Beyond (Models of) Disability?

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The strategy of developing an ontology or models of disability as a prior step to settling ethical issues regarding disabilities is highly problematic for two reasons. First, key definitional aspects of disability are normative and cannot helpfully be made value-neutral. Second, if we accept that the contested concept of disability is value-laden, it is far from obvious that there are definitive reasons for choosing one interpretation of the concept over another. I conclude that the concept of disability is better left ethically openended or broad enough to encompass the examination of various ethical issues (such as oppression, minority rights, or physical discomfort). Alternatively, the concept of disability could be altogether abandoned in order to focus on specific issues without being hindered by debates about the nature of disability. Only political costs, rather than conceptual considerations internal to the models, could be weighed against such a conclusion.

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I. A TALE OF TWO MODELS

Anyone familiar with disability studies will be aware that there are various models of disability, that is, various ways to conceptualize what "disability" means, descriptively and normatively. In spite of a multiplication of models, a general distinction can helpfully be made between individual and social ones.

The "social model" of disability took off in the seventies, propelled by disability activists¹ and later theorized by Vic Finkelstein (1980) and Michael Oliver (1990), among others. The social model was a reaction to the individual "medical model," which conceptualized disability as a tragedy or

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problem localized in an individual body or mind, the definition and solution of which were to be provided by medical experts.² By contrast, the social model presented disability as a social phenomenon caused by social oppression and prejudices, rather than by individual "impairments" in the person. The social model thus defines impairments as defective limbs or mechanisms in the body, and "disability" as the exclusion from which impaired people suffered. This exclusion is the real problem; it is caused by a social failure to make proper inclusivist arrangements rather than by individual biological dysfunctions.³

Although the individual/medical model remains influential in biomedical circles, at least insofar as disability is often assumed to be a negatively valued state associated with a physical anomaly (Silvers, 2003), healthcare professionals are doubtlessly increasingly aware of environmental factors contributing to disability (e.g., Field and Jette, 2007); the discipline of disability studies considers that the social model is the "new paradigm" and heavily criticizes the medical model, perceived as outdated and oppressive.

It may immediately seem odd to have sociologists and disability activists telling medical doctors what to do because these experts seem to speak from different disciplines. Their common language, however, is power, and social modelists maintain that individualist conceptions of disability are constructed along ideological guidelines while claiming to have a scientific objectivity (Oliver, 1990). Disability theorists aim at reversing unjustified assumptions inherent to the medical model and at empowering disabled people as their slogan, popularized in the 1990s, "Nothing About Us Without Us," suggests.

Although it is wise to remember that policies about health and medical discourses may conceal ideological content, it also seems quite radical to argue that disability is exclusively a social phenomenon to be dealt with by social measures. Yet, such is the claim of social modelists.

As the "new paradigm," the social model of disability, underwent various criticisms; this essay suggests that many of them misfired by attempting to be ontological rather than political arguments. Conversely, I also suggest that social modelists may overstep the boundaries of their criticism of the ideological/oppressive use of the medicalization of disability by being over-suspicious of all individualist/experiential standpoints on disability. It is not clear whether all such standpoints hinder the full inclusion of disabled people within society; in fact, their proponents think the contrary. My overarching claim is that the disagreement between individual and social modelists about whether disability should qualify individual experiences or social experiences, or both, is largely based on the political consequences of doing so. Since individual and social modelists have substantially different ethical issues in mind, it may be a more productive approach to focus on these more specific ethical issues and either use an ethically open version of the concept of disability or abandon it altogether. I grant that potentially valid political reasons may be weighed against such a proposal. These reasons,

however, should be presented in terms of political costs,⁴ rather than as confused ontological arguments.

II. THE DICHOTOMY CRITICISM

One very widespread and important criticism of the social model is that it severs the connection between impairment/biology/medicine, on the one hand, and disability, on the other. When we talk about "disability," social modelists hold that we ought to be referring only to a social phenomenon rather than to a medical one.

This disconnect is negatively criticized because it is said to amputate important dimensions of disabled people's lives. Some people experience disability as an individual rather than a social problem, such as people with severe and chronic illnesses that cause them constant discomfort. Still others do not perceive themselves to be an oppressed minority and resist the idea that they have a false consciousness or have internalized the oppression victimizing them (Shakespeare and Watson, 2001, 9). Some may well associate their identity with discrimination (for instance, toward their gender, race, or sexuality) but not mainly with disability. The social model focuses on a standpoint external to these individual experiences of disability and therefore neglects and discredits them (Morris, 1991; Shakespeare and Watson, 2001).

Social modelists indeed claim that (these subjective experiences of) impairments ought not to contribute to an understanding of disability. Because the social model of disability creates a clear dichotomy between impairment and disability by denying the causal relation or equivalence between both, let us call this criticism the *dichotomy criticism*.

The dichotomy criticism is the most obvious criticism one can make of the social model. It is also one of the gravest, one that the social model could not survive if it were accurate. It is the most obvious and fatal criticism because it squarely denies its starting point. The initial insight offered by the social modelist is that we ought to take our distance from the medical model because this traditional model of disability is masquerading a social problem as an individual one and is dissimulating social oppression under medical categories and biological misfortune.

III. HOW THE DICHOTOMY CRITICISM MERGES INTO THE "NEGLECTING/DENYING IMPAIRMENTS" CRITICISM

It is facile to criticize the social model for its claim that we ought to disconnect the notions of impairment and disability because it is their main and most provoking or counterintuitive claim. Critics need to provide arguments to substantiate their criticism and we should expect these arguments to say why it would be unwise to follow the apparently well-founded social modelist agenda of reserving the word "disability" for social barriers and oppression.

It is striking, however, how little argument is provided to support the dichotomy criticism per se. These arguments exist,5 but they are not generally brought up along with the dichotomy criticism in a way that would substantiate a constructive discussion about this disagreement. Instead, the denial of the validity or desirability of the impairment/disability distinction is surprisingly tautological. When authors write that "in maintaining that disability is squarely socially caused, the social model theorists are oversocialising their position" (Terzi, 2004, 152), or that "it would be neither straightforward or desirable to make the distinction between impairment and disability that [Oliver] takes for granted" (Shakespeare and Watson, 2001, 18), they are saying little more than that they disagree with making disability an exclusively social affair. When others write that impairment cannot be considered separately from disability "[b]ecause the dichotomy between impairment and disability ... is not ontological" (Anastasiou and Kauffman, 2013, 447) or "precisely because impairment and disability are not dichotomous" (Shakespeare, 2014, 25), they are saying little more than "there is no dichotomy because there is no dichotomy."

This kind of answer is evidently insufficient. Social modelists no more take the impairment/disability dichotomy for granted than others take the impairment-disability causality for granted. Social modelists cannot be criticized only for not being in sync with what people commonly mean by "disabilities," because it is precisely this common meaning that they are denouncing as being rooted in prejudices and oppression.

Putting problematic tautological claims aside, many authors substantiate the dichotomy criticism with the claim that the social model underestimates the importance of impairment (Morris, 1991, 10; Anastasiou and Kauffman, 2013, 445). This is a common conceptual confusion that I want to dispel here. The claim that the social model underestimates the importance of impairment does not necessarily support the dichotomy criticism. Instead, it supports what could be called the "Neglecting/Denying Impairments Criticism." This criticism takes various forms as it attacks various distinct claims that it associates with the social model. It criticizes the social model for "neglecting," "denigrating," "denying," or "dismissing" the phenomenon of impairment (Anastasiou and Kauffman, 2013, 445; Shakespeare, 2014, 18). Normatively, the social model is criticized for underestimating the intrinsic gravity or badness of impairments or certain biological conditions (Morris, 1991, 10). Ontologically, it is criticized for denying the objective reality of impairment (Terzi, 2004, 151).

Although there is some sophisticated literature arguing against and in favor of the objective reality of impairment, and whether it should be characterized as a "fact of nature" or a social construct (Abberley, 1987; Amundson, 2000;

Vehmas and Mäkelä, 2009, 42; Boorse, 2010), not all variants of the social model of disability are wedded to a social constructivist view of *impairment* as they are to a constructivist view of *disability*. Mainstream versions of the social model—or at least its UK version, best represented by Oliver and Finkelstein—simply do not deny that impairments are real and that they matter. One senses a clear irritation in Michael Oliver's writings (Oliver, 2013, 1024), because he has spent two decades repeating that the social model never meant to deny that impairments are real and important or that they may cause real harm independently from social intervention:

As a severely disabled tetraplegic, who every day of my life needs to make the necessary arrangements to be able to get up in the morning and go to bed at night and, indeed, use the toilet, I find such suggestions galling ... Of course, [we] are aware of the limitations that impairments impose. (Oliver, 2009, 48)

The social model need not deny that these personal experiences related to biological realities exist and matter or should be taken care of. If anything, Oliver suggested that a "social model of impairment" be developed alongside a sociology of disability (Oliver, 1996, 42). What he denies is only the idea that we should call them "disability."

Therefore, the "Neglecting/Denying Impairments Criticism" misses its target (at least when authors aim it at this mainstream social model, as they still do (cf. Anastasiou and Kauffman, 2013)).

However, some critics of the social model insist that the Neglecting/ Denying Impairments Criticism can count as a Dichotomy Criticism. They argue that the fact of creating a dichotomy between impairment and disability and of choosing to focus on disability has the harmful implication of undervaluing the importance of impairments. Sometimes, this claim is about the theory itself: it is a necessary implication of the social approach. Sometimes, this claim is about the badness of the consequences that the implementation of such a theory is likely to bring about, empirically speaking (Shakespeare, 2014, 17–9).

I believe that the second line of argument is promising because it engages with what the social model actually holds by challenging the way in which it assesses the political cost of using disability to refer to individual or social phenomena. However, before turning to those arguments, I want to suggest how the first kind of criticism made against the social model—according to which its exclusive focus on social dimensions of impairment-related limitations obliterates the importance or existence of personal or individual experiences of "disability"—is either very weak or question-begging and should be abandoned. Here is an illustration of this kind of claim:

The proponents of the social model use the distinction between impairment and disability in a radically different way, that of ontological (or social) constructionism. First, they draw a vertical line between biological properties and social dimensions of disabilities. After that, they argue only about social processes, that is, subject-dependent properties. However, by choosing to theorize only on sociological grounds, they detach biological and mental elements from the disabled subject. As a consequence, by neglecting or denying the underlying biological conditions of people with disabilities, they leave out a big part of their existence and activity. Finally, their disabled subject is not an individual with a full set of properties (biological, psychological, social) but, at best, a "half-person" with only social properties; a "half-man," biologically naked and only subjected to social values and roles.

In the social model, the methodological distinction between impairment and disability gradually slides into a false distinction that assumes an ontological quality. This is a basic tool of social constructionism, which results in reducing the multidimensionality of disability in a single-sided social constructionist dimension—a narrow caricature of real human conditions and considering disabled humans as "half-humans." (Anastasiou and Kauffman, 2013, 445)

Oliver has answered to this kind of criticism that he does not mean to represent the whole of personal experiences of limitations, pains, or vulnerabilities, but only the experience of being socially oppressed or limited. It is simply a "conceptual misunderstanding" to expect more from his theory: "the social model is not about the personal experience of impairment but the collective experience of disablement" (Oliver, 2009, 48).

It is hard to see how social modelists, focus on social oppression, and institutionalized ableism would imply that they do not care about, or discredit, other dimensions of human welfare. Yet, the argument presented above capitalizes on this sort of ad hominem evaluation.

To illustrate how tempting and yet dangerously speculative this kind of criticism is, consider another example: a similar argument could be levied against John Rawls for developing a contractualist theory of distributive justice that does not conceptualize severely disabled people as subjects of justice. The fate of these individuals is left for moral and political philosophers to determine at a later time. This is because Rawls's key interest, i.e., what he sees as "the fundamental question of political justice," is "what is the most appropriate conception of justice for specifying the terms of social cooperation between citizens regarded as free and equal, and as normal and fully cooperating members of society over a complete life?" (Rawls, 1993, 20).

The automatic assumption that not spending one's academic or even political effort on a cause means that one thinks little of the value of that cause or even that it does not exist is wrongheaded. Granted, it can be the case, in certain academic or political specific contexts, that ignoring an issue speaks volume, but it is far from obvious what exactly is being voluminously spoken. It could be, for instance, a particular theorist's belief or worldview. To judge people for picking the wrong value to spend their time maximizing or engaging with (for learning German instead of Spanish, for instance) is a rather epistemologically presumptuous terrain for one to step on. To further imply that valuing one thing implies undervaluing another is similarly risky.⁶ with impairments is certainly a worthwhile endeavor, and that to read in it a denial of the importance of other political and philosophical items—either by putting on a psychoanalyst hat or by finding it to be a necessary implication of one's theory within a specific cultural context where this theory may become an ideological vector—is a conceptually and empirically dubious effort. It would also jeopardize all scientific or philosophical endeavors by keeping their validity hostage to a dangerously speculative scrutiny at best and an ideological witch-hunt at worst.

Just like Rawls thought that the key question of political justice was a contractual one, social modelists think that the key question of disability is a social one. It may be held that both are wrong in thinking this, but not that they do not care about other issues, such as the personal experiences of disabled people. Indeed, both have explicitly attested to the contrary. We have to take these arguments at face value if we are to respect the kind of rational discussion that philosophy aims at achieving. Suspicions of prejudices or harmful cultural consequences lurking behind a theory can be used by a critic to better detect the weak points of an argument (inaccurate or conceptually implausible premises), but it is these formal weaknesses that must serve to discredit an argument, not the suspicions.

Unless they can avoid falling in the previously mentioned traps, I therefore suggest that critics of the social model should no longer use the impairment/disability dichotomy and/or the exclusive theoretical commitment of the social model on social oppression and barriers as indications of a shortcoming inherent to the theory itself. To blame the social model for proposing a truncated ontology of human beings is "to criticize the social model for not being something that it has never claimed to be" (Oliver, 2009, 49). To further suggest that social modelists are implicitly adopting such an ontology is either question-begging or too speculative and weak an argument.

IV. CAN THE DICHOTOMY CRITICISM BE CONCEPTUALLY SUBSTANTIATED?

To sum up, social modelists do not deny that impairments exist or matter. However, they do deny that impairments should in any way be called, or seen as causing, disabilities. As we saw, criticisms of that view (the Dichotomy Criticism) take some tautological or speculative forms that are dead-ends. The critics hold that disability is at least partly due to impairment or biological conditions. The social view holds that disability is wholly caused by socially constructed barriers.

The social model could limit itself to a strictly pragmatic claim: we ought to reserve the name of "disability" for social oppression alone because of the bad consequences that doing otherwise would have. We will examine this claim afterward. However, social modelists are (or at least many of them sound) ontologically bolder and reserve the term of "disability" to connote a "social situation" (UPIAS, 1976, 3–4) out of politico-semantic opportunism. For instance, social modelists traditionally use a historical-materialist line of argument to argue that disability is a "social relationship." To understand disability, they claim, is to understand "a definite relationship to the way in which the material conditions of life are created and recreated" (Finkelstein, 1980, 9; Oliver, 1990).

The immediate answer to that claim is a counterexample: many individuals who would uncontroversially be said to qualify as "disabled" in society would still be "disabled" if a Utopian discrimination-free society came about (Terzi, 2004). Blindness, for instance, would still constitute a biological dysfunction that would cause, independently of social structures, many experienced limitations. The social modelist's counter-answer is that the blind person is only disabled when society disables her. Otherwise, she is impaired or limited, but not disabled.

These claims and counter-claims make it look like both sides to the debate are emitting a semantic fiat. This is a natural place to already state my conclusion: they are, but their attempt to justify it would be better served by political rather than ontological arguments. Both sides have important but distinct concerns, and their war over naming their respective concern "disability" is doomed to fail. Here is how it could have succeeded.

Their fundamental dissension has to do with the causal dimension of disability (whether it is caused by biology or society). In order for the ontological disagreement to progress, we need a benchmark definition that does not include a prior commitment to either view, that is, a definition of "disability" that is neutral on the causality issue. The party who comes up with (1) the most convincing causality-neutral definition of disability that (2) then is best matched by their causality-committed definition of disability will have provided a valid argument for integrating their view of causality in the definition of disability.

A neutral definition of disability could look like this one: Disability is not only a (1) limitation (e.g., like not being able to read minds), but (2) a limitation that one has which most people around one do not have (it would have statistical and species-related features). (3) It is a long-lasting or recurrent state and (4) it affects people with an impairment, understood as a biological dysfunction.⁷

However, it turns out that any such definition will be incomplete because all sides agree that disability has a normative component, in that it calls for a response, medical, social, or otherwise. To know how to respond to disability, one must know the roots of disability: one must know, therefore, what causes the aspects of disability that must be addressed. A thinner concept is imaginable but would be unhelpful. If the idea of causality is key to the notion of disability, disability would be an essentially contested concept.⁸ If disability is a relational, comparativist, normative notion, an uncontested notion of disability would be a holy grail. It would provide clear answers to a plethora of difficult moral questions concerning whether and how stringently society must attend to the needs of disabled people.

We must examine my claim that an axiologically neutral concept of disability would not do much work in solving these difficult questions: is it really the case? Anita Silvers was perceptive to the problem of different theorists or practitioners speaking at cross-purposes when using the concept of disability. This essay also unmasks some confusions typical of this mutual misunderstanding. I am, however, skeptical that conceptual disagreements about the ontology of disability can, or should, be overcome (although I believe that political and empirical disagreement about the consequences of the use of a specific definition of disability might be). Silvers, however, appears more optimistic and proposes a neutral concept of disability. She suggests "some constituents of, and constraints upon the adequacy of, [a neutral notion of disability]," that is, a notion of disability that is not valueladen (Silvers, 2003, 473).

Silvers is particularly interested in suspending the assumption of neutral or positive value associated with being disabled.⁹ (She is particularly interested in the conceptual clashes between bioethicists and disability advocates, just as I am interested in the conceptual disagreement between proponents of individualist and social disability models.) According to her neutral view of disability, one should assume neither that being disabled makes one's life worse off (she associates this view with the bioethicists) nor that it is neutral (she associates this view with disability theorists).

To say that "disability" can connote both positively and negatively valued states does not necessarily translate into a neutral notion of disability. It can just as well translate into two categories of disabilities: those that have (a) no negative impact on the person and those that are (b) negatively value-laden. That seems plausible, if not evident. Silvers suggests that we take "disability" to mean (c) a neutral notion that has not yet fallen into either category (a) or (b). Surely that is good advice for theorists who assume that all disabilities are to be negatively valued and for theorists who assume that all negative value of disability is medically and socially constructed. These two sides appear sometimes unduly to generalize what only holds for some cases of disability.

However, I wonder how much philosophical work this neutral notion of disability is supposed to accomplish. My worry is that it is limited to allowing heated debates to cool down. If so, it would contribute to a discursive ethics between proponents of the medical and of the social models, or between (most) (utilitarian) bioethicists and (most) disability theorists. As such, a proto-axiological (i.e., yet to be qualified in terms of value) version of disability is useful but only plays the role of a modest, tactful, peaceful, explicitly ontologically fallible way to engage with contrary views. My concern is that it does not help us otherwise.

To put my point more forcefully, Silvers's proposal could be read as a proposal to abandon the notion of "disability" altogether from ethical discussions and deal with more specific value-laden elements-such as pain, loss of options, limitations (including particular socially-caused limitations), oppression, etc.-instead of the blanket, ambiguous notion of disability, which could, or not, imply all, some, or none of these other notions. This is undoubtedly one of Silvers's explicit ambitions: that we do not conflate disability with these. What to make, then, of her proposal to develop a "theory" based on a neutral account of disability (Silvers, 2003, 485)? I am not sure that this idea qualifies as a theory as much as a call to keep existing social/ medical/normalizing theories in their proper places. It reminds us not to jump the gun by assuming that disability is a bad thing or by assuming that it can never be intrinsically bad but that only social failures create (it and) its badness. However, disability becomes ethically interesting as a phenomenon when it is value-laden, and so it seems that we will quickly have to drop the general proto-axiological/neutral conception of disability as the moral and political discussion about any particular case progress.

I note that the neutral conception of disability may still have an identitybuilding use; this use might helpfully remain value-neutral. Silvers's analogy with the "construction of a neutral conceptualization of women's differences" as "one of the great conceptual achievements of the twentieth century" points in this direction (Silvers, 2003, 483). A space for women and disabled people to say "I am neither better or worse off; I am just different" seems desirable, but that kind of claim may be more profitable within identity-building endeavors or claims for recognition than within the kind of moral and political discussions that Silvers has in mind (notably, on issues of inclusion and redistribution).¹⁰

To be potentially valued (or associated with more specific notions that are valued) in positive, negative, and neutral ways does not make a concept neutral: it makes it pluralistic value-wise. This is why I find that Silvers's argument, while pointing to the "possibility and desirability of constructing a neutral conception of disability," actually buttresses the case for letting go of the essentially contested concept of "disability" in ethical discussions and using more specific items of discussion, such as "oppression" or "physical pain and discomfort." "Disability" could still be used as a shorthand for these notions: disability qua oppression, disability qua medical condition, etc. It could be that some of these understandings of disability would be wrongheaded (such as disability qua tragedy or disability qua punishment for sinful former lives), but one would then criticize these specific notions (such as being punished for a sinful former life) for their own wrongheadedness, rather than for not matching an objective concept of "disability."

I conclude that (1) the concept of "disability" cannot be used as an objective ontological benchmark because disability is too contested a concept and (2) a neutral version of this conception would not take us far enough to settle substantial disagreements.

In light of this discussion, we can understand my suggestion to altogether abandon the concept of "disability" as far as ethical considerations are concerned. The debate around the causes of disability is not an empirical debate about what the factual cause of disability is, but rather a normative disagreement about the nature of disability. In fact, more often than not, it seems to be a disagreement about which problem ethicists, disability activists, and policymakers ought be looking at or prioritizing (for instance: social oppression versus medical care).

The concept of "disability" is used to raise irreducibly different ethical problems, and I see no good reason why we should not look at them all—and why we should not seriously question the helpfulness of a concept that is preventing us from doing just that. It seems unproductive when debates around "disabilities" have the effect of confusing the ethical problem that one means to examine. Spending too much time discussing whether we could give the additional name of "disability" to this problem (or answering someone who says we could not) is time not spent on the problem itself. One could echo Oliver's impatience to that effect as he repeats that his model is meant to be used against oppression, and that theorists should deal with *that*, rather than saying that he is misusing the concept of "disability" when referring to that problem and no others. I could not agree more, but would also urge social modelists, in turn, not to blame others for calling a medical condition a "disability," as long as they are making progress in their examination of this medical condition and its ethical implications.¹¹

Let me illustrate how an open-ended view of disability would prove more fruitful than any reductionist conceptual monopoly over "disability." Consider the debates around cochlear electronic implants that are designed to enable deaf persons to hear sounds and yield a range of successful results from being aware of environmental sounds to engaging in conversations as hearing people would (National Institute of Deafness and Other Communication Disorders [NIDCD], 2013). The debate has often been posed in terms of culture *versus* medicine and on whether deafness was considered to be a culture or a disability (e.g., Davis, 1997; Lane and Grodin, 1997). Since the 1980s, members of "deaf culture" have mobilized against cochlear implants, comparing it to a form of genocide, as they were not seen as "curing" a "disability" but as erasing a culture (Sparrow, 2005). Others held that refusing cochlear implants for children in the name of "deaf pride" amounts to child neglect (Savulescu, 2009).

However, an attentive look at the various issues related to cochlear implants reveals that medical research to improve this technology is not as antithetical to cultural criticisms of the social construction of language and hearing as one may think. Heated public debates too often reduce the multifaceted complexity of a situation into a dichotomic caricature that eclipses specific

issues that are important to the lives of those people who are actually grappling with this situation. For instance, biomedical engineers (Eshraghi et al., 2012) and developmental biologists (Duncan and Fritzsch, 2012) will focus on improving the functionality of cochlear implants. Jurists will analyze legal and policy matters such as informed consent, the best interests of children, and the boundaries of surrogate decision-making (Brusky, 1995). One might object that the very fact of recognizing the value of scientific research and of legal or policy work in relation to the use of cochlear implants already takes a normative stand in favor of these projects. In a trivial sense, much of what we do or say carry some normative weight, simply because the author of an action or a statement often implicitly suggests that she endorses or values her own endeavor or decision. I do not deny that specific public policies, laws or widespread individual choices can have a damaging impact on some disabled people or feed an ableist ideology. This has been called the "expressivist objection" in the context of assessing the morality of prenatal testing for instance (Parens and Ash, 2000; Klein, 2011). However, identifying such "expressive harms" is tricky: there is a risk that the fear of such alleged harm would be unfounded just like there is a risk that insidious, ideological harms go unnoticed because complainants have trouble identifying a concrete victim or a clear causal connection between the "expression" and the harm. In any case, detecting elusive forms of harm requires more than an a priori claim that punctual, microscopic events or work done within a specific field of expertise to improve the situation of people with disabilities, necessarily entails a macroscopic normative stand on disability and disabled people. Short of a more substantial description of harms, vague cultural allegations hardly constitutes an argument against the worth of these endeavors to the people who undertake, desire, or benefit from them. Although cultural criticisms of the normalizing effects of cochlear implants on the deaf community is also desirable, it is hard to say that research about, for example, the correlation between meningitis and cochlear implants (Cohen et al., 2005) is worthless to parents considering whether cochlear implants are in the best interests of their child. It would be undemocratic or paternalistic on the part of the deaf community to deny the voice of their members, especially on the ground of lofty comparisons of medical treatments with a genocidal project. People who received cochlear implants may choose to use it or not for primarily physical rather than cultural reasons. For instance, one research indicated that children who did not use cochlear implants were "not necessarily against them in principle, admitting that they had friends for whom an implant proved to be helpful," but rather disliked the discomfort or pain that it caused (Watson and Gregory, 2005, 53). As time passed, the dichotomic caricature slowly dissolved as tenants of a reductionist understanding of the function and implications of cochlear implants came to acknowledge that this medical intervention had multiple dimensions that

called for multiple accounts and professional competences, rather than a single response. Psychologists Leigh and Paludneviciene wrote in 2011 that:

It took decades of struggle before culturally Deaf adults who decided on cochlear implantation began to be viewed by opponents of the procedure no longer as automatic traitors, guilty of betraying their Deaf culture values but rather as individuals who wanted exposure to different sensory experiences, in this case auditory stimulation, while holding on to the use of their signed language. (Leigh and Paludneviciene, 2011, vii)

I conclude that the concept of disability is better left open-ended and broad enough to encompass the possibility that different cases of "disability" could have very different ethical implications: the could be evaluated negatively or neutrally, call for various solutions from, and translate into different kinds of moral blames or moral demands made to various social actors. To emphasize that I do not think that we can make great theoretical use of this "ethically neutral" concept, I would rather call it "ethically open" or "proto-axiological" and suggest we think of it as an umbrella concept, or a shorthand, for a group of phenomena categorized as statistically abnormal limitations and associated with (though not necessarily caused by) atypical modes or levels of human functioning.¹²

However, some experts from various fields (medicine, disability theory, sociology, bioethics, and policymaking or activists) would resist these suggestions, because they think it would result in politically harmful consequences. This set of considerations is external to the individual or social theories or models: they are concerns about the badness of the consequences that using a theory or model within particular social contexts will bring about. These are the important but essentially distinct considerations to which we now turn.

V. THE REAL DEBATABLE ISSUE: THE COSTS OF THE SOCIAL MODEL

There are practical costs for using individual or social models of disability, both in and out of the academic sphere. Calculating these is largely an empirical issue, and a hard, perhaps partly insurmountable task easily biased by one's normative stand. I only wish to briefly present these costs here and suggest that they are the only reason why the definitional disagreements about disability should keep going.

First, from a political viewpoint, it starts making sense to conflate the dichotomy criticism with the "denying/denigrating impairments" criticism. This conflation may be the result of a misunderstanding or misinterpretation of the social model and nonetheless have real, harmful effects. As Tom Shakespeare puts it, while prudently acknowledging that this is a criticism about the use of the theory rather than the theory itself:

The social model so strongly disowns individual and medical approaches, that it risks implying that impairment is not a problem. ... The social model suggests that people are disabled by society not by their bodies. Rather than simply opposing medicalization, it can be interpreted as rejecting medical prevention, rehabilitation or cure of impairment, even if this is not what either UPIAS, Finkelstein, Oliver, or Barnes intended. (Shakespeare, 2010, 269–70)

Similarly, the criticism that the social model is not looking at the most urgent problem, or the most fixable one, also starts making sense as an empirical claim.¹³ For instance, some theorists have criticized the social model for "the privileging of sociological or any other expertise to replace medical or psychological expertise," because the "experience" of disability thus contemplated is too incomplete; they suggest that "when it comes to mundane technological intervention what is needed is a [more individualist] position from which to understand disability," one that considers "how individuals practically understand it and how it practically affects their everyday life" (Dewsbury et al., 2004, 156). I find it telling that their main concern is "with *wby* it is that the various commitments and concerns of what we class as the social model are proving of little help to us" (Dewsbury et al., 2004, 145). Leaving the "why" aside, we can simply read that the social model is not helping *them* to deal with the particular problem with which they are concerned. Why not opt for another model?

Many of these theorists do not feel that they can put the "why" question aside and embark on a further endeavor to debunk the social model, rather than using another one better suited to the issue at hand. In my opinion, the philosophical quest to establish either (1) that the social model is useless or mistaken in the abstract, or (2) that individual problems are the only one with which theorists of "disability" should be concerned is a questionable preliminary step, at best theoretically immodest and distracting, and at worst doomed to fail. Their insistence may be due to the fact that the social model has become such an important paradigm that there is a real fear that alternative models would be discarded as not heeding the social model's insights and therefore have to position themselves either as an incrementation to the social model or as a substantial refutation of it. That this apprehension is caused by factors external to the model itself does not make it irrational. For instance, Tom Shakespeare and Nicholas Watson (2001, 12) reported a tendency "to evaluate ideas on the basis of their conformity to social model orthodoxy" reflected in the international journal Disability and Society (see, however, Oliver's answer, 2009, 50).

Analyzing the experience and needs of a particular group of disabled people and finding that the social model "explicitly undergirds the discourses and practices of this group," another author reported the

dangers that the social model can be interpreted in a way which privileges some impaired identities over others, sanctions a separatist ghetto which cannot reach out to other groups of disabled and disadvantaged people, and weaves a tangled web around researchers who adhere to the emancipatory paradigm. (Humphrey, 2000, 63)

The most convincing claim that can be levied against the social model is not that it does not care about the right thing or has a bad metaphysics—something it never tried having. It is that as a mainstream paradigm, it marginalizes some people and some important problems by indirectly discrediting their claims. How much it does that (and how much would getting rid of the social paradigm help) is a difficult empirical question. For one thing, I note that while most disability theorists find that the social model is the undefeated paradigm of disability (Pfeiffer, 2001; Shakespeare and Watson, 2001), the dominant view in bioethics remains an individualist framework (Silvers, 2003; Vehmas, 2004, 34).¹⁴ Hence, one may worry that experts misevaluate the political influence of using one framework or another, given their own fields of practice, teaching, and research.

At the opposite end of the political spectrum, social modelists have good reasons for wanting to keep "disability" a public matter and to insist that we think of "being disabled" as being disabled by society, rather than by our body or natural misfortune. Finkelstein and Oliver think that "the limitations that our functional impairments impose upon us are an inadequate basis for building a political movement" (Oliver, 2009, 48). Furthermore, Oliver argues that a theoretical and political "[focus] on impairments and difference will only de-politicise the social model and will not lead to the development of [useful alternative models]" (Oliver, 2013, 1025).¹⁵ This is a controversial claim, considering the various proposals of alternative models.¹⁶ Whether or not Oliver's claim about the negative social costs of using a model of disability other than the social one is correct, however, is an empirical claim.¹⁷

Certainly, there is a clear political advantage in vindicating the idea that disabilities are a social failure, because this conceptualization would help individuals not to interpret their disabled status as a natural misfortune they have to put up with, or one for which they cannot ask help, at least not with the sense of entitlement generally underlying right claims rather than charity. It would also improve individuals' self-respect and confidence: they are not the problem, society is.¹⁸

As someone working in and promoting the nascent field of "disability ethics," my own leaning is to focus on specific ethical problems, to get semantic confusion out of the way, and to put rhetorical and political questions back in their place. I am also generally skeptical when political interests cross over to the conceptual side to criticize a theory because of its uses, and even its misuses. That said, my main argument is not to side with either view about the political costs of defending an exclusively social or a partly medical model of disability. There are clearly sound empirical arguments to be made on both sides. Rather, I want to suggest that these questions are the only ones needing to be settled as far as using the term "disability" in ethical issues.

It seems to me that it is very hard, or not particularly productive, to criticize disability theorists for their choice of models based on *theoretical* grounds. Of course, conceptual frameworks can create or perpetuate as many problems as they solve. But, if that is the charge, I would encourage a closer criticism of a particular theoretical oversight or failure rather than a global rejection or defense of a universal model, especially since we are dealing with a profoundly contested concept.

VI. CONCLUSION

Circumventing the disability debate and dealing with more specific ethical issues seems like a more productive solution than engaging in a sterile disagreement about the definitive meaning of disability.

As Lorella Terzi suspects, taking seriously the possibility of dealing with various notions called other than "disability" "opens up the chance of a proliferation" of terms other than disabilities to denote "inability or being unable to do things." She holds that such a possibility is *politically* correct but "appears less justified *theoretically*" (Terzi, 2004, 152, my emphasis). I believe just the contrary: it appears theoretically sound to focus on specific ethical issues regardless of whether we should call them "disabilities," but this may come at an unacceptable political price.

From a *theoretical* point of view, a proliferation of concerns bearing various names other than "disability" does not worry me. Disabilities do raise various different ethical issues irreducible to one another. If anything, giving various essentially different problems the same name may cause more confusion—theoretically and politically—than good, as the mutual misunderstandings exposed in this essay reveals. On the other hand, the *political* implications of owning the term "disability" and using it to push one's ethical concerns up the political agenda remain an issue up for debate, but not a problem with the theories and models themselves.

NOTES

1. Although the earliest social constructionist roots can be dated back to the late 1940s (e.g., Barker, 1948), the UPIAS's *Fundamental Principles of Disability* are generally quoted as the effective starting point of the "social model:" "Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society" (UPIAS, 1976, 3–4).

2. This is a presentation of the traditional medical model of disability as it is presented and criticized by its opponents, rather than the more plausible version sensitive to social factors that are increasingly widespread in the medical profession (Field and Jette, 2007). Although I am debunking general claims to the effect that sociologists of disabilities or disability activists ignore the medical model of

disability, I would just as much oppose simplistic claims to the effect that medical doctors ignore the social model of disability. These broad attacks on either side of the social/medical divide engage with straw men and are not productive.

3. Although there are numerous variants of the individual and social models, these general definitions are commonly used and sufficient for my argument. In particular, the criticism of the social model that I will examine is generally addressed to variants of the American constructionist version and of the English historical-materialist version of the social model. For a survey of different versions of individual and social models, I recommend Pfeiffer (2001); for a good summary of the social model's creed, see especially Pfeiffer (2001, 44–45).

4. I take political costs to include personal or emotional costs to individuals making use, or not, of disability politics or discourse in the construction of their identity or claims for recognition.

5. There are some good arguments that are provided about the cost of disconnecting disability from impairment (see Shakespeare, 2014, 17–19; also Terzi, 2004, 152); we will come back to them.

6. It is not that such evaluations can never be made. On the contrary, we ought to question the worthwhileness of the endeavors of both the person who spends her day counting blades of grass and the theorist of blades of grass counting.

7. Social modelists have no problem granting (4): disability affects only biologically impaired people. Impairment is closely, but not causally, related to disability: it is a vector of it; it characterizes the victims of social oppression, like the trait of being a woman or an ethnic minority.

8. As Anita Silvers (2003, 473) defines it: "Essentially contested concepts have underspecified definitions that permit people with different beliefs to flesh them out in different ways. Although initially introduced as a technical philosophical term, [it] now is used in political science to characterize theoretical notions that necessarily will be understood differently by people whose political value differ."

9. Silvers is concerned with whether disability is intrinsically bad or not, rather than whether it is caused by biological impairments or oppressive social structures. However, her argument to achieve a neutral conception of disability can meaningfully be applied to the latter disagreement, *mutatis mutandis*.

10. Issues of (recognition of) identity can merge into issues of social, political, economic inclusion, but when they do so they have become value-laden. For instance, women may demand that their caring work be socially redistributed otherwise or better paid, for instance, but that is underlaid by claims about the undervaluation of such work. The same goes for disabled people whose skills or whose input to society are being undervalued, and for their pain, loss of options or opportunities, and problems that deserve medical treatment or compensation.

11. If, for instance, proponents of the medical model actively deny that society is partially to be blamed for a particular disabled patient's lowered quality of life, then social modelists can argue that they are wrong for specific reasons applying to that case. But to systematically assume that using the concept of disability to qualify an individual situation or experience implies a denial that social structures may affect or create disabilities or corollary-specific kinds of moral responsibilities is unwarranted—and medical modelists have often replied that social modelists underestimated the capacity of individualist models of disability to take social factors into account.

12. See Silvers (1998) and Amundson (2000) for the distinction between modes and levels of human functioning.

13. As we saw, it is implausible to criticize a political effort for being mistaken about the value of its endeavors or to suggest that caring about oppression was a (comparatively) worthless endeavor. This argument would work with a theory of counting blades of grass, but not for a model focusing on social oppression. To put an objective evaluative bar so high would be metaphysically immodest.

14. There is an important distinction to be made between kinds of "individualist focuses" that one can take: (1) a reductionist understanding of disability as a strictly individual phenomenon and (2) a focus on the individual qua object of one's professional competences. Environmental factors are not denied in the latter case, but they are only considered to the extent that one has the competence to deal with them. This distinction opens the door to further discussions about whether experts can be de facto reductionist, even though they do not wish to endorse a reductionist model in principle, and whether some kind of reductionism is not sometimes desirable. Dealing with these questions thoroughly falls beyond the scope of this essay.

15. Elsewhere, he writes: "I do not deny the influence (some positive, some negative) of medicine, charity and welfare in the lives of disabled people but none of these offers a sufficient foundation for building a distinctive model of disability" (Oliver, 2009, 43).

16. See, for instance, Shakespeare and Watson's (2001) continuum/variation version, and French and Swain's (2004).

17. For instance, Oliver (2013) invoked "cuts in [disabled people's] benefits [now] being justified on the grounds [of an individualist impairment-focused model of disability]." Anecdotes or empirical intuitions such as these suggest that social modelists may not have seized how much empirically stronger their claim must be if it is to succeed as a political claim.

18. Of course, clear conceptual distinctions can be made between causes of disability, attribution of blame (if any), and responsibility to eliminate disability or address disabled people's needs. However, we are concerned here with the social perception of disability, which generally, for better or worse, conflates these issues.

REFERENCES

- Abberley, P. 1987. The concept of oppression and the development of a social theory of disability. *Disability, Handicap and Society* 2:5–19.
- Amundson, R. 2000. Against normal function. *Studies in History and Philosophy of Science Part C* 31:33–53.
- Anastasiou, D. and M. Kauffman. 2013. The social model of disability: Dichotomy between impairment and disability. *Journal of Medicine and Philosophy* 38:441–59.
- Barker, R. G. 1948. The social psychology of physical disability. *Journal of Social Issues* 4: 28–38.
- Boorse, C. 2010. Disability and medical theory. In *Philosophical Reflections on Disability*, eds.D. C. Ralston and J. Ho, 55–90. Dordrecht: Springer.
- Brusky, A. E. 1995. Making decisions for deaf children regarding cochlear implants: The legal ramifications of recognizing deafness as a culture rather than a disability. *Wisconsin Law Review* 1995: 235–70.
- Cohen, N., A.Ramos, R.Ramsden, W.Baumgarten, A.Lesisnski, G. O'donoghue, T. Lenarz, and B. Fraysse. 2005. International consensus on meningitis and cochlear implants. *Acta Oto-Laryngologica* 125: 916–17.
- Davis, D. S. 1997. Cochlear implants and the claims of culture? A response to Lane and Grodin. *Kennedy Institute of Ethics Journal* 7: 253–8.
- Dewsbury, G., K. Clarke, D. Randall, M. Rouncefield, and I. Sommerville. 2004. The anti-social model of disability. *Disability and Society* 19: 145–58.
- Duncan, J. S. and B. Fritzsch. 2012. Evolution of sound and balance perception: Innovations that aggregate single hair cells into the ear and transform a gravistatic sensor into the organ of corti. *The Anatomy Records* 295: 1760–74.
- Eshraghi A. A., C. Gupta, O. Ozdamar, T. J. Balkany, E. Truy, and R. Nazarian. 2012. Biomedical engineering principles of modern cochlear implants and recent surgical innovations. *The Anatomy Records* 295: 1957–66.
- Field, M. J. and A. M. Jette, eds. 2007. *The Future of Disability in America*. Washington, DC: National Academies Press.
- Finkelstein, V. 1980. Attitudes and Disabled People. New York: World Rehabilitation Fund.
- French, S. and J. Swain. 2004. Whose tragedy: Towards a personal non-tragedy view of disability. In *Disabling Barriers—Enabling Environment*, 2nd ed., eds. J. Swain, S. French, C. Barnes, and C. Thomas, 34–40. London: Sage.
- Humphrey, J. C. 2000. Researching disability politics, or, some problems with the social model in practice. *Disability & Society* 15: 63–85.
- Klein, D. A. 2011. Medical disparagement of the disability experience: Empirical evidence for the "expressivist objection." *AJOB Primary Research* 2: 8-20.
- Lane, H. and M.Grodin. 1997. Ethical issues in cochlear implant surgery: An exploration into disease, disability, and the best interests of the child. *Kennedy Institute of Ethics Journal* 7: 231–51.

- Leigh, I. W. and R. Paludneviciene. 2011. Introduction. In *Cochlear Implants, Evolving Perspectives*, ed. I. W. Leigh and R. Paludneviciene, vii–xi. Washington, DC: Gallaudet University Press.
- Morris, J. 1991. *Pride Against Prejudice: Transforming Attitudes to Disability*. Philadelphia: New Society Publishers.
- National Institute of Deafness and Other Communication Disorders (NIDCD). 2013. Cochlear Implants [Online]. Available: https://www.nidcd.nih.gov/health/hearing/pages/coch. aspx (accessed November 1, 2015).
- Oliver, M. 1990. The Politics of Disablement. London: Palgrave Macmillan.
 - —. 1996. Understanding Disability: From Theory to Practice. New York: St. Martin's Press.
- ———. 2009. *Understanding Disability: From Theory to Practice*. 2nd ed. Hampshire, England: Palgrave MacMillan.
- 2013. The social model of disability: Thirty years on. Disability and Society 28: 1024–26.
- Parens, E. and A. Asch, eds. 2000. *Prenatal Testing and Disability Rights.* Washington, DC: Georgetown University Press.
- Pfeiffer, D. 2001. The conceptualization of disability. In *Research in Social Science and Disability: Exploring Theories and Expanding Methodologies*, eds. S. N. Barnartt and B. M. Altman, 29–52. New York: Elsevier Science.
- Rawls, J. 1993. Political Liberalism. New York: Columbia University Press.
- Savulescu, J. 2009, July 13. Refusing cochlear implants: Is it child neglect? *Practical Ethics' Blog.* [Online]. Available: http://blog.practicalethics.ox.ac.uk/2009/07/refusing-cochlear-implants-is-it-child-neglect/ (accessed November 1, 2015).
- Shakespeare, T. 2010. The social model of disability. In *The Disability Studies Reader*. 3rd ed, ed. L. J. Davis, 266–273. New York and London: Routledge.
 - —. 2014. Disability Rights and Wrongs Revisited. 2nd ed. New York: Routledge.
- Shakespeare, T. and N. Watson. 2001. The social model of disability: An outdated ideology? In *Research in Social Science and Disability: Exploring Theories and Expanding Methodologies*, eds. S. N. Barnartt and B.M. Altman, 9–21. New York: Elsevier Science.
- Silvers, A. 1998. A fatal attraction to normalizing: Treating disabilities as deviations from "species-typical" functioning. In *Enhancing Human Traits*, ed. E. Parens, 95–123. Washington, DC: Georgetown University Press.
- 2003. On the possibility and desirability of constructing a neutral conception of disability. *Theoretical Medicine* 24: 471–87.
- Sparrow, R. 2005. Defending deaf culture: The case of cochlear implants. *The Journal of Political Philosophy* 13: 135–52.
- Terzi, L. 2004. The social model of disability: A philosophical critique. Journal of Applied Philosophy 21: 141–57.
- UPIAS. 1976. Fundamental principles of disability. Union of the Physically Impaired Against Segregation [Online]. Available: http://www.leeds.ac.uk/disability-studies/archiveuk/ UPIAS/fundamental%20principles.pdf (accessed November 1, 2015).
- Vehmas, S. 2004. Dimensions of disability. *Cambridge Quarterly of Healthcare Ethics* 13: 34–40.
- Vehmas, S. and P. Mäkelä. 2009. The ontology of disability and impairment. In Arguing About Disability: Philosophical Perspectives, eds. K. Kristiansen, S. Vehmas and T. Shakespeare, 42–56. London and New York: Routledge.
- Watson, L. M. and S. Gregory. 2005. Non-use of cochlear implants in children: Child and parent perspectives. *Deafness and Education International* 7: 43–58.