# Disease versus Disability: The Medical Humanities and Disability Studies

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*Preface: Presenting this paper literally in the shadow of the American Cancer Society—whose headquarters are next door to the conference facility where the Disability Studies and the University meetings were held—made me acutely aware of the importance of medical institutions when we are trying to overcome the stigmatization of disability. In that spirit, I read a quotation I'd seen down the street, engraved on the entrance to the M. B. Seretean Center for Health Promotion, a part of Emory University's medical school. I would like the attitude it urges to haunt the rest of the paper:*

> *When health is absent*
> *Wisdom cannot reveal itself,*
> *Art cannot become manifest,*
> *Strength cannot fight,*
> *Wealth becomes useless,*
> *And intelligence cannot be applied.*
> *—Herophilus, physician to Alexander the Great, 325 BC*

ONE OF THE CONSISTENT PROBLEMS I FIND IN the work I do—which is focused on women and the cultural representations of illness—is classification. There was not really a category of "disability studies" when I started this work in the 1980s, and I would have resisted that label even if there had been. Since embracing the field of disability studies, I have wondered about my early resistance to it. At first, I attributed it to my own ableism (and I don't think I am necessarily wrong about this), but as I have continued to work on the issues, I am coming to see it more as a result of a disciplinary divide between the medical humanities and disability studies. My first job teaching literature was in a medical school, and I was early on immersed in the idea of the medical humanities, an idea I am beginning to think is antithetical to disability studies (though not to disability itself). My talk today discusses the source of that divide, the problems I see with it, and suggestions for what we can do about it. I want to examine the two interdisciplinary fields in terms of their disciplinarity, and in the interest of time, I'll use a shortcut to do this; I will compare two relatively recent MLA publications, *Teaching Literature and Medicine* (2000) and *Disability Studies: Enabling the Humanities* (2002).

Many of the presenters at this conference have already heard me describe the problem I face in my work of connecting illness and disability: most people in the disability community do not want to be considered ill, and most people who are ill don't want to be considered disabled. That basic point of labeling makes political and intellectual cohesion complex and can get in the way of important aspects of our work. There are some obvious conditions that are easily distinguished—the flu is not a disability, and missing a limb is not a disease—but how should we classify post-polio syndrome? cancer? AIDS? I offer here a matrix to sort out how we define the differences between disease and disability so we can understand what such distinctions might mean.

The definition of disability used in disability studies focuses not on the body but on the social; disability is not something that a person possesses but something one encounters when dealing with other people or with physical spaces that are inaccessible. Disease, on the other hand, is almost always understood as located in the body itself. It might be useful to maintain this distinction, except that this way of defining the difference can obscure more problems than it solves. For instance, if I am in an asymptomatic stage of AIDS but coworkers urge my employer to fire me, is that

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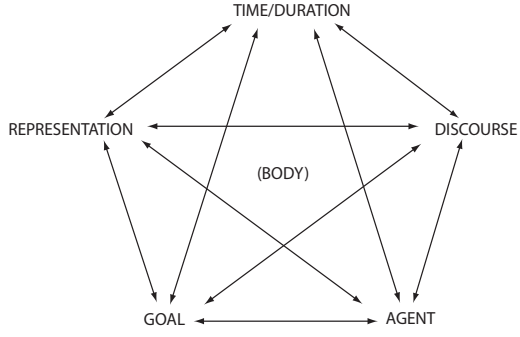
more clearly an issue of disability discrimination than if I were symptomatic? More important, I think, maintaining a difference based on location—in the body versus in society—continues the practice of seeing disability and disease as things rather than as relations.

There are important reasons to maintain a distinction between the two states, if only so that we do not dilute the definition of disability to the point that it loses its political efficacy. If we are all disabled in some way, then we cannot possibly discriminate against the disabled, and there can be no legal protections and no serious attempts at making venues accessible. By the same token, if all disabilities are seen as illnesses, then it becomes almost impossible to refuse medical interventions aimed at eliminating difference. Below I list five topoi in distinguishing disease and disability:

*Time/duration:* ontological state versus temporary condition
*Agent:* patient definition of condition versus practitioner definition
*Discourse:* within what context? who is in charge?
*Goal:* cure versus accommodation, access, empowerment
*Representation:* as tragedy, end-of-life-as-we-know-it, difficulty, or change of mode

I think of these as a "matrix," but because none of these functions without interaction with the others, they could also constitute a system. This relationality is what all the arrows on the diagram at right are meant to suggest. I do not want to belabor these points, but I do think they bear some explanation, especially since most conditions do not easily fit into the binary oppositions I've laid out here. The most obvious example of this is the first, time. I've delineated "ontological state versus temporary condition" here as a shorthand, but if there is one true thing about bodies, it is that there is no "permanent" or "ontological" state of the body. What I mean to indicate is the sense of whether it is reasonable to expect a condition to be lasting or not, and "reasonable" here depends on the interaction of several of the other elements. *If* I consider my physicians the authorities, and they think I need intervention, and *if* I accept an ableist representation of the world and of me that demands that I be fixed rather than the environment be changed to accommodate me and others like me, *then* I will likely accept as reasonable that my condition is temporary and that my goal should be to fix it.

What is absent from my matrix is any concrete notion of disease and disability as fixed materially in bodies, and you'll notice that while the body is at the center, it is parenthetical. This isn't to deny the materiality of disease and disability but to foreground the ways that our interpretations of that materiality matter and to highlight the way that the body is central but not an object that is itself defining. This may be the point at which disability studies and the medical humanities are most clearly at odds. Many, if not all, disability studies scholars would agree with Paul Longmore's claim in "*Why I Burned My Book*" that "for most people with most kinds of disabilities most of the time the greatest limitations are not somatic but social: prejudice and discrimination, inaccessibility and lack of accommodations" (2), and with Simi Linton's argument in *Claiming Disability* that we should "challenge . . . the notion that disability is primarily a medical category" (2). In contrast, medical humanists most often take the physician's medicalized point of view of bodies and




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disabilities. For example, in the introduction to *Teaching Literature and Medicine*, Anne Hunsaker Hawkins and Marilyn Chandler McEntyre see medicine as having an important materialist pressure on literary study:

> [T]he tendency in recent literary and cultural studies to dissolve reality into subjective perception or ideological construct must take into account the hard and sobering factuality of the body, the materiality of our mortal flesh. Literary interpretation becomes daily more abstract and conceptual, while medicine—for all its scientific advances—remains grounded in concrete experiences of sickness and pain and in the pragmatic strategies of healing. (2)

Hawkins and McEntyre acknowledge, in the next sentence, that "medical practice is not, strictly speaking, a science" and that it is deeply interpretive. But they insist finally on the difference between "a disease with a definable pathogen" and one that they acknowledge to be "social[ly] construct[ed]," like anorexia (3). They do not equivocate this position by examining the ways that the experience of even such a clearly definable disease as tuberculosis is deeply affected by social constructions like whether the disease is considered romantic or nasty or the degree to which the culture determines standards of treatment that might lead to patient noncompliance and the evolution of a more virulent strain of the disease (as explained by Katherine Ott in *Fevered Lives*).

I am tempted to describe the differences between disability studies and the medical humanities in terms of their attitudes toward poststructural and postmodern theory. The entire first section of *Disability Studies: Enabling the Humanities* is dedicated to theory; by contrast, *Teaching Literature and Medicine*, though not hostile to theory, nonetheless skirts it. Its editors acknowledge this by arguing, "Most courses in literature and medicine in medical school settings have not kept pace with scholarship in the field in finding ways to incorporate various theoretical approaches . . ." (7). They offer a paragraph to explain why it is almost impossible to get medical school students or doctors to deal with theory. But without a poststructural paradigm, I would argue, it is hard to get anyone to understand what it means to locate disease or disability somewhere other than in a concrete, physical body.

I hope you will allow me to postpone a discussion of why we might want to do this. First, I want to try to understand the difference between the two fields in terms of their histories. Disability studies originated from the activism of people with disabilities; the medical humanities evolved as a way to try to balance the heavily technological bent of physician education that stressed science too heavily. One salient factor, to my mind, is that the medical humanities began in the institution of the medical school and for the most part has relied on institutional funding or at least the benevolence and interest of physicians; the support for such programs is often tenuous as they are seen as supplemental, at best. Were the medical humanities to take on changing the profession as a charge, with the implicit criticism of medicine that such a move implies, funding would almost certainly disappear. Medical humanists (at least those who work in medical schools) therefore find that to be heard at all, their message cannot alienate physicians. Thus, while disability studies takes as its primary goal changing policies, environments, and minds, medical humanities seeks to improve the status quo.

Despite such different rhetorical emphases, however, one might still expect there to be a fair amount of crossover between the fields. Yet there is surprisingly little. I've done a quick citation analysis of the tables of contents, indexes, and works-cited lists of the two MLA publications I've mentioned so far; it seemed to me a quick way of "placing" the books in their disciplines.[1] Except for Tom Couser, the contributors are mutually exclusive. Even the indexes represent practically

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no commonality; Sander Gilman is the only other author in *Disability Studies* cited in *Teaching Literature and Medicine*, and Kathryn Montgomery Hunter the only *Literature and Medicine* author cited in *Disability Studies*. In other words, almost no one in either field is citing the other. I suspect this may mean we are likewise not reading each other's work. There is even remarkably little in common in terms of the other work (including primary texts) that we are all citing.

To explain how this mutual exclusion becomes problematic, I am going to look closely at one essay in *Teaching Literature and Medicine* as a case study. The first section of the book is devoted to sample syllabi, and I was greatly heartened by the inclusion of a course called The Tyranny of the Normal, by Carol Donley and Sheryl Buckley, who teach at Hiram College and have edited an anthology by that name; Donley is an English professor, and Buckley is a physician. The course originates from an essay by Leslie Fiedler that many disability scholars also cite. In many ways, it is a good course and is right intentioned, but it has no shred of a disability studies perspective. It is aimed entirely at the able-bodied health provider, it assumes a clear line between the able and the disabled, and it is focused on helping providers develop empathy for patients. I'll repeat, it is well-meaning. But even though Donley and Buckley explain that using terms like *abnormal* is problematic, they argue that it is necessary. Even though the stated goal of their course is to challenge ideas of there being a norm, they fall into the trap of assuming the normal. To offer you a sense of this, I'll quote their last paragraph:

> In conclusion, it is obvious that in our encounters with deformed or mentally abnormal people we ought to control reactions, both verbal and nonverbal, that might be hurtful. But even if we can accomplish that difficult task, we still need to meet these people as they are, where they are, and in their context. Literature can help us develop the ability to put ourselves imaginatively in another person's position. If we understand, even indirectly, what it is like to be an "other," we can develop a genuine sense of empathy for such persons. (173)

I have also written about empathy and the hope that literature can help us break down barriers between people who are different ("Style"), so I do not necessarily disagree with the sentiment. And certainly, if given the choice between a health provider who will be visibly repulsed by my visit and one who won't be, I'll go for the nonrepulsed provider every time. What bothers me most about this paragraph is its assumption of the absolute barrier between "we" normal providers and "the other," "abnormal," "deformed" patient, who lives in some other context from "us." The point of disability studies is that "their context" is, or at least should be, also ours; if it isn't, it is because of the barriers that "we" have set up to exclude "them."

There are other places where the absence of a disability studies perspective from the literature-and-medicine volume seems glaring. For instance, Martin Donohoe's essay refers to poverty, stigmatization, and war as public health issues but does not mention disability; H. Bruce Franklin's essay about *Frankenstein* focuses exclusively on the role of the doctor, using the term "monster" to describe his creation without any acknowledgment of the creature's consciousness. None of the essays in the book deals explicitly with disability as an issue for the medical humanities.

By the same token, *Disability Studies: Enabling the Humanities*, and the discipline as a whole, could not be described as overly physician friendly. We tend to use the term *medical model* as the definitive antithesis of our position. To give just one example from the MLA volume: Nancy Mairs writes, "A great many people with disabilities like their lives a lot. I happen to be one of them. We tend to repudiate the medical model of disability, which

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views us as sick and in need of a cure" (168). Like many other disability studies writers, Mairs writes about Jack Kevorkian, and he comes in many ways to stand in for the whole of the medical profession. In the prophysician essay in the *Disability Studies* volume, Leonard Cassuto has to begin his essay with a defense of his own pro–Oliver Sacks position.

There could be many explanations for the distance between the two disciplines besides the history that I mentioned above; from a physician's point of view, disability represents a failure, one that most medical school curricula do not highlight. It may also be that disability studies is still new enough that it has not yet made inroads into the literature-and-medicine curriculum but will. There are indications that this may be the case; in an analysis of the contents of the journal *Literature and Medicine* since 1995, I find that the number of essays that either explicitly deal with disability or reference a disability studies perspective has been steadily on the rise, culminating, in the Fall 2003 issue, with the first essay that lists "People with Disabilities" as a subject heading and, even more exciting, with a whole section devoted to disability in the Spring 2004.

I raised a question earlier to which I now return: Why is it so important to locate disease or disability somewhere other than in a concrete, physical body? More to the point, why should the medical humanities take up this point of view? Hawkins and McEntyre set up three justifications for the medical humanities: to teach physicians how to listen to patients with more subtlety, to heighten physicians' "personal awareness" and ability to scrutinize themselves, and to help physicians "to think both critically and empathetically about moral issues in medicine" (5). Reading disease and disability as existing in a complex interaction of relations enhances all these goals. But it also enhances the practice of medicine: recognizing the ways that agency and representation, for example, may affect a patient's compliance with a physician's orders can lead to more successful treatment. Understanding that the physician's representation of a disability as horrible may not match up with patients' own representations of their conditions as just the way their bodies function (I'm thinking of Mairs's claims above) may allow physicians to better help patients with what *patients* consider important.[2] Surely that has to be a goal of all ethical health care.

If we in disability studies are so right, then, about the social construction of the body, why might we need to bother with the medical humanities? Michael Bérubé, in his afterword to *Disability Studies*, offers us one reason:

> [W]henever we get too blithe about the possibility that social constructions can be constructed otherwise, too complacent in our belief that we can change a socially constructed world by the end of next week, we need to remember . . . that there's a *there* there, that the biological materiality of the body is susceptible to a finite (and sometimes severely delimited) number of constructions. It's also worth remembering that most of our culture is socially constructed along the medical model to begin with. (341)

While I am sure that medical humanists are too committed to a medical model of the body that sees it as the "*there*" that is really there, I also think that Bérubé is probably right that disability scholars are so committed to a model of an almost infinitely malleable social construction of the body that scientific disciplines may ignore us. The medical humanities has the attention of many physicians and the institutional space to make changes in medical practice. We have the critical consciousness to redirect that change so that it better serves the needs of patients, especially patients with disabilities. But if we continue to hold these positions without paying attention to one another, I fear none of us will accomplish what we hope to do.

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## Notes

[1] This effort is not wholly adequate. The index of *Teaching Literature and Medicine* does not include topics and does not fully index all the texts included in the syllabi section of the books, leaving out many possibilities for overlap. I have tried to compensate for that but admit there may be oversights.

[2] I am tempted to point out here, too, that it could lead to a considerably less litigious environment for doctors.

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# Voices from the Classroom

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As a former trainer in a teaching program and an educational psychologist specializing in disabilities, I have viewed learning from two perspectives: that of the teacher and that of the learner. My more recent role in administration has caused me to consider these perspectives in a more unified manner, concentrating specifically on the link between teaching and learning in higher education. Here at Emory, my responsibility is to view the total academic experience of students with disabilities and to work with faculty members to develop policies and procedures that will allow our students full access to educational opportunities. I am asked to build bridges between teaching and learning at an institution that has until recently taken for granted that everyone is equally endowed for learning and learns similarly. The unwritten understanding has been that if one passes the threshold of admission into this community, one does not have needs that might be considered "special."

My first venture into education, in the early 1980s, was at a large state university. The field of disabilities was relatively new, learning disabilities and attention deficit disorders were virtually unknown on campuses, and individuals with sensory or motor impairments were not invited. A university campus was a pretty inhospitable setting for one with a difference, let alone a disability, though there were exceptions. Those who came and stayed were the rare students who had developed a full measure of compensatory strategies and who tolerated the inconvenience of inaccessi-

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