioning, thereby protecting opportunity (Daniels 1981, 1985). Brock then argues that a "normal" wide opportunity range is a necessary condition for a high quality of life (Brock 1993, 1995, 2000).

The objective normality of biological function was inferred from biomedical science. The linkage from Boorse to Daniels to Brock completes an argument, apparently founded on biological fact, that people with impairments will (must?) have a low quality of life. High QOL is

dependent on wide opportunity range, which is dependent on biological normality, which is an objective fact of the natural world.

I believe that this chain of reasoning is flawed at every step. Boorse's contribution misrepresents biomedical science. Daniels's step embodies the prejudices of the Medical Model of disability, and so its shortcomings. Brock's contribution shares Daniel's commitment to the Medical Model, and in addition assumes an epistemologically privileged knowledge of others' lives that is unjustified by the facts.

4. Critique of Normal Function (Boorse)

Intuitive as it is, Boorse's reification of the normal/abnormal distinction is not implied by modern biological theory. I have argued this claim in detail elsewhere, and will outline my concerns here. (See Amundson 2000 for details.) On Boorse's view, we should expect natural species to be composed of members that have a narrow range of functional variation, forming a bell curve with steep sides. In fact, information from a wide range of biological disciplines can be seen to challenge this sharp distinction between normal and abnormal function. A wide range of functional variation is to be expected. First, evolutionary biology does not imply functional uniformity as an outcome of evolution. Indeed, functional variability is a basic assumption of Darwinian natural selection. Second, the facts of developmental biology do not imply conformity among species members. Developmental plasticity and functional adaptation should lead us to expect variation, not strict conformity, in the functional organization of the bodies of species members. Third, many empirical studies of anatomical and physiological diversity in humans show a wide range of variation, too wide for a supposed "normal range" to be neatly designated. Fourth, genetic studies of various kinds indicate enough genetic diversity in humans and most other species to allow a wide range of function, even ignoring the developmental plasticity that allows identical genotypes to divergently adapt into distinct phenotypes. Functional uniformity may be Henry Ford's ideal of industrial mass production, but it is not a scientific discovery about the biological world.

On my view, Boorse's reified concept of *normal function* can be compared to the historically reified concept of race. In years past the dominant scientific view was that the traditionally named human races (Caucasian, Negroid, etc.) designated biologically real categories of humans. This view has been abandoned; racial categories no longer have

scientific validity. This is not to say that human variation does not exist. Of course it does, and some of the variation (hair color and texture, etc.) is statistically correlated with the traditionally named races. But when we take *all* human variation into account, the distribution of variation does not match the races. The naming of races was a social and economic phenomenon that simply did not match up with biological facts. The same (I say) is true of the normal/abnormal distinction. There is a great range of functional variation among humans, as among the members of any species. The variation is so great, and so multidimensional, that the belief in an objective dividing line between normal and abnormal is just as scientifically untenable as a dividing line between Caucasian and Negroid. Biology shows us that we must learn to deal with variation on its own terms, and resist the temptation to prematurely categorize. History shows us that premature biological categories sprout constantly from social prejudices about the “true natures” of human beings. When I say that race and biological normality are *reified*, I mean that they are falsely conceived to reflect real, objective aspects of the natural world, determinable by biological science. Instead they reflect social strategies for the management of human diversity.

5. Critique of the Dependence of Opportunity on Normality (Daniels)

So I doubt the scientific basis of “normal function” from the start. But I will consider the subsequent steps on their own terms, and set aside my skepticism about normal function. Even if reified normal function existed, Daniels’s inference that abnormal function inevitably reduces opportunity range presupposes without argument the correctness of the Medical Model of disability. The Social Model asserts that the opportunities lost to impaired people come from environmental design, not from biology itself. People with atypical *modes* of function (e.g. people who read with Braille, communicate with American Sign Language, or travel with wheelchairs) can nevertheless function at a high *level*, at least if the environment poses no obstacles to them. Nevertheless, these atypical modes are stigmatized. The assumption that unusual functional modes *necessarily* reduce one’s opportunity is itself a manifestation of that stigma (Silvers 1998). The very purpose of the ADA is to remove the barriers to opportunity that disadvantage these “abnormals.” To assume that “normal opportunity range” is available only to a certain narrow range of body types is to assume that the Social

Model is false and the ADA fruitless. The notion that discriminatory barriers to opportunity are unavoidable facts of nature is no more justified in the case of disability than it would be for race and sex discrimination.

To be sure, a philosopher could cleverly define "opportunity" so narrowly that certain impairments limit them by definition -- complete paraplegics by definition do not have the "opportunity" to walk or blind people to see. But the same trivialization could be applied to sex and race. African Americans lack the "opportunity" to be white, and women the "opportunity" to sire children. But this is just obfuscation. Whether or any of these "lacks" (non-whiteness, non-siring, non-walking, non-seeing) restricts employment, the freedom to live where one chooses, and social status depends on the social structures in which they are embedded. The assumed "naturalness" of the linkage of normality to opportunity harms the interests of disabled people, just as the linkage of race and sex to opportunity has been harmful to other disadvantaged groups. The claim by disability rights advocates that they are being *unfairly* discriminated against must be met head on. The notion that opportunity is *by definition* out of the reach of disabled people is rightly rejected by them, just as the same claims were rejected by women or minorities.

6. The Standard View and "Objective" Quality of Life (Brock).

Dan Brock discusses the quality life in the context of the work of Boorse and Daniels. In series of papers beginning in the early 1990s, he acknowledges the Anomaly but does not consider it as an important challenge to the Standard View. He sometimes presents the Standard View as a definitional truth. "Serious disabilities or handicaps will, by definition, typically reduce a person's quality of life." (Brock 1995, p. 179) "[S]ince disabilities by definition under the ADA substantially limit one or more major life activities, they will reduce an individual's health-related quality of life" (Brock 2000 p. 226-227). According to the ADA definition, disabilities limit one or more major life activities. Why must we assume that unlimited major life activities are *by definition* required for a high QOL? Walking and seeing are often given as examples of major life activities. It might be argued that it is a matter of empirical fact that limitations in walking and seeing are associated with lower QOL. This would require empirical data about the correlation. Brock offers no data of this sort. The language of the ADA makes a semantic link

only between disability and limitations, not between limitations and reduced QOL. Brock is assuming some additional conceptual connection. I suggest that this conceptual connection is the Boorse/Daniels linkage between biological normality and “normal” opportunity discussed above. With the right kind of philosophical account, empirical evidence can appear irrelevant.³

In order to explain the Anomaly (and by the way protect the Standard View from refutation) Brock distinguishes between subjective and objective QOL. Subjective QOL is how happy or satisfied one is with one's life. Objective QOL is how well one's life is *really* going. "To be satisfied or happy with getting much less from life, because one has come to expect much less, is still to get *less* from life or to have a less good life" (Brock 1993, p. 309). Reports of high QOL from disabled people are merely subjective.

What are the objective aspects of QOL? In the 1993 paper, Brock discusses with approval an instrument called the Health Status Index (HSI). One of the scales on the HSI is said to judge the "mobility" of the individual. The highest ranking is 5, for those who are able to use public transportation alone. Someone who requires assistance to use public transportation is scored 4, and someone who needs assistance to go outside scores 3. Brock refers to this sort of scale as measuring "functions of the 'whole person'" (Brock 1993, p. 298). The mobility measurement is conceived as a biomedical attribute of the individual being measured. A low mobility score constitutes a part of the objective basis on which the person's QOL is judged as objectively low whatever the person's subjective opinion about that life.

Is "mobility" as thus measured a biomedical attribute of the individual? The slightest acquaintance with the Social Model of disability will show that the answer is no. Imagine a set of identical triplets, sisters with paraplegia who use wheelchairs and who live in different cities. The first lives in an inaccessible building, and needs assistance to go outside. The second lives in an accessible building, but in a city in which public transportation is not wheelchair accessible. The third lives in an accessible building in a city with accessible public transportation. These three score 3, 4, and 5 respectively on the "mobility" measure even though they are biomedically identical. It is utter confusion to attribute their scores to their biomedical conditions. The least mobile (call her Sister 3) is biomedically identical to the most mobile (Sister 5). The difference in mobility scores is caused by differences in environmental barriers. Blinkered by the Medical Model of disability, Brock and the

HSI present “mobility” as a measure of biomedical traits of individuals. It is not.

The same example illustrates the flaw in Daniels’s identification of biological normality with opportunity range. The three sisters are biomedically identical, and so equally “abnormal” by Boorse’s criteria. But Sister 5’s opportunities are immensely broader than Sister 3’s. This demonstrates that individual normality does not determine opportunity. The HSI “mobility” scores do measure something, but not a biomedical characteristic of the sisters. As the Social Model shows us, it is the accessibility of their respective environments.

7. The Happy Slave and the Happy Hick.

In 1993 Brock explained the Anomaly as a mere effect of the lowered expectations of disabled people, and in 1995 presented the Standard View as a definitional truth. In later papers he recognizes that disabled people might accommodate their goals to their opportunities without necessarily *lowering* their expectations. But even with this less-belittling possibility, Brock remains committed to the Standard View, and dismisses the Anomaly as reflecting subjective rather than objective QOL. Recent endorsements no longer appeal to specific definitional truths (i.e. disability defined as QOL-reducing). His intention is more generally to articulate *our concept of a good life*. This concept, according to Brock, contains both subjective and objective factors, and the objective factors include the absence of significant disabilities.

I am not at all sure what kind of evaluation standards are appropriate to an analysis of "our concept" of QOL. Social critics, after all, claim that some of society's dominant concepts are flawed and objectionable. A correct account of a flawed concept has great charms to those who do not recognize the flaw. Is such an account good because it is true to the concept, or bad because the concept is flawed? A correct account of "our concept of race" to white Americans in the 1830s would surely have included innate variations in intellectual and moral capabilities among races. So I am tempted simply to grant Brock the correctness of his account of the Standard View as "our concept of QOL" and go on to critique that concept itself. The fact that it's "our concept" doesn't make it right. However, Brock does not merely assert the accuracy of his account. He gives one argument for it, involving the example of the Happy Slave. I will therefore examine the extent to which the Happy Slave example supports the Standard View.

If a slave happened to have a high degree of subjective satisfaction with his life, would we be compelled to agree with him? Would we agree with those oppressed women in sexist societies who experience their lives to have high quality? Brock says that we would not. Slavery and oppression reduce the qualities of lives even for those of the oppressed who do not subjectively recognize the fact. In order to be able to judge that an oppressed person is mistaken about the quality of his or her own life, we must be able to distinguish between subjective and objective QOL. Since we already need to use the objective/subjective QOL distinction to deal with the Happy Slave example, that same distinction can be deployed on the Anomaly.

I am willing to accept the coherence of the distinction between objective and subjective QOL exemplified by the Happy Slave. But the epistemic status of this kind of judgment about other people's lives is far from sturdy. The logical coherence of objective QOL is a necessary but not a sufficient condition for the correctness of the Standard View. Besides a proof of coherence, Brock needs evidence of *truth*. At best, the Happy Slave implies only coherence but not truth. It shows that logic alone does not prohibit a third-person judgment of QOL that differs from the judgment of the subject. But something more than logic is needed to warrant specific judgments. How are we to separate the judgments that are objectively grounded from those that merely express one's prejudices? Separating the wheat from the chaff requires more than logic. It requires epistemology.

The Happy Slave case is effective because its epistemological credentials are built into the case. We (the third-person judges) can understand a slave's failure recognize an injustice or a social alternative that outside observers (like us) can perceive. We recognize oppression, and the possibilities of liberation, in ways that slaves and women in sexually oppressive societies do not. Our superior knowledge allows us to trump their subjective judgments with our objective ones. But not all judgments are made from such high epistemic vantage points. The epistemics of the Happy Slave case cannot be extrapolated to every other case in which we want to pass judgment on someone else's life.

Take, for example, the Anomaly. The disabled subjects in these studies know full well their own impairments. They are able to describe in detail the day to day difficulties that they can cause, and they realize (sometimes with amusement) that nondisabled people assume them to have a low QOL (Albrecht and Devlieger 1999). Many acquired their impairments late in life, and so had lived both with and without impairments.

In contrast, most members of the nondisabled public never experienced life with a significant impairment, and know it only through its social stigma. Who is judging from ignorance? On what grounds does Brock favor the opinions of nondisabled over disabled people, when the issue itself is the QOL of disabled people? The Happy Slave is presumed to be ignorant of the delights of freedom. What ignorance burdens disabled people, and why is it so much greater than the ignorance of the nondisabled majority? Does the advocate of the Standard View really want to claim that nondisabled people *know better than* disabled people what the different lives are like?

Come to think of it, the answer is obvious. *Of course* the advocate of the Standard View wants to claim this. Testimony of disabled people about their lives has been dismissed in favor of nondisabled "experts" for a very long time, as historians have documented (Longmore and Umanski 2001). The real question is this: *When* nondisabled people claim to know better than disabled people what the different lives are like, why should they be believed? Why should the opinions of nondisabled people be epistemologically privileged over those of disabled people?

Judging the lives of others is epistemologically hazardous, even if irresistible. The life of a pious person, or an urbanite, or a parent of a large family is bewildering to me. I gossip and joke about it when I'm with like-minded people. I would never voluntarily exchange my situation for that of a person in any of the above categories. Even so, it would be presumptuous of me to claim that the quality of one those lives is merely subjectively high, and that on objective grounds (known to me and my like-minded friends) it is low.

People who live in rural areas are called *hicks* by some urban people who feel themselves to have superior lives. (Why would anyone give up the symphony just to breathe clean air?) The happiness of hicks is regarded as merely subjective by the sophisticates who judge them. Some of the more reflective sophisticates (some college professors, for example) might realize that their feeling of QOL superiority over hicks is not really an objective judgment trumping a subjective judgment. It is merely one person's subjective judgment clashing with another person's. The Happy Slave example illustrates the coherence of objective judgments on the quality of other peoples' lives, using a plausible case of a correct judgment. But it gives us no hints how to tell correct judgments from mere prejudices. The Happy Hick exemplifies mere prejudice in a logically similar judgment.

The Standard View is very widespread. Is that because of the superior knowledge of nondisabled people about the lives of disabled people? Or is it merely a reflection of the stigma of disability? The Happy Slave has nothing to tell us. The fact that we *can* trump subjective QOL judgments with judgments *that we believe* are objective does not mean that we are correct when we do so. When our “objective” judgments happen to match our own social prejudices, that coincidence alone should make us wary about our own objectivity. The Happy Slave example gives no epistemological support to Brock’s judgment that he knows better than disabled people about their QOL. In the absence of a genuine epistemological basis, it’s just a conflict between subjectivities.

Nevertheless, the mere coherence of the objective/subjective distinction does leave open the possibility that a legitimate epistemological basis might be found for an objective assessment of the QOL of disabled people. Considerations below will lead us further in that direction.

8. Penalizing Health Care Priorities by QOL.

This section will discuss one application of the Standard View of disability and QOL to health care policy. The particular application is not one that the philosophers so far discussed have endorsed. In fact Dan Brock specifically rejects it (Brock this volume). But the case does show that the Standard View can be a direct and tangible threat to disabled people. The notion of *quality adjusted life years* (QALYs) is common in discussions of health care rationing and prioritization. If health care funds are prioritized to maximize QALYs, then funding for people with low QOL should receive a lower prioritization for the same kinds of care than people with high QOL. On this approach, the Standard View would entail lower levels of health care for disabled people than nondisabled people.

This section will discuss one particular justification of the policy of health care priority penalization for disabled people. I will term this the Menzel Criterion because of its expression in a paper by Paul T. Menzel, though he may not endorse this use (Menzel 1992).⁴ The Menzel Criterion states roughly that priority considerations that are applied to nondisabled people can be justly applied to disabled people as well. A criterion would only be unjust if it were applied to disabled people but never applied to nondisabled people. This is a very weak criterion, in that a policy that satisfies it may be unjust in many other ways.

I do not believe that priority penalization satisfies even this weak criterion, but it fails in an interesting way. The failure is revealing about the Standard View. Here is how the Menzel Criterion would apply to QALY priority penalization of disabled people.

Let us use the term "discrimination" in a morally neutral sense, so that some cases are just and some are unjust. Unjust cases of discrimination are those in which it is directed against a member of a "protected class," a class of people against whom discrimination has been applied for social reasons unrelated to the legitimate goals of a practice. If one is hiring a carpenter, discrimination against people who are unskilled carpenters is not unjust. This is true even if the unskilled carpenter happens to be a woman, a member of a protected class. It is unjust to refuse to hire the woman only if her sex rather than her carpentry skill was the basis of the decision not to hire. An employer could defend against a complaint of unjust hiring practices by showing that other women with higher carpentry skills were hired, and that men who had skills comparable to the complainant were not hired. This would demonstrate that discrimination was based on skill level rather than protected class membership, and so was not unjust.

Health care discrimination might be defended in the same way. Suppose a member of an ethnic minority were refused a heart transplant on the grounds that the operation had a low probability of success. Suppose the decision were challenged as unfair discrimination against an ethnic minority. The decision could be defended by showing that other members of the minority whose probability of success were higher did receive the procedure, and non-minority patients whose probabilities of success were similar to the patient's were also refused the procedure.

Consider disability in place of minority status. If some feature X that happens to correlate with disability reduces a patient's ranking in health care prioritization, but the priority judgments are made on the basis of feature X and not on the disability status *per se*, then it could be argued that the discrimination is just (if discriminations on the basis of X are otherwise just). Evidence that the priority rankings were based on X rather than on disability could come from that fact that disabled people who do not have trait X are not priority-penalized, and that nondisabled people who do have trait X are priority-penalized.

Does the use of the Standard View together with QALY health care rationing pass the Menzel Criterion? If people with equal QOLs are treated equally by the scheme, then low QOL rather than disability is the discriminatory factor. Are the advocates of QALY calculations willing

to apply the same standards to nondisabled people with low QOL that they apply to disabled people?

It doesn't matter whether objective or subjective QOL measures are used for this purpose. A workable system would probably require the use of objective measures. (Although it is entertaining to imagine a government bureau of sadness-detectives, whose job is to unmask unhappy patients who were only *pretending* to be happy in order to increase their health care coverage.) By the line of reasoning so far discussed, the primary objective measure of QOL is range of opportunity. Discriminating against disabled people because of their narrow range of opportunity passes the Menzel Criterion only if nondisabled people are penalized by reduced opportunity range in the same ways as disabled people.

If disability-penalization is replaced by narrow-opportunity-range penalization, who else would suffer? Brock mentions in passing two examples of opportunity reduction from other sources than disability. "In the absence of a disability, many of us undergo more-limited changes of this sort as a result of changes in opportunities which accompany such major life changes as a move from city to rural life, taking up a very different occupation, and so forth" (Brock 1995, p. 183). How much opportunity loss is experienced by a person with urban aims and goals who is forced by contingencies to live in a rural environment (or for that matter, vice versa)? How much is lost in a major unwanted job change -- or, for that matter in long term unemployment? How much opportunity loss is associated with unwanted pregnancies? With family illnesses? I do not know, but neither does the advocate of QALY rationing. The most obvious and dramatic cause of opportunity loss is surely poverty. Children born in poverty have extremely low ranges of opportunity. Is this a reason to cut back on health care for poor people?

I do not claim that disabled people as a class have wider opportunity ranges in today's world than the other classes of people cited above. I just don't know. But neither do the advocates of QALY health care rationing. I submit that the public at large would not tolerate the lowering of health care priorities for people with reduced ranges of opportunities *who are not disabled*. I therefore conclude that the use of the "objective" measure of opportunity range in the priority penalization of disabled peoples' health care fails to satisfy the Menzel Criterion. It does not apply equally to disabled and nondisabled citizens. Opportunity loss is a smoke screen hiding the real grounds for discrimination -- the stigma attached to disability itself. Opportunity losses *could only* be

socially accepted as justifications for priority-penalization if they are sustained by disabled people. This practice does indeed discriminate unfairly against people with disabilities -- it discriminates against them *only because* they are disabled.

I must repeat that the Menzel Criterion is a very weak criterion of justice, and social policies that pass it might well fail on other grounds. Even this low hurdle is too high for the policy of QALY priority penalization for disabled people.⁵ I will now discuss one higher hurdle, a hurdle that I believe would block priority penalization for disabled people even if we were to change our minds, and decide that to apply QOL equally to people with equally low QOL. This criterion would disallow practices that perpetuate an existing injustice, even if they did so in a way that satisfied the Menzel Criterion.

9. Just and Unjust QOL Reduction.

One problematic feature of QALY criteria for prioritization is that they are insensitive to the causes of reduced QOL. Intuitively, one might think that unjust reductions in life quality might receive a different treatment than just ones. Perhaps a naïve assumption is being made that all of the influences on QOL are matters of fortune, undeserved by the recipient but not unjust. But suppose that reduced QOL arises from social oppression. If we use opportunity range as the operationalization of QOL, it would be easy to argue that women and African Americans have significantly lower opportunity ranges in the U.S. with respect both to employment and freedom from harassment. Could these very real opportunity losses be used to justify reduction in health care priority? I seriously doubt it -- at least not without strong resistance from the affected groups.

Why haven't QOL reductions been discussed as a factor in health care prioritization for *nondisabled* people? I suspect that it is because opportunity loss due to sex and race is seen as unrelated to health care, while the same reductions are seen as a health care issue when they coincide with disability. This is simply another begging of the question in favor of the Medical Model and against the Social Model of disability. According to the Social Model, the opportunities lost to disabled people are taken away by unjust and discriminatory social barriers, not by biomedical conditions. Similar social barriers disadvantage women and racial minorities. If we are unwilling to penalize women and racial minorities for the QOL consequences of the discrimination they experience, it is unjust to penalize disabled people for the same consequences.

The concept of *health related* quality of life (HRQOL) is sometimes used in this context. This use of HRQOL as a substitute for QOL is simply the gerrymandering of social problems into medical ones. If disability is defined as a health-related problem, then the QALY advocates can use health care priorities as a stick to beat disabled people. The same treatment would not be tolerated for sex or race. Consider again the three sisters. They are biomedically indistinguishable, but they differ immensely in their HSI-defined “mobility.” The opportunity restrictions experienced by Sister 3 (the least mobile) are caused not by her biomedical condition but by her inaccessible surroundings. This fact is merely disguised by referring to it as “health related quality of life.” Sister 3 is already penalized by her inaccessible environment. To compound the penalty by cutting her health care because of her inaccessible environment would surely be unjust.

I submit that a policy of priority penalization for people whose low QOL stems from social oppression could not be socially negotiated. (Surely the wretched medical treatment of slaves in the American South prior to emancipation is in no way excused because they had a low QOL anyway.) I further submit that a policy of priority-penalization based on "objective" factors such as reduced opportunity ranges could not be negotiated so long as it was applied without discrimination. For these reasons, I conclude that the application of these penalties to disabled people is based *only on their stigmatized status*, and not on their alleged low QOL.⁶

The outcome of this discussion is not entirely negative. Notice that I have been comparing objective QOL measures of both disabled and nondisabled people. I have not been relying on subjective reports alone. This opens the possibility for an empirically grounded and epistemologically respectable comparison of disabled and nondisabled QOL. Such a comparison might replace the subjective (nondisabled person's) intuition that disability *must* reduce QOL. Some details about the subjective QOL reports of disabled people (the Anomaly) will suggest some possible avenues of study.

10. Details of the Anomaly

Let us now consider some details of the various surveys relating to the QOL of disabled people. One pair of correlations is especially interesting (Fuhrer et al. 1992, Bach and Tilton 1992, Nosek et al. 1995). First, within categories of impairment (e.g. spinal cord injury,

or polio paralysis) the reported QOL of disabled people does not statistically correlate with the severity of their impairment. But it does correlate with measurements of what the World Health Organization (WHO) used to label "handicap." (The WHO has since revised this vocabulary, but I will retain it because it was used in the cited research.⁷) WHO handicap refers to the extent to which a disabled person is able to fulfill the social roles that are considered normal for the person's age, gender, and culture. Aspects of handicap that were measured in these studies included reduced social integration, reduced "occupation" (spending time in ways typical of one's peers, as in employment or homemaking) and reduced mobility. As we saw in the discussion of the HSI above, mobility is not a characteristic of an individual. Rather it is the interactive effect of a person's physical abilities and the environment in which the person lives. As seen in the case of the three sisters, WHO handicaps vary greatly among people with identical impairments.

The correlation of reported QOL with WHO handicap rather than degree of impairment shows that the self-perceptions of disabled people are not reflected in the Standard View. Subjective QOL did not track the degree of the person's impairment ("abnormality"), but rather the accessibility of their environment whatever their impairment happened to be. People who were unable to occupy themselves appropriately, to maintain social contacts, and to move about in their community had a lower QOL. People who were able to do these things had higher QOL.

Consider again the way WHO defined "handicap": a person is handicapped when the person has impairments *and* the person is unable to fill certain the usual social functions. Let us call those social functions the *social correlates* of WHO handicap. Notice that the social correlates apply to many people who are not disabled. Many nondisabled people lack mobility, are unemployed, and socially isolated. Those people would probably report a low subjective QOL just like people who have WHO handicaps. People who are able to spend their time in culturally appropriate ways (e.g. employment, domestic activities, and recreation), who have strong social ties, and who can move throughout their community are happy. People who satisfy the WHO social correlates for handicap (e.g. are unemployed and socially isolated) are unhappy whether or not they also happen to be disabled. The factors that differentiate between people with high and low QOL can be seen as objective factors that are *only contingently associated* with impairment. Perhaps we can make epistemologically sound judgments about the QOL of disabled

people after all! We need not rely on intuitive conceptual connections between disability and low QOL -- we can study the patterns of correlation between impairments and the objective correlates of QOL.

If the factors that relate to high and low QOL are really the same for disabled and nondisabled people, then one way of making an objective assessment of QOL of disabled people is to measure those correlates. Here we can actually find evidence of a lower QOL for disabled people. Consider QOL-lowering factors like unemployment, isolation, and being a crime victim. Disabled people score significantly higher than nondisabled people do on these factors. These are demographic facts, not philosophical intuitions or implications of "our concepts." Wouldn't these empirically measurable facts serve the biomedical ethicists better than conceptual analysis in proving the inherent superiority of the normal?

In fact I believe they would not. When we get down to actual causes of disadvantage, and we study them in a way that allows unbiased empirical comparison between disabled and nondisabled people, the social causes become more apparent. Each of the demographic QOL-lowering factors that applies to disabled people at a higher rate than nondisabled people *does so for social reasons*. The impact of the Social Model is much clearer when we attend to specifics than when we abstractly think of reified *abnormality* as a person-type. For example, consider crime victimization. Disabled people are no more responsible for the crimes committed against them than are the victims of rapes; victimhood is no more *essentially* tied to disability than it is to womanhood. Consider unemployment and isolation. An important cause of unemployment and isolation is the lack of suitable transportation. This fact is true for disabled and nondisabled people alike. A wheelchair user in a town with wheelchair inaccessible transportation is in a very similar position to a nondisabled person in a location that has no transportation. Neither can hold down a job, and each has limited social contacts.

Certain customary ways of talking disguise the fact that disabled and nondisabled people alike share the problem of transportation. Our bioethicists (and others) often label transportation that is accessible to disabled people as "special transportation." This label is merely one more way of stigmatizing disability, by falsely making it appear that "abnormal" people have different needs than "normal" people. Everyone needs transportation. No one needs *special* transportation! (Are racially integrated lunch counters *special* lunch counters?) When we look at the details, we see shared social problems. For these demographic facts to

support the bioethical endorsement of normality, the bioethicists would have to *argue* that the Social Model is wrong and the Medical Model is right, that transportation is a different thing for disabled and nondisabled citizens. This is much harder to do when we attend to the actual causes in the world than when we assume it as an aspect of "our concept."

The Social Model of disability is not familiar to most disabled people who are not academics or activists. Nevertheless their QOL reports indicate no correlation of low QOL to degree of impairment, and a positive correlation of low QOL with exactly those things that cause low QOL among nondisabled people. Life quality is best explained not by the disabled person's degree of "normality" but by environmental accessibility.

11. Conclusion

The Medical Model of disability and the Standard View of the low QOL of disabled people are shared by popular and academic culture. Biomedical discourse assumes that the disadvantages of disability are intrinsic to the disabled state itself, and abnormality is penalized by nature itself. To the contrary I have argued that

- 1) low QOL is less typical of disability than popularly perceived,
- 2) philosophical arguments to the contrary are unconvincing in the face of the Social Model,
- 3) the moderate lowering of QOL that is actually experienced by disabled people is more likely due to discriminatory treatment than to any intrinsic feature of disability,
- 4) the use of low QOL to discriminate against disabled people in health care prioritization is unjust unless nondisabled people are treated in the same ways according to criteria that can apply to both, but that
- 5) the nondisabled public would never tolerate this treatment for themselves,
- 6) a truly objective and demographic study of low QOL among disabled people would show that it is caused by the same factors that cause low QOL among nondisabled people,
- 7) these factors are not essentially tied to impairment or abnormality but follow from social arrangements, and
- 8) the social arrangements that lower QOL are the same for disabled and nondisabled people alike.

Nevertheless, from one perspective I cannot quarrel with the philosophical analyses examined in this paper. They indeed represent “our concept of a good life,” in the sense that they represent the dominant values and biases of popular and academic culture. The stigma of disability is embedded in those biases. Even a familiarity with the literature of the disability rights movement does not change that bias very much. The recent book *From Chance to Choice: Genetics and Justice* is co-authored by two of the bioethicists discussed above and two others, Allen Buchanan, Dan W. Brock, Norman Daniels, and Daniel Wikler (Buchanan et al. 2001). The book contains a great deal of discussion of disability activists' critiques of the uses of genetic technology. The authors give their liberal endorsement to the general goals of the disability rights movement, while rejecting almost every specific argument of its advocates. My interest is not in the authors' rejection of the disability rights arguments. It is rather in the fact that the authors show only a verbal understanding of the Social Model. Even after reporting, reasonably accurately, on the perspective itself, the authors immediately refer to the biomedical conditions of impairment and disability as the *direct causes* of disadvantage. Two examples:

We devalue disabilities because we value the opportunities and welfare of the people who have them. And it is because we value people, all people, that we care about limitations on their welfare and opportunities. We also know that disabilities as such diminish opportunities and welfare ... (Buchanan et al, p. 278)

People with disabilities have more to gain from these [genetic] techniques than others do since their deficits, real and imagined, serve to marginalize and exclude them. (Buchanan et al., p. 332)

Disabilities (all by themselves) limit welfare and opportunities. Deficits (all by themselves) marginalize and exclude people who have them. Elsewhere in the book, the authors acknowledge that social arrangements contribute to the disadvantage of people with impairments. But when they find themselves pledging their respect for people with impairments, the social causes of disadvantage are forgotten. This is the power of the Medical Model over biomedical ethics. No matter how sincere the authors' respect, the social causes of disadvantages are the first things to slip from their minds. From the perspective of the Social Model, the problem of disability has been whitewashed. The ethicists' explanation of exclusion as due to impairments makes no more sense

than if they were to explain racial segregation as caused by *race itself*, as if the social phenomenon of racism played no part in the matter.

I confess that I have given the reader very little reason to actually *accept* the Social Model, and to think of the range of impairments along the lines we now think of race and gender. That argument must be given elsewhere. But I will end with two observations that I consider relevant to the question. First, less than a century ago race and sex were themselves considered by the scientific community to be *literally* disabling. It was not a simple scientific discovery but a social change that gave rise to modern egalitarianism regarding sex and race. Disability activists envision a similar social change for disability itself. It will require a change in "our concept of a good life," but a change no greater than those that have already happened regarding race and sex.

Finally, many bioethicists express a widespread but utopian hope that medical advances can wipe out or drastically reduce impairments ("... we are committed to the judgment that in the future the world should not include so many disabilities ..." Buchanan et al., p. 278). This vision is misplaced. Medical science does more than repair and prevent impairments. It also allows people to survive while living with impairments. A simple example is the fact that a person newly quadriplegic from spinal cord injury had a life expectancy of less than a year prior to World War II. Today the same person's life expectancy approaches that of an unimpaired person. The demographic consequence is that quadriplegics are a larger proportion of the population today than fifty years ago, and the same applies to many other impairments. Greater numbers of increasingly "abnormal" people are living among us, and the trend will continue. This spectacular achievement goes unnoticed by the biomedical advocates of normality. Despite the utopian rhetoric one sometimes hears from some enthusiasts of the Human Genome Project, tomorrow's world will contain a greater proportion of people with impairments than today's. The social movement for the civil rights of disabled people will certainly continue. It will not be rendered moot by idealistic dreams of biological perfection.⁸

Notes

¹Here is a brief explanation of why I intend neither to defend the Social Model nor to work a compromise between the models. The Medical/Social contrast is a kind of nature/nurture debate. When a modest advocate of the

importance of nurture finds herself debating an extreme genetic determinist, her best tactic may be simply to try to prove that the genetic determinist has not taken social causes into account. She need not present an entire theory of the interplay of nature and nurture in order to successfully demonstrate that her adversary has failed to take account of nurture. I consider the Medical Model to be so dominant and so determinist that my only ambition is to convince the reader that an important perspective is being ignored. If it sounds to the reader as if I consider biology irrelevant to disability, that appearance is a byproduct of my tactic.

² Notice that I am already speaking as an activist. The Medical Model was given its name by advocates of the Social Model. Advocates of the Medical Model typically do not see it as a model at all, but as the simple truth.

³ The correlation between extremely wide opportunity range and QOL asserted by Daniels and Brock deserves further discussion. It does not seem to me to describe the expectations of average people. I consider it a kind of American cultural ideal that is satisfied in very few, very privileged people. Most people expect to make good lives within the limitations they encounter, and to make the best of what they have. Many things in life have very large effects on one's opportunity range. Few of these carry the stigma that disability carries.

⁴ Menzel suggests that QOL considerations used in rationing health care to disabled people should be "regarded as contrary to the ADA only if we would reject them as legitimate considerations if they were not sometimes to deny care to persons with disabilities" (Menzel 1992, p. 24).

⁵ At least two stronger criteria for unfair discrimination exist. One would reject facially neutral practices that embodied biased conceptions of the individuals under assessment, such as physical requirements for fire fighters that are biased towards physical performances that are easier for men than women. A second would require that practices be designed to redress past wrongs, such as affirmative action policies.

⁶ It has been pointed out that Section 8 does not, while Section 9 does involve the Social Model in arguing against potentially discriminatory treatment of disabled people. This seems correct. The only relevance of the Social Model to Section 8 is that *if* general social discrimination were ameliorated as the Social Model implies it should be, then (according to the Model) disabled people would not be grouped together with people of low QOL in the first place!

⁷ The 1980 document has been superseded by the International Classification of Functioning, Disability, and Health, from which the term "handicap" has been removed. See www.who.int/icidh.

⁸ This paper benefited from comments by the participants in the workshop. Anita Silvers, David Wasserman, and Jerome Bickenbach helped especially on points related to the ethical principles in Sections 8 and 9. Thanks also to Shelley Tremain for discussion of *From Chance to Choice*, and to Larry Heintz for early wise advice.

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