The Social Meaning of Disability. A Reflection on Categorization, Stigma, and Identity

As disability becomes an ever more salient concept in international political and legal discourse, its social meaning must be better understood. Traditionally defined in medical terms and as an individual problem, it has for the last several decades increasingly become a socio-politically defined phenomenon. Disability pride has emerged as a social movement patterned after ethnic minority and sexual orientation movements. The one billion people who count as disabled nevertheless have illnesses and impairments that are largely understood as medical problems. Medicine continues to exert great influence on the social meaning of disability in general and the social valuation of various illnesses and impairments in particular. Whereas specific conditions may be socially valued, the overall category and label of disability connotes marginality and stigma. Under these conditions, disability policy, which ought to be a universal concern, risks being construed as a marginal and special-interest issue rather than a broadly relevant topic; this has potentially negative consequences for the majority of disabled people.

Key words: Disability, categorization, stigma, impairment, illness, prototypes, social meaning.

Introduction

Over the last few decades, disability has increasingly come to be defined in sociopolitical terms, as a matter of protection from discrimination, access to rights, and grounds for the redistribution of resources. This tendency is visible in national legislation (United States, 1990), international conventions (United Nations, 2007), and the work of international agencies (World Health Organization, 2011). The tendency is reflected and reinforced by the emergence of the interdisciplinary field of disability studies, which is to some extent built around the construal of disability as a historically contingent, socio-culturally constructed category (Lennard J Davis, 2013).
The latter point can be taken to mean one of two things. The first interpretation is that while the label of “disabled people” and “disability” only gained currency over the last century or so, there has always existed a distinct category of people with “long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations, 2007, p. 4). One of the early classics of the field, A History of Disability (Stiker, 1999), argued that the history of this category can be traced, *mutatis mutandis*, back to antiquity. Another, perhaps more radical interpretation, is that both the label and the category are relatively recent inventions. The British school of neo-Marxist sociology of disability, for example, linked the emergence of the category to the spread of wage labor and the exclusion of people with various impairments from the labor market (Oliver & Barnes, 2012; Oliver, 1990).

However one looks at it, disability today is a label that signifies bodily difference and social marginalization. But that is far from all. The political, and academic developments have coincided and to a considerable extent been influenced by disability activism, some of which was foundational to future scholarly work (UPIAS, 1976), some of which greatly influenced legislation (Pelka, 2012). The three developments effectively constitute a social movement, one inspired to a considerable extent by social movements based in ethnic minority status and sexual orientation, not to mention feminism. There are annual disability pride marches in many cities, as well as academic explorations of the analogies between impairment, sexual orientation, and sex/gender as components in cultural identity formation (McRuer, 2006).

Though the analogies exist, disability is also very unlike the other categories around which social movements have been built. For example, while movements based around ethnic minority status have sought to discredit racist assumptions about systematic biophysical differences between people, the disability movement has, necessarily, focused on the *valuation* of really existing biophysical differences, though also on the criteria that makes some but not all biophysical differences socially significant. And while the gay pride movement has increasingly emphasized the diversity of its membership and the importance
of “allies” in the mainstream heterosexual population, it remains founded on a single feature – sexual orientation – that has no obvious parallel in the disability movement.

The upshot of this is that the social meaning of disability is in flux. International treaties and national legislation that define the concept of disability also bring it into an increasing number of social fields, ostensibly as a label signifying access to rights and protections, as an argument for redistribution of resources, and, ultimately, as a means to achieve social justice.

Simultaneously, disability – as a category and as a label – has a social meaning influenced by well-established conflicts internal to the disability field. Some of these stem from the complex relationship between disability and its two most important “membership criteria”, having an impairment and having a chronic illness. Some stem from the relationship between these criteria themselves, and the ambiguous border between the two. Some stem from the continuing influence of medicalization (Conrad, 2008) upon the field of disability, the general movement toward sociopolitical frames of reference notwithstanding. This article explores the intersection of these three causes and their effect upon the social meaning of disability, with a view to understanding what the future of disability as a social category will be like.

The social meaning of disability as a distinct category

If there is a single, easy way to define disability, it has yet to be found. Most definitions involve some variation of the terms invoked in the UN Convention on the Rights of Disabled Persons as cited above, i.e. a social as well as a bodily component. Some attempts to model disability and disablement give great emphasis to social, political, and economic factors (Oliver & Barnes, 2012), some pay greater attention to psycho-emotional and interactional factors (C Thomas, 2007; Carol Thomas, 1999), some describe disability as a predicament involving multiple factors (Shakespeare, 2013), some stress the cultural dimensions of the concept (Snyder & Mitchell, 2006), but as far as I am aware no current theory has seriously attempted to entirely ignore either people’s bodies or the societies in which they live when considering disability.
A related, recurring feature of disability – as indicated in the introduction – is the conceptual distinction between disability as a historically contingent, socially constructed phenomenon, and those aspects of bodily structure or function that are a necessary condition for someone belonging to the category of disabled people. I mention this distinction with some trepidation, as it is a highly contested point within disability studies, and I do not wish to enter a discussion about whether biophysical features of individuals are ontologically prior to social phenomena such as disability.

Instead, I mention the distinction in order to make the following points. One, it is possible for a person to be disabled without recognizing themselves as such. Two, it is possible for a person to be disabled without being recognized as such by others. In fact, it seems entirely possible that the vast majority of the world’s disabled population recognizes itself (and is possible recognized by others) as members only of distinct categories of ill or impaired people – for example blind people, deaf people, people with multiple sclerosis, people with depression, people with schizophrenia, and people with specific kinds of intellectual disability – and not as members of a single category that is anything like “disability” as understood in academia, in laws, in treaties, or in policy documents (Shakespeare, 2013; World Health Organization, 2011).

This, of course, is the substantive point at which many if not most disability activists, scholars and social movement members are trying to get. It is one of the key points which has motivated neo-Marxist analysis of disabling political-economic mechanisms, post-structuralist analysis of cultural marginalization of people with all kinds of bodily abnormalities, as well as legislative efforts that very expressly do not generate lists of specific impairments as the basis for inclusion under anti-discrimination provisions. “Universalization” of disability policy, perhaps particularly associated with I.K. Zola (1989), is one of the central concerns of a great many people who work in the field.

Nevertheless, the dynamic identified above leaves considerable room for the negotiation of the social meaning of disability, both as distinct from the social meaning of specific impairments and illnesses and as a category which retains a
considerable degree of stigma. Therefore, we should probably pay some attention to reasons why someone might consider themselves (or others) a member of the category of disabled people, insofar as they are aware of the existence of that category, or ‘merely’ a member of impairment-specific or illness-specific categories.

*Disability stigma*

Sociological research on *disability stigma* derives primarily from the tradition after Goffman (1963), who joined “the concept of stigma to that of deviance” (Susman, 1994, p. 15), and opened up the social meaning of disability to further inquiry. In this tradition, disability is a form of involuntary social deviance, signified by physical signs, that causes negative responses. More recently, Link, Phelan, et al. (2014, 2001, 2006) have worked extensively on the conceptual definition and consequences of stigma, proposing that it exists when “elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them” (Link & Phelan, 2001, p. 377).

That power situation is particularly relevant to the broad category of disability, which expressly connotes marginalization, alternatively oppression and exclusion. As far as I am aware, the disability movement has not produced, nor disability scholars described, an understanding of disability that connotes disability-specific positive valuation. There have been attempts at articulating an affirmative model of disability (Cameron, 2008; Swain & French, 2000), and the disability social movement as well as many non-governmental organizations value solidarity, commonality of purpose, and a shared enemy in the form of ableist attitudes, structures, and actions. Still, there are as yet few disability-specific positive connotations.

Such connotations are perhaps more common when it comes to specific impairment groups; the perhaps most well-known example is Deaf culture, which has been described as analogic to gay and lesbian culture (Berbrier, 2002; Breivik, 2005). However, the Deaf movement is also to some extent predicated on a re-valuation of not being able to hear, i.e. on redescribing the absence of the ability to hear as a value-neutral feature of human variation rather than as an a
priori negatively valued impairment. A similar strategy was attempted in the early days of the British social model, where the inability to walk was repeatedly described as a negative attribute only in specific, ableist forms of society. Though in many instances polemic, such claims and strategies underline the basic point. Even if disability is something very different from bodily limitation, the fact that the world's disabled population have some form of bodily limitation, but few if any neutral or positively valued characteristics, in common makes it fairly difficult to identify positive attributes of the category itself.

Some studies have found positive associations linked to disability – though often still linked to social distance (Susman, 1994, p. 17). Moreover, the reactions may be linked to specific subcategories of disabled people, such as wheelchair users (Cahill & Eggleston, 1995), rather than the category in a more general sense.

The closer one looks at the category of disability, the more fragmented it appears – and much of the fragmentation likely stems from the now familiar conceptual distinction between bodily and social aspects of disability. The disability NGO field, for instance, is commonly structured in two ways – according to medically defined diagnostic groups, and according to political aims (Grue, 2009). Within such structures, individual people can effectively be members of the category of disabled people without having to be aware of it, and with little incentive to identify themselves as such – as a disabled person alongside other disabled people. Indeed, there are socially perceived hierarchies in which specific impairments differ considerably in terms of prestige (Deal, 2003; Grue, Johannessen, & Rasmussen, 2015).

In these hierarchies, it would appear that medicalization is linked to higher rather than lower prestige. If this is the case, it would further increase the risk of status loss associated with the category of disability – as opposed to many individual categories of illness or impairment.

These issues are fraught with tension. As Link and Phelan point out, research on disability stigma runs the risk of perpetuating the problem it investigates by focusing on individual physical signs (Goffman's "blemishes") and ignoring the social structures that produce the perception that something is a blemish. Hence
the first element of their definition: *labeling*. Some differences are perceived as significant and deserving of a label; others are not.

Disability, however, is a label that is not associated with a single physical difference. If anything, it is associated with social structures and arrangements – above all, with social marginalization and programs that are intended to compensate for such marginalization. As a proxy for the connotations linked to the category disability – its semantic coloring – searches of the Corpus of Contemporary American English show that it is strongly associated with programs such as SSDI (Social Security Disability) and SSI (Supplemental Security Income) (Davies, 2008).

*Disability in public: A prototypical category?*

It follows from the above that disability is a club with considerable membership dues. Disability scholars have investigated what it means to appear as disabled in public; historically, appearing as such has often been a matter of risking censure or hostility. The hostility was often linked to the suspicion of malingering or an attempt to profit off the sympathy of others; at least since the Victorian era, the display of bodily signs that connote unemployment or penury have been deeply problematic in many contexts and in certain cases even prohibited by law (Schweik, 2009).

Disability in public is, for some, a matter of trying to avoid stigma by passing as non-disabled, i.e. concealing or minimizing signs of problematic identity (Clair, Beatty, & Maclean, 2005); however, disability is also matter of explicit identity management and performativity (Garland-Thomson, 2009; Siebers, 2008). For some, it is impossible not to display signs that might, in Goffman’s terms, trigger suspicion of deviance. In those cases, managing the signs so that they become more likely to indicate disability, rather than, say, intoxication, may be a preferred strategy. Many signs of disability, along with perhaps the majority of identity markers, are inherently ambiguous. An unsteady walk, indications of sensory impairment, or
slurred speech may indicate any number of things – though they are all likely to be noticed and thus trigger the need for an explanation. Disability, however, also has a more explicitly symbolic dimension, partly due to the ubiquity of symbols marking disability accessibility and adaptations, e.g. wheelchair symbols (and the visibility of actual, physical wheelchairs and wheelchair users). Disability is not a singular or simply structured category, but it is associated with a number of signifiers, including but not limited to wheelchair, white canes, and hearing aids. These signifiers may be more strongly linked to the category of disability than to categories of illness, and it is the people who use them – who are seen to use them – that unambiguously appear as disabled people in public.

This suggests that disability in public may be viewed as a prototypical category – a category of identity with some typical and some atypical members, none of whom share a single defining feature. Originally, Eleanor Rosch (1973) introduced the concept of prototypes in order to study the semantic domains of color and form, which are classical topics in the philosophy of language. Rosch argued that there are “natural” categories in both domains, i.e. that some categories are easier to learn than others. Moreover, natural categories are structured around centrally prototypical exemplars (Rosch, 1999). The category of “bird”, for example, has a sparrow as a more centrally prototypical member than either an ostrich or a penguin.

The benefit of Rosch’s prototype system, which has since been developed and extended to many other domains by linguists and cognitive scientists (Lakoff & Johnson, 1980; Lakoff, 1987), is that it allows for graded category membership and so captures the not-always-binary way we think about the world. Prototypes are not simply value-neutral stereotypes (stereotypes are much more specific and narrowly construed); prototypes are sets of characteristics, none of which are by themselves necessary for category membership. A bird is still a bird even if it lacks flight; it is merely not as central to or representative of its category.

The system is also flexible along a vertical axis. Rosch argues that basic-level categories (birds, dogs) are more readily accessible than either sub-categories (beagles, Great Danes) or hyper-categories (mammals, plants). Is disability then
a hyper-category of identity – one that is abstract, not in itself very active in social interaction, but a principle that organizes other, basic-level categories to which we have readier access? Arguably there are “classical” types (World Health Organization, 2011, p. 7) of disability that strongly resemble basic-level categories, namely wheelchair users, Deaf people, and blind people.

*Changing the social meaning of disability: Scholarly and political problems*

Returning to the question of the social meaning of disability, the above analysis would suggest that disability is a problematic category of identity. It may well remain a hyper-level category, belonging to legal, political, public discourse, and connoting welfare programs, unemployment and marginality – as has historically been the case (Stone, 1984). Even if basic-level categories such as “wheelchair user” or “blind person” may change in their connotations, inviting less stigma, this need not change the social meaning of disability per se.

If so, this presents a strategic problem for disability activists, advocates, and organizations, and an analytical problem for disability scholars. The problems are interrelated, as both of them have to do with the dividing line between disabled and non-disabled people, between normality and (different forms of) deviance.

The strategic problem for the disability movement has to do, at least in part, with getting people to identify themselves and others as disabled – specifically, with getting people that would not ordinarily accept an identification as disabled to “come out” as such. This metaphor – borrowed from the LGBTQ movement – suggests that disability is an authentic identity obscured by an inauthentic, but more socially acceptable identity. But if disability is a higher-level, more abstract identity than identities oriented towards specific illnesses or impairments, and the disability community can only be conceived in fairly abstract terms, this project may prove more challenging than has previously been assumed.

The related, scholarly problem has to do with the critique of normality that has been a central part of disability studies for the last two decades or so (Lennard J Davis, 1997). In this line of reasoning, disability connotes not only a form of
human variation that deserves preservation for the sake of both social diversity and biodiversity (Garland-Thomson, 2012); it is also imperative to reanalyze the dichotomies between negatively and positively valued features of human physiology.

Another way to frame the problem might be as follows. As disability studies has emerged as a substantive and vibrant academic field (Lennard J Davis, 2013; Garland-Thomson, 2013), it has argued in favor of two propositions. First, that disability is a rich analytical concept that uniquely describes the experiences of one out of the world's seven billion people. Second, that those people do not constitute a unique category at all, but belong to a continuum of human capability and function.

This way to frame the problem is meant to be an exaggeration; the two propositions need not actually be contradictory. Disability (or, if one prefers, ableism) can well describe the structures, arrangements, and traditions that shape the lives of a billion people with very different physiological, mental, and social characteristics, while simultaneously referring to a socially constructed and historically contingent dichotomy.

Even so, the problem becomes analytically acute when related to the international political and legal developments referred to in the introduction of this essay. As the use of the category of disability expands, what kind of developments can we expect if it proves to be the problematic basis for identification and social mobilization that the present analysis suggests?

**Indications for further research**

The above topics are complex and deserving of further research; I suspect that a relevant key word is backlash. It is well known that disability legislation easily triggers blowback, a salient example being the implementation of the Americans with Disabilities Act (Colker, 2005; Krieger, 2003). Arguments over the cost of adaptations and the imposition of regulatory or financial requirements on state agencies and private companies are often framed as a matter of the many being made to bear an unreasonable burden of behalf of the few.
Disability advocates may counter that the few are in fact the many – after all, one out of every seven human beings is disabled. But this argument rests on a comprehensive political understanding that such is in fact the case, and is undermined by narrow construals of the category of disability, and a social meaning connoting marginality and exclusion.

In conclusion, the social meaning of disability – and the precise way in which the category is understood in social interaction – deserves further attention. Neither the relationship between disability and specific types of illness and impairments, nor the way in which people identify with or identify others as members of one or the other category is sufficiently understood.

References


