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### On a Bioethical Challenge to Disability Rights

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## On a Bioethical Challenge to Disability Rights

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*Tensions exist between the disability rights movement and the work of many bioethicists. These reveal themselves in a major recent book on bioethics and genetics, From Chance to Choice: Genetics and Justice. This book defends certain genetic policies against criticisms from disability rights advocates, in part by arguing that it is possible to accept both the genetic policies and the rights of people with impairments. However, a close reading of the book reveals a series of direct moral criticisms of the disability rights movement. The criticisms go beyond a defense of genetic policies from the criticisms of disability rights advocates. The disability rights movement is said not to have the same moral legitimacy as other civil rights movements, such as those for women or “racial” minorities. This paper documents, and in some cases shows the flaws within, these challenges to the disability rights movement.*

**Keywords:** *bioethics, civil rights, disability, disability rights*

### I. INTRODUCTION

Thirty years ago the field of bioethics and the disability rights movement were in their formative stages. In many ways, people within these two groups had similar attitudes: skepticism about the power and paternalism of the medical establishment, and a strong desire to protect the medical consumer and the autonomy of the patient (Asch, 2001).

In other ways they diverged and the divergence has continued. As far back as 1989, a disability rights advocate and scholar observed that bioethicists' interests in physical disability were limited to the conditions under

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which it was morally right or permissible to end or to prevent disabled lives (Wendell, 1989).

Advances in molecular genetics led to broader applications of what has become the standard medical policy to encourage prenatal testing and the abortion of fetuses that have molecular markers associated with impairments (henceforth the “prenatal policy”). This became a special target of criticism from disability rights (henceforth DR) advocates.

The DR arguments were all but invisible at first. Few of the advocates held academic posts or had access to scholarly journals. But the arguments of the DR community slowly began to be noticed by bioethicists and the disagreements became more apparent.

*From Chance to Choice: Genetics and Justice* (Buchanan, Brock, Daniels, & Wikler, 2000), addresses modern genetic technology and the justice implications that arise out of it. The book is coauthored by four bioethicists who are unquestioned leaders in their field.

The criticisms of the prenatal policy brought forth by DR advocates are an important topic in the book. One of these criticisms is that the prenatal policy is based on disrespect for the lives and the civil rights of people with impairments. In response, the authors of *From Chance to Choice* (henceforth FCC) claim that it is perfectly possible to simultaneously endorse the civil rights of people with impairments and the prenatal policy.

In addition, the authors analyze and criticize several other positions that they attribute to DR advocates. Some of these positions are narrowly focused on the prenatal policy, but others are more broadly related to the civil rights claims of the DR movement. The book’s attention to the DR arguments is mentioned by most reviewers of FCC, often with approval for the book’s refutation of those arguments.

The discussion of the DR movement is such a prominent aspect of the book that it seems to have become a selling point; bioethicists who are unfamiliar with DR arguments can use FCC to gain a perspective. The prominence of the book and its authors, especially in comparison to the lack of such prominence among DR advocates and their publishing venues, means that DR advocates must take these criticisms seriously.

This article will examine FCC’s presentation and critique of a number of positions advanced by the DR movement. We are not particularly concerned with the prenatal policy, but rather with FCC’s characterization of the DR movement and the flaws it claims to detect in the general arguments of the DR advocates. The book combines a sophisticated understanding of the theoretical basis of the movement with a number of very strong criticisms.

At best, FCC supports a much-attenuated version of civil rights for people with impairments. This is true even though the authors claim that their bioethical conclusions are consistent with a respect for disability rights.

Our primary purpose is to identify the basis of the conflicts that persist between the two fields. FCC's conclusions regarding the moral legitimacy of DR must be analyzed before we can understand the complex and strained relations between DR advocates and practitioners of bioethics.

## II. CONCEPTUAL BASIS OF THE DISABILITY RIGHTS MOVEMENT

Disability is socially constructed. This claim is at the core of the DR movement and it is one of the primary grounds on which the movement has been criticized. However, FCC accepts the DR concept of social construction and bases its critique on more subtle grounds.

Social construction is traditionally expressed by use of a certain dichotomy regarding the etiology of disability. The dichotomy distinguishes a biomedical categorization from the social disadvantages that can accompany such a categorization.

- *Impairment*: a biomedical categorization of an individual (or a feature of an individual) as abnormal.
- *Disability*: the disadvantage that accrues to individuals with impairments due to environmental (social and physical) barriers that limit the participation of such people.

Disability is seen as an interaction between biomedical condition (impairment) and social environment, rather than a straightforward property of an individual. The movement stresses the importance of the social environment in creating disability. The exact terminology is not crucial, but the distinction is. The initial source of this innovation is unclear, but it may have originated with "The Fundamental Principles of Disability," a 1976 manifesto published in the UK by the Union of the Physically Impaired Against Segregation (UPIAS 1976).<sup>1</sup> The distinction has been termed "the leading theoretical achievement of the disability rights movement" (Wasserman, Bickenbach, & Wachbroit, 2005, p. 13).<sup>2</sup>

FCC accepts the dichotomy, the vocabulary, and (at least provisionally) the social construction of disability that follows from that reconceptualization (pp. 284 ff.; unless otherwise noted all page citations are to FCC).

The impairment/disability distinction is widely used for conceptualizing the social construction of disability, but it has shortcomings. One problem is that it assigns a technical, stipulative meaning to a term of ordinary language (disability).

Another problem is the asymmetrical contrast between impairment and disability: impairment is a biomedical category whereas disability is a certain kind of disadvantage. We offer a simpler dichotomy to express the social construction of disability, one that distinguishes between two kinds of

disadvantages. Some disadvantages result directly from impairments themselves and other disadvantages result from the social conditions in which people with impairments live.<sup>3</sup>

- Conditional Disadvantages of Impairment (CDIs): Disadvantages that are experienced by people with impairments, but which are produced by the social context in which those people live.
- Unconditional Disadvantages of Impairment (UDIs): Disadvantages that are experienced by people with impairments, but which are produced irrespective of their social context.

The expression CDI, rather than the technical, stipulative term *disability*, will carry the theoretical weight in our discussion. The social construction of disability is the claim that the disadvantages experienced by people with impairments are predominantly CDIs. The term UDI will designate a category of disadvantage that has heretofore gone unnamed: disadvantages that flow directly from impairments, without significant social contribution.

On the traditional view, almost all disadvantages of impairment are UDIs. Removal of UDIs can only be accomplished by removal of the impairment itself. Because impairments are properties of individuals (not societies or social contexts), the *problem of disability* is seen as a problem of individuals, to be dealt with (if at all) by medical cures and rehabilitations. DR advocates have labeled this view *the medical model* of disability.

The least contentious examples of UDIs are the tautological ones: people who are blind cannot see; people with paraplegia cannot walk. Blindness and paralysis are diagnostic categories of impairment; the inability to see and walk are (tautological) UDIs that are associated with those categories. Traditional thinkers have mistakenly assumed that blindness and paralysis entail all sorts of other inabilities—non-walkers cannot move through town on their own or use public transportation; blind people similarly cannot navigate on their own or read in libraries. Until late in the 20<sup>th</sup> century it was commonly assumed that neither paraplegic nor blind people were eligible for a free public education and their lack of education was a direct product of their impairments.

The DR movement has amply demonstrated that the inabilities just listed (except the tautologies) are CDIs—they are conditioned by the inaccessible environments that people who have impairments now live in. The DR movement sees *the problem of disability* as the CDIs. Impairments and UDIs are taken as brute facts of human variation. They are simply not a topic of direct DR interest.

The assumption that impairment inevitably involves extensive disadvantages (UDIs) is, according to the DR movement, merely an expression of the stigma that society has always placed on impairment. By assuming that almost all disadvantages of impairment are UDIs, innate to the impairments

themselves, members of the majority (nonimpaired) society are freed from the responsibility to remedy those harms.

When non-DR thinkers imagine living with an impairment, they dwell on vague intuitions of dread, pity and the social discredit that constitutes the stigma of disability (Goffman, 1963). This stigma itself constitutes a higher order social condition for disadvantage, because it draws attention away from more direct social causes of disadvantage.

A person who unconsciously accepts the stigmatizing assumption that people with paraplegia are “home-bound” may fail to recognize that such people’s isolation is caused by inaccessible buildings and transportation. The DR movement concentrates on identifying disadvantages that are socially constructed (CDIs such as environmental barriers) and finding ways to eliminate them.<sup>4</sup>

Philosophers of the analytic tradition are often leery of the concept of social construction because it is associated with a kind of relativism that seems to ignore the objective world (Hacking, 1999). Such worries are irrelevant to this discussion. The social construction of disability from impairment very often refers to objective, literal, material construction. Examples are buildings with stairway entrances that are barriers to wheelchairs and libraries that lack Braille or electronically readable texts.

Other barriers are matters of social behavior (e.g. discrimination in hiring) and so are less literally constructed than these examples. But barriers are real things; the fact that they are socially constructed does not detract from their material reality. The choice to construct barriers is a choice to segregate our population, privileging the groups that can pass beyond the barriers and penalizing those that cannot.

### III. THE CIVIL RIGHTS CONTEXT OF THE MOVEMENT

DR activists see their movement as strongly analogous to the movements for racial civil rights, women’s rights, and other similar movements (gay rights, immigrant rights). Those who fail to appreciate the civil rights nature of the DR movement tend to patronize and trivialize it as a mere variant of the disease- and impairment-based charities that have dominated the twentieth-century public image of disability.

The DR movement’s self-conscious alignment with other civil rights movements is crucial for understanding its arguments. Without it—with only the perspective of the medical model—the arguments are incoherent. The civil rights status of the DR movement is often criticized by use of a simple disanalogy. It is said that there is nothing innately disadvantageous about race and sex, but impairments are innately disadvantageous. Some early critics considered this to prove the blatant futility of the DR movement. Because social remedies cannot make a blind person see or a paralyzed

person walk, disabled people should just face facts and get on with their lives (Wendell, 1996, p. 55).<sup>5</sup>

The disanalogy does pick out a general feature of impairment that is not shared with race or sex. But the disanalogy ignores the distinction between CDIs and UDIs. The DR movement is directed only towards the remediation of CDIs, disadvantages that are socially mediated. So the fact that UDIs cannot be socially remedied is irrelevant to the DR claim for justice.

The same distinction can be hypothetically applied to other civil rights movements. Suppose there really were innate biological grounds for disadvantage of a particular race or sex—for example, diseases for which the disadvantaged group was susceptible. Would that fact reduce the legitimacy of a group's claim for remediation of the remaining disadvantages that were socially (not biologically) maintained? Surely not.

The political ideology used to justify racism, sexism, and oppression of people with impairments is the assertion that disadvantages of these groups are not socially mediated, but are biological and innate and therefore unavoidable. This view has been rejected within the academy with respect to race and sex.<sup>6</sup>

As we will see, it has yet to fall in the case of impairment. Disadvantages are often still assumed to be innate and the DR movement is seen to be asking for the impossible (i.e., social cures of UDIs). But just as the cures of sickle cell disease and breast cancer were not goals of the civil rights movements for African-Americans and women, the removal of UDIs is not a goal of the DR movement.<sup>7</sup>

Although the social construction of disability is explained and endorsed in FCC, we will show that the endorsement is misleading. The authors find special reasons to challenge the justice claims of the DR movement while affirming those of other civil rights movements. In a society governed by the conception of justice urged in FCC, disabled people would be in a uniquely vulnerable position.

#### IV. OUR AUTHORS ON THE SOCIAL CONSTRUCTION OF DISABILITY

From page 284 to page 287 the reader of FCC is presented with an articulate and accurate account of the core distinction of the DR movement. The distinction between impairment and disability is laid out almost exactly as we did in the introductory section of this article.

Impairments are biomedical facts about individuals and disabilities are the disadvantages that are produced for people with impairments by the environment in which they live.

Whether an impairment . . . results in a disability depends on the social environment of the individual. . . . [I]t is a mistake to assume that the only way or the preferable way to prevent disabilities—and hence to achieve equal opportunity—is by preventing the physical or mental impairments that result in disabilities. Instead, we can break the connection between having an impairment and being disabled—if we are willing to make sufficient changes in our social environment. (p. 287)

The DR advocate who reads this passage will feel quite at home. Disabilities are the socially conditioned disadvantages of impairment. These disadvantages can be removed without removing impairments, simply by changing the environment.

What more could the DR advocate ask for? We will consider two additional expectations. The first is the *generality expectation*: Do the authors acknowledge the social construction of disability whenever it is relevant throughout the book and not only in this single discussion? If disability is truly conceived as socially constructed, then social influences on disadvantage should be acknowledged when they are relevant.

The second expectation is the *parity expectation*: Do the authors of FCC infer the same justice consequences from the social construction of disability that are inferred for other civil rights movements? The authors affirm their support for the justice claims of other civil rights movements (pp. 16, 172, 188, 220–221, 283). Social responsibility for removing the barriers should apply equally to the socially constructed disadvantages of disabled people.

Neither the generality nor the parity expectation is fulfilled. The failure of the generality expectation can be covered briefly. The parity expectation is a more complex topic, and will be addressed in the following sections.

Is the social construction of disability acknowledged in appropriate contexts throughout the book? No. Except in the core discussion of social construction, the terms disability and impairment are used as synonyms throughout the book. Only once is the social construction of disability again mentioned in its full, material sense (p. 319)

The concept of social construction is mentioned in two other places, but is given a trivialized interpretation that has no impact on social policy. Social construction is said to be a mere social convention about what names to use, such as when to *call* an impairment a disability (p. 117, n. 2) or an abnormality an impairment (p. 150). Elsewhere in the book the disadvantages of disabled people are blamed directly on biological conditions, with scarcely a thought given to social mediation.

For example, one of the authors' major conclusions is that genetic interventions to prevent disabilities (for example the prenatal policy) are not only permissible but are required by justice. Their summary of the grounds for this conclusion is this: "Justice includes a commitment to equal opportunity,

and genetically based disabilities, like other disabilities, impair opportunity” (p. 270). The term “disability” in this passage clearly means “impairment” (simply because social mediation cannot be “genetically based”). Disadvantages are attributed directly to the biomedical condition, without social mediation. As in almost all of the book, this passage ignores the social construction of disability.

## V. RADICAL SLOGANS AND PSEUDOSLOGANS

The core discussion of DR occurs in Chapter 7, beginning with a section entitled “Challenging the Rhetoric: The Radical Disabilities Rights Advocate’s Complaints” (p. 264). The significance of the term “radical” is somewhat unclear. At first it appears that radical views are those that criticize the prenatal policy. But the term is later used of a more general position that is not associated with genetics (the “change society not people” slogan to be discussed shortly).

The contrast between radical and moderate DR opinions is never explained. We are not told which DR principles the authors accept, but only the ones they reject. On careful reading, the criticisms imply a very broad rejection of DR principles and not merely a defense of the prenatal policy against the DR critiques.

One problem with interpreting the arguments put forth in FCC is the extremely poor documentation of what they take to be the DR position. Other topics receive numerous citations. The discussions of theoretical ethics are well cited throughout the book, and the history of eugenics in Chapter 2 is richly documented.

The DR challenges, comprising four distinct categories of argument and covering twenty-two pages, are documented by only two citations from DR sources. One is to a forty-three-page position paper internally published by a non-governmental organization entitled *Just Technology* (International League of Societies for Persons with Mental Handicap, 1994) and the other a five-page journal article that happened to have appeared in a bioethics anthology (Asch, 1989).

Two of the categories of DR arguments are reasonably similar to arguments in DR literature, the so-called expressivist argument and the argument from diminished support (see Parens & Asch, 2000, for a balanced discussion). However, two other alleged DR arguments were so unfamiliar that we decided to look into them further.

The first of these is a small issue, but it indicates a distressing lack of care regarding the DR literature. We include it because it is one of the very few attributions that are documented by a citation.

DR advocates are said to use what is called the “justice trumps beneficence argument.” This argument is said to claim that when considerations of

beneficence (welfare) conflict with justice, justice always wins regardless of how large the benefit or how small the injustice. “[O]bligations of justice are the weightiest obligation in all circumstances” (p. 271).

The authors refute the principle with no difficulty; it is a foolish principle. We checked the cited source, *Just Technology*. Although no page was given, it was easy to find “the principle of justice” in the short document. However, *Just Technology* simply does not state that justice always wins over beneficence. It only states that justice is always *relevant* (besides beneficence) to a government decision. Beneficence cannot be “the sole basis of governmental obligation” (International League of Societies for Persons with Mental Handicap, 1994, p. 24).

A much more important attribution is derived from the alleged slogan “change society not people.” This slogan is discussed, off and on, from page 261 to page 294. Like the justice slogan, this was unknown to us. The slogan embodies an obviously false dichotomy. Why should the desire to change society be coupled with the requirement that we *not* change people? We were puzzled that the authors did not point out the false dichotomy.

But they do not. Instead they take the slogan “at face value” (absurdity and all) and draw implications from it which they then attribute to the DR movement: “Taken at face value, this critique condemns any effort to eliminate disabilities . . . For if taken literally the slogan would require accommodating those with impairments *rather than* using medical science to prevent or correct impairments” (p. 265, emphasis in original).

The authors proceed to “take the slogan literally . . . at face value” and attribute those implications to radicals of the DR movement. We are given no evidence that anyone ever intended the slogan to be interpreted in this way. The slogan shapes the treatment of social construction for the rest of the chapter.

For example, the authors declare that they “still need an account of why our society should, as the slogan says, prevent disabilities by modifying social arrangements rather than by modifying people” (p. 287). The absurd implication that impairments should never be cured or removed is presented as a central contention of the DR movement (or at least of its radical wing).

As usual, no citation was provided for the attribution. So we searched for the source. The results were surprising. In a Google Internet search performed during October of 2005, we found only four hits for the slogan “change society not people” (with or without a comma). The very first hit was an Internet site containing the chapter of FCC that discusses the slogan.

The second was an accidental use of the four words in a sentence with another meaning. The last two were web pages created by social conservatives who quoted the slogan as a way to discredit progressive social movements. Absolutely no web site, DR or not, used the slogan affirmatively.

As far as we can tell “change society not people” is not a slogan of the DR movement, or of any other movement. It is a pseudoslogan used as a stalking horse by conservatives who falsely attribute it to progressive groups because it is so easy to ridicule. We know of only one other use of the pseudoslogan: an earlier paper by one of the authors contains the same refutations of the DR movement as Chapter 7, including the pseudoslogan (Buchanan, 1996).

As a control we did a Google search on a genuine slogan of the DR movement, “nothing about us without us.” This slogan received 63,300 hits. DR slogans are out there, but “change society not people” is not. In conclusion, about half of the arguments attributed to the DR movement in FCC are straw men. They are easy to refute, but they do not represent the views of DR advocates.

We insist that it is not hard to find sophisticated expressions of the goals of the DR movement.<sup>8</sup> Problems for the DR movement do not end with its mischaracterization, however. The authors of FCC proceed to directly challenge the parity expectation. They offer a series of arguments that the DR movement does not share the legitimacy of other civil rights movements; morally important asymmetries exist between the DR movement and other movements.

## VI. CRITIQUE #1: DR THREATENS THE BASIC COOPERATIVE FRAMEWORK

The authors acknowledge that the barriers that segregate people with impairments are socially constructed. The DR movement proceeds to argue that these barriers are unjust and should be removed. Does FCC agree? No.

Their account of social construction is followed by a series of arguments supporting the claim that the duty to remove barriers for people with impairments is weaker than the duty to remove barriers for other groups that are disadvantaged in the same way (i.e. by social construction). Nondisabled members of society are said to have a legitimate interest in maintaining the barriers that segregate people with impairments. The interests of other dominant groups (men, Caucasian Americans, heterosexuals) to maintain the barriers that privilege them over other disadvantaged groups (women, African Americans, homosexuals) are said to be illegitimate. In other words, an asymmetry is said to exist between the DR claims and other civil rights claims. This has the potential to alienate advocates of other civil rights movements from the DR movement.

The first argument alleges that, unlike the other movements, the DR movement implies unacceptably radical changes to the economic system. The argument appears in a section entitled “Options for Eliminating Disabilities.” This section begins with a chart of four different ways in which (the

authors say) equality of opportunity could be created for people with impairments (p. 288). The first two ways involve changing people with impairments, using medical or educational means, so that they can access the benefits of society. The next two ways involve changing society, the DR approach.

Number three is to increase access by “removing barriers in the physical infrastructure of social interaction.” This would include creation of accessible buildings and sidewalks, Braille reading materials and captioned television broadcasts.

Number four is described as being more “far-reaching” because it goes beyond the physical infrastructure to change the institutional infrastructure of social interaction. This last category is said to entail major changes in the fundamental socioeconomic structures of society—what the authors call the “basic cooperative framework.”

The final two approaches collapse two distinctions. The first distinguishes physical from institutional infrastructure. The second distinguishes degrees of change, moderate versus extreme. The authors consider physical infrastructure (approach #3) to involve minor modifications, but institutional changes (approach #4) to affect the “basic cooperative framework,” the very core of our social and economic system. This produces the illusion that physical change is never radical but institutional change is always radical.

With no more argument than this, the authors proceed to allege that the DR movement is committed to radical and fundamental economic change, because that is the only kind of world in which disabled people can be integrated. Nowhere do the authors document or argue that this is an implication of the DR movement.<sup>9</sup>

Some DR advocates, like some advocates of other civil rights movements, do claim that capitalism is the source of repression (Russell, 1998). This is a minority opinion within the movement and not at all a defining feature. The assertion that the DR movement requires a full economic restructuring of society is unsupported.

## VII. CRITIQUE #2: DISADVANTAGES REMAIN

Two more arguments for the asymmetry between DR and other civil rights movements begin with the following passage, which explains why civil rights for blacks and gays are more legitimate than those for disabled people:

The limitations a gay or black person suffers are injustices in a quite uncontroversial sense: they are forms of discrimination. While deaf people and others with disabilities certainly do continue to experience discrimination, *they would continue to suffer limited opportunities even if*

*there were no discrimination against them . . . .* The fact that it is costly to remove barriers of discrimination against blacks or gays has no moral weight because no one can have a morally legitimate interest in preserving unjust arrangements . . . . the costs of changing society *so that having a major impairment such as deafness imposes no limitations* on individuals' opportunities are not so easily dismissed. Those costs count from a moral point of view, because there is a morally legitimate interest in avoiding them [i.e. avoiding the costs]." (pp. 283–284, emphases added)

The first argument is based on the fact that limitations would still remain for disabled people after discrimination is removed. This will be addressed in the present section. The second, that there is a "morally legitimate interest" in avoiding the costs of accommodation, will be discussed in the following section.

The passage states that when discrimination is removed from black or gay people, all of the problems related to their condition (being black or gay) are solved.

This is not so in the case of people with impairments. When discrimination is removed, other disadvantages remain—those caused directly and immediately by the impairments. This is true of course; the UDIs remain. But if discrimination is removed, then the CDIs will be removed. Keeping this distinction in mind, the alleged asymmetry can be restated as follows:

Although people with impairments do experience discrimination that produces CDIs, ("disabilities" in the social construction sense) they would continue to suffer limited opportunities (namely UDIs) even if there were no discrimination against them.

This is true but irrelevant. UDIs are not a part of the argument. Why should the existence of UDIs weaken the civil rights argument against the CDIs? Suddenly the authors appear to assume that the movement demands that all limitations of impairment must be remedied—as they put it, ". . . changing society so that having a major impairment such as deafness imposes no limitations on individuals' opportunities."

But no DR advocate has ever claimed that justice requires the removal of *all* disadvantages of impairment. Like other civil rights movements, DR advocates demand only the removal of discriminatory treatment and remedies for its past effects. The fact that *other* disadvantages would remain is irrelevant to the justice of the DR claim. If it were proven that women or African-Americans had innate biological disadvantages beyond those of discrimination, would that weaken their claim to equal treatment? We assume the answer is no. The same holds true for the DR movement. If the authors believe that it does not, they owe us an explanation of the difference.

We do not mean to imply that the distinction between UDIs and CDIs is an easy line to draw. It is not. Disadvantages do not come brightly stamped with labels of “Socially Caused” and “No One’s Fault.” Social policy regarding these issues must be determined by serious moral, factual, and political debate.

But the same is true of every other civil rights movement. Differences of opinion about social responsibility for the effects of racial discrimination are reflected in conflicts over affirmative action. Opinions also differ regarding social responsibility for the loss of income that may be connected to a women’s biological role in childbearing. Mandatory paid maternity leave and government-subsidized childcare are examples of solutions that address these concerns, but are currently controversial.

Similar debates must take place on the specific policies related to disability. Disadvantages might still remain even after it is decided that unjust social barriers are removed. The fact that “disadvantages will still remain” for people with impairments is no reason to single out the DR movement as uniquely unjustified. The recognition that *some* (not all) disadvantages of disability were socially caused was the entire point of the social construction of disability.

### VIII. CRITIQUE #3: THE MAXIMIZING INTEREST AND “GO FISH”

The third argument for a moral asymmetry concerns the special nature of the interest that a nondisabled member of society has in opposing the civil rights demands of DR advocates. As previously quoted, the authors claim that no one can have a morally legitimate interest in preserving discriminatory barriers against blacks or gays (p. 283).

They say that this does not apply to discrimination against disabled people because their integration into a nondisabled workforce (for example) violates the “maximizing interest,” a very important moral interest that is not violated by the integration of blacks and gays: “Each individual has an important and morally legitimate interest [the maximizing interest] in having access to a cooperative scheme that is the most productive and rewarding form of interaction in which he or she can participate effectively” (p. 292).

This ideal scheme is later described as the most “enriching” and “fulfilling” (p. 294). How could anyone challenge this worthy goal? According to the authors, the DR movement challenges it. The authors claim that a world in which disabled and nondisabled people were fully integrated would be less productive, rewarding, enriching, and fulfilling for nondisabled people.

Discussion of the maximizing interest begins with an analogy that is meant to depict the true relationship between nondisabled and disabled people.

Suppose we wish to play a card game in which everyone in a mixed group of individuals from 5 to 50 can successfully participate. . . . Choosing an institutional infrastructure [for society] means choosing which game, defined by which set of rules, will be played. If the game chosen is contract bridge, then some individuals in the group—namely, the 5 year olds—will not be able to participate effectively. . . . A simpler game (a less demanding infrastructure for social interaction) can be chosen so that everyone will be able to participate successfully. We can play “go fish.” (p. 288)

Nondisabled people are like adults. Disabled people are like five-year-olds. A card game that integrates five-year-olds is not the most rewarding and enriching for adults. Likewise a society that integrates disabled people is not the most rewarding and enriching for nondisabled people. The authors go on to say:

As the example of the very young children attempting to play contract bridge shows, participation by “disabled” individuals can cause “discoordination” and reduce the benefits that the “abled” might otherwise reap from complex forms of cooperation. The abled—those whose capacities can meet the demands of the more complex scheme of cooperation—have an interest in having that scheme chosen. Let us call this the “maximizing interest” . . . (p. 290)

We assume the authors are unaware of how aggressive this analogy will seem to a disabled person who reads their book. The analogy likens disabled people to children and nondisabled people to adults. Disabled people are not the first to have been labeled (and treated) as girls and boys. African-Americans and women were both infantilized during their long histories of discrimination.

The go-fish analogy is central to the authors’ critique of the DR movement. It is said to illustrate flaws in the movement and it is repeatedly cited as having demonstrated those flaws. It is assumed to be transparent in its implications, with no argumentation needed.

We are not shown, for example, that wheelchair-accessible sidewalks are less enriching to walk on for nondisabled people, or that television broadcasts with captions are less fulfilling than noncaptioned broadcasts to those that can hear, or that libraries with large collections of computer-readable texts are less rewarding than those that are accessible only to people who can read visual print.

The “go-fish world,” in which disabled people are integrated but nondisabled people live unfulfilled lives, is never described in detail. In particular, no reasons are given for why an integrated world must be a *simpler* world.

The authors offer no grounds for their assumption that disability rights require that the entire society must be structured so that every citizen must

be able to do every job. Legitimate job requirements are not discriminatory and the DR movement has never argued against them.

The DR movement would like to see much more attention paid to identifying jobs that can be accomplished by individuals with various impairments, removing artificial barriers to those jobs (such as inaccessible workplaces and tools), and matching the jobs to those who can do them. The laws that now prohibit discrimination in hiring are unequal to the task of producing equality in employment of many groups that have been historically discriminated against, such as women and African Americans. This is dramatically true of people with impairments (35% of such people are employed fulltime as compared to 78% of nondisabled people).

But the policy that every single job must be designed so that every single human being could accomplish it is no part of the DR movement. The go-fish world has no resemblance to a world that treats disabled people with justice.

A truly integrated society would not be simpler, as the go-fish analogy alleges. It would be more complex and more flexible. Alternate accessible means would be available for individuals to accomplish any goal that was inaccessible to them. The moderate accommodations that already exist show the value of this flexibility. Curb ramps are used by people with mobility impairments, but also by parents with strollers and workers with hand carts.

Captioned television programs accommodate people with hearing impairments, but also assist in learning to read, in learning a second language, and in enjoying television in the same room as others who do not want the disturbance of the audio program. These examples illustrate that improvements in access increase everyone's choices, not only those who absolutely need them.

The go-fish analogy, with its least-common-denominator concept of integration, is a false depiction of the goals of the DR movement. The discussion of the maximizing interest together with the demeaning go-fish analogy grossly misrepresent the goals of the DR movement.

## IX. DO ACCOMMODATIONS HARM THE NORMALS?

The authors of FCC have a persistent anxiety that the nondisabled majority will be unjustly harmed if disabled people are granted the kind of civil rights that are granted to women and minorities. This anxiety can be seen even in passages that seem intended to be conciliatory.

For example, "Our society has learned through its efforts to accommodate people with disabilities that in many cases lowering the barriers to participation need not be unduly burdensome to others" (p. 320). This may sound innocuous to people who are not familiar with the DR movement.

But FCC's talk about *lowering* barriers is subtly different from the DR movement's talk of *removing* barriers. It suggests that the barriers are there for a reason—that barriers somehow improve the quality of an institution rather than (as the DR movement has it) arbitrarily prohibiting the participation of citizens with disabilities. This was the message of the go-fish analogy; the barrier to children's participation (the complexities of the rules of contract bridge) was exactly what made the game rewarding for adults. The analogy implies that the integration of disabled people *should be expected* to spoil things for nondisabled people—and that it is a surprise that “in many cases” it does not!

The claim that civil rights for disabled people “need not be unduly burdensome” sounds like a very grudging endorsement to us. Are we being too picky about the authors' words in this passage? Do they really intend to question the legitimacy of DR? Yes, they do. The passage continues as follows:

Still, many accommodations involve losses as well as gains. Tax codes and forms that might be fully comprehended by the cognitively impaired, for example, might be insufficiently detailed for efficient and fair allocation of tax burdens, and the gains for the few would not justify these losses. (p. 320)

The case sounds convincing, until we look into it. Have intellectually impaired people requested easier tax forms? Would the provision of such accommodations force the country into badly allocated tax burdens?

Here are the facts. In 2003 only thirteen percent of the U.S. population prepared their own taxes by hand. Sixty-two percent went to professional tax-preparers and twenty-five percent used computer assistance (Guyton, Korobow, Lee, & Toder, 2005). Eighty-seven percent of the country appears to be tax-preparation-impaired. Tax assistance is like curb cuts: it accommodates the “normals” just as much it accommodates those who are labeled cognitively impaired.

Like the go-fish scenario, the tax form scenario is a manufactured worry. It is a fantasy that serves only to fan the fears of integrating disabled people into the “normal” world. The imaginations of the authors caused this problem, not the DR movement. Historians of racism and sexism can tell similar tales about the overheated imaginations of earlier civil rights opponents.

If our concern with the tax form example seems exaggerated, we must point out that it is the nearest thing to a real-world case of a harmful accommodation in the entire book. How would civil rights workers for minorities and women respond to the following comments?

“Our society has learned through its efforts to accommodate African-Americans that in many cases racial integration need not be unduly burdensome to Caucasian-Americans,”

or

“. . . we have learned through our efforts to accommodate women that in many cases sex integration need not be unduly burdensome to men.”

These are expressions of condescending opposition, not of support for the rights of women and minorities. The same is true when such statements are made about disability.

The authors of *FCC* repeatedly express their support for civil rights—but not for disability rights. Lists of civil rights movements are discussed in seven separate places in the book. In four of these lists, disability rights is omitted. These four lists all include race/ethnicity and sex/gender, with class and religion added to some of them (pp. 16, 172, 188, 220–221).

In a fifth list, disability is claimed to have less legitimacy than two other civil rights categories because it conflicts with the maximizing interest (the case discussed previously, from pp. 284 ff.). Only two out of the seven lists include disability rights without criticizing it. One is a historical summary of protected classes (p. 126), and the other a list of the victims of the eugenics movement (p. 110).

These final two lists, the ones that include disability rights without criticizing it, occur in factual contexts that carry no moral commendation. They are mere historical reports, not judgments of moral correctness. In contrast, the four lists that exclude disability occur in contexts that affirm the moral correctness of anti-discrimination against the listed classes. Never is discrimination against disabled people morally condemned in this way. (Incidentally, each of the universities with which the authors are affiliated has a non-discrimination policy that includes disability.)

None of the other protected classes—race, sex, religion, social class, or homosexuality—is subjected to the kinds of challenges that face disability in this book. No special majority interests are discerned that give legitimacy to people who wish to discriminate against homosexual people, people of particular races, or women. But disability must face the maximizing interest. The pseudoslogan “change society not people” could as well be (mis)attributed to the gay rights movement as to the DR movement—but the DR movement bears its brunt in this book.

For other kinds of discrimination the authors insist that “no one can have a morally legitimate interest in preserving unjust arrangements” (p. 283). But they deny that the same principle holds for discrimination against disabled people. They find ways to defend such discrimination and invent scenarios (such as the go-fish analogy and the tax-form example) that throw doubt on the legitimacy of disability rights.<sup>10</sup>

Our purpose in examining *FCC* was to try to discern the basis of the continuing conflicts between the DR movement and mainstream bioethics. We have learned, in this particular case, that the conflict is much more direct than we had anticipated.

The authors endorse the social construction of disability and they claim that the prenatal policy is consistent with a belief in the legitimacy of DR. But their defense of the prenatal policy directly leads them to challenge the legitimacy of DR. This suggests (if it does not prove) that the two positions are actually *inconsistent*, at least in the authors' minds. The authors may honestly believe that they give disability rights all the respect *that it deserves*. But they do not believe that DR deserves the respect that ordinary, moderate DR advocates claim for it—namely the same respect that is granted to other civil rights movements.

*From Chance to Choice* was not intended to be a book about disability rights. The DR critiques were not examined for the purpose of evaluating the DR movement, but of defending the prenatal policy and other applications of genetic medicine.

But the defense of the prenatal policy smoothly segues into a challenge to the legitimacy of DR. Does this mean that bioethicists' rejection of DR is the key to the longstanding conflicts between DR and bioethics? Of course not. It would still seem to be *logically* possible to fully endorse disability rights and the prenatal policy simultaneously (even though these authors fail to do so).

Nevertheless, it is important to recognize that one of the very first sustained attempts by prominent bioethicists to deal with the DR critiques of the prenatal policy ended up with the bioethicists rejecting disability rights (at least as those rights are understood by their advocates).

One of FCC's coauthors has elsewhere acknowledged the tension in this combination of beliefs:

It takes considerable rhetorical agility to urge the public to support screening programs so as to prevent the conception of handicapped individuals while at the same time insisting that full respect be paid to such developmentally disabled adults as are already among us. (Dan Wikler quoted in Reinders, 2000, p. 1. For discussion see Asch, 2003).

This rhetorical agility was not exercised in FCC—disability rights were challenged. A fuller understanding of possible relationships between bioethics and the DR movement must await the work of bioethicists who seriously study the DR literature and are willing to dialogue with its advocates. As the real DR slogan says, "Nothing about us without us."<sup>11</sup>

## NOTES

1. Other early sources include the World Health Organization (1980) and Beatrice Wright (1983); see discussion in Amundson, 1992; Wendell, 1996; Wasserman, 2001.

2. The authors of FCC recognize this distinction, but (remarkably) document it by citing three of their own publications (p. 20). It is unclear whether they believe that it is their own innovation. Except for Wikler's early recognition that mental competence is determined in part by social environment (Wikler, 1979), the cited works are all after 1990—far too late to count as innovation.

3. Our expression “from impairments themselves” should be read as “from impairments together with their non-social contexts.” We mean to distinguish between socially-caused disadvantages and disadvantages that are *not* socially caused. See the discussion in note #4.

4. Both the impairment/disability distinction and our CDI/UDI distinction are pragmatic tools, meant to elucidate the issues of political debate. Their metaphysical status can be challenged. For example, some authors have argued that the impairment category itself is socially constructed: impairment should not be treated as an objective scientific category in the way the impairment/disability distinction may be taken to imply (Amundson, 2000; Tremain, 2001, 2002). In a different approach, Anita Silvers urges the creation of a “neutral conception of disability” that does not presuppose disadvantage. She claims that no impairment is disadvantageous *in itself*; disadvantages can only happen in environmental contexts (Silvers, 2003). The point is correct. Nevertheless, our concern is to distinguish social contexts, for which society can be deemed responsible, from, e.g., physical contexts (such as the law of gravity) for which society has no responsibility.

5. The expression “disabled people” is currently disfavored in much of North America because “disability” is used as a biomedical category, equivalent to what we term “impairment.” Our version of the impairment/disability dichotomy, just introduced, follows the British usage. Disabled people are people who are disadvantaged by social barriers, not people who receive a particular biomedical diagnosis of disabled. The objectionable implications of disabled person do not apply.

6. We do not deny that racism and sexism exist in the academy, only that they are openly endorsed.

7. Claims for proportional medical attention to diseases that are disproportionately suffered by disadvantaged groups (sickle cell disease, breast cancer) are quite a different kind of argument from claims that those diseases must be cured as a condition for social justice. The latter claim has never been made, just as the DR claim for the cure of UDIs has never been made.

8. We have included in the References a few easily available sources prior to publication of FCC (Eisenberg, Griggins, & Duval, 1982; Oliver, 1990, 1996; Shapiro, 1993; Linton, 1998).

9. Perhaps they take this to follow from the slogan “change society not people.” As we have shown, this slogan is itself specious.

10. Eventually the authors do acknowledge that disabled peoples' interests in employment may outweigh the majority interests in segregating disabled people from the workforce in many cases (p. 301). However, the maximizing interest still hangs over the heads of disabled people. At any time, the scales of justice (of the relative importance of conflicting legitimate interests) might tip towards the nondisabled majority. No other civil rights group is forced to live with this threat.

11. This paper has greatly benefited from conversations with Adrienne Asch and Larry Heintz, and comments from Anita Silvers and two anonymous referees. RA's work was supported by a grant from the National Institutes of Health (No. S06-GM08073).

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