

Disability Studies: The Unexpected Guest in Health Law Discourse

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As is often the case for me, my thoughts about this presentation crystallized a few hours before my deadline for carving it into digital stone. As a result, the title that I would now propose for this presentation appears nowhere on your program. This new and improved title is “Disability Studies: The Unexpected Guest in Health Law Discourse”. There is a certain irony perhaps that not only my title, but my virtual presence at this conference are all situated in the realm of the unexpected, but that irony is tangential to my present intentions.

Let me explain first that my title comes from a commentary entitled, “Reflections on Social Justice and Personal Identity”¹. The author, Adrienne Asch, a pioneer in disability studies, describes her experience of all-too-frequent reminders that, as a blind woman, she is an unanticipated participant in both professional and social gatherings. I’ll quote briefly, from an anecdote that Asch uses as point of departure for her reflections:

Sitting beside a stranger waiting for a lecture to begin at an academic conference, the stranger whispers loudly *not* ‘Hello, my name is Carol,’ but ‘Let me know how I can help you.’ What help do I need while waiting for the speaker to begin? Why not introduce herself, rather than assume that the only sociability I could possibly want is her help? When I respond by saying that she can let **me** know if I can help **her**, she does not get the point and I am all too well aware that the point is subtle; instead she needs to be thanked for her offer and reassured that I will accept it – and then many pleasantries later perhaps we can discuss why we are at the lecture and whether we like it and what workshop we will attend that afternoon.

When I complain of countless such incidents to most of my nondisabled friends and colleagues, I am told that I must understand how unusual it is to see a person with a disability in such a setting, that people are awkward, anxious, afraid of doing the wrong thing, only trying to be nice.

My friends are right, and I will not get to know new people unless I tolerate these encounters and find ways to smile and be gracious and put people at ease.²

Adrienne’s story, of course, puts no one at ease, and I hope you will forgive me for resorting to it as a provocative device in leading off this session. I do think,

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¹ Adrienne Asch, “Critical Race Theory, Feminism and Disability: Reflections on Social Justice and Personal Identity” (2001) 62 Ohio St. L.J. 391.

² *Ibid.* at 396.

however, that the notion of the “unexpected guest” can be a helpful metaphor in mapping out the relationship between Disability Studies and Health Law. In the next few minutes, and in the interest of putting people at ease, I’d like simply to introduce the discipline of disability studies, to argue what disability studies has to offer to the field of health law and to suggest what disability studies will demand from health law for its part of the bargain.

What is Disability Studies?

Who is this unexpected guest?

Like women’s studies, aboriginal studies, queer studies or African-Canadian studies, Disability Studies is an intellectual pursuit that looks at history, law, culture, politics, art, science and medicine from a previously marginalized perspective. The experience of people with disabilities becomes the lens through which social, political and legal phenomena are analyzed and critiqued. Put in other words, disability studies “takes for its subject matter not... [particular] variations... in human behavior, appearance, functioning, sensory... and cognitive processing, but the *meaning* we make of those variations.”³ According to Simi Linton, it is “a field that explores the critical divisions our society makes in creating the normal versus the pathological, the insider versus the outsider, or the competent citizen versus the ward of the state”.⁴ The project of Disability Studies, according to Peter Monaghan, is to “pull apart concepts about disability to see what cultural attitudes, antagonisms, and insecurities went into shaping them”⁵.

Like the fields it resembles, disability studies embraces an agenda for social reform. It draws heavily from the work of French philosopher Michel Foucault, uncovering the relations of power inherent in a “medicalized view of human beings”⁶, and beyond this, examining the ways in which our culture imposes meanings and conditions on the human body.

The official definition adopted in 1993 by the Society for Disability Studies notes, among other things, that “Disability Studies [seeks] to disentangle impairments from the myth, ideology and stigma that influence social interaction and social policy”. Further Disability Studies seeks to uproot “the idea that the economic and social statuses and the assigned roles of [disabled people] are inevitable outcomes of their [impairments].”⁷

³ Simi Linton, *Claiming Disability: Knowledge and Identity* (New York: New York University Press, 1998) at 2.

⁴ *Ibid.*

⁵ Peter Monaghan, “Pioneering Field of Disability Studies Challenges Established Approaches and Attitudes” (1998) 44:20 *Chronicle of Higher Education* A15 at A16.

⁶ *Ibid.*

⁷ Simi Linton, S. Mello & J. O’Neill, “Locating disability in diversity” in E. Makas and L. Schlesinger, eds., *Insights and Outlooks: current trends in disability studies*. (Portland, Maine: The Edmund S. Muskie Institute of Public Affairs, 1994) 229.

Health Law's encounters with this unexpected guest will be evident, I expect, in the papers to be presented by Archie Kaiser and Patty Peppin this morning. But well beyond the comfort zone of this panel, indeed across the full range of themes and issues raised in this conference program, I hope that questions of disability status and position will, like unexpected guests, be wrestling their way into the discussion.

What Does Disability Studies Offer?

This leads me to my second question. What does disability studies offer, to the pressing issues of concern for health law practitioners: research ethics, genetics and biotechnology, competence and consent, prenatal screening and selective abortion, new reproductive technology, euthanasia and assisted suicide – decisions of profound legal and moral weight at the thresholds of life and death?

Fundamentally, our unexpected guest offers a new understanding of disablement. Let me explain this way. At the very beginning of this presentation, before I had even opened my virtual mouth, most of you who are “sight-reliant” – meaning, not blind – will have already made certain observations about me. Without any conscious attention, analysis or judgment, you will have observed from my transgressive body that I belong in the category of disabled. I'm not about to critique that observation (which is perfectly natural) or dismantle that category (which is perfectly accurate). What I do want to do, is examine two very different meanings that may be assigned to that category depending upon, as the saying goes, “where you're coming from”.

You won't find these meanings in the average dictionary – but if I were asked to compose a pair of definitions, they would read something like this:

Disabled. Meaning number 1

Can't walk

Can't do what the rest of you do all the time. Can't do what almost everyone *can* do. Can't do what's *normal* and expected in terms of mobility – or cognition or communication or perception. Can't do – but, in this enlightened era, still equal – therefore deserving of recognition and special support.

Disabled. Meaning number 2

Not taken into account

Not taken into account at square one. Not taken into account in a preponderance of architectural plans, policy initiatives, strategic objectives, organizational structures, systems, budgets, procedures, laws and decisions. Not taken into account, except occasionally, mostly as an afterthought, and often with great hullabaloo.

There is a world of difference between these two meanings. To illuminate that difference, I'm going to have to offer you more than a couple of self-styled

dictionary definitions. No problem, I still have 5 1/2 minutes, let me tackle the encyclopaedia versions.

Meaning number 1

Can't walk

Looking at disability through the lens of medicine

In the medical textbooks, disability is understood as something anatomically, neurologically, psychologically, genetically or chemically off the mark. We are in some fundamental way, broken or gone wrong. As a direct result of our impairments, abnormalities or deficiencies, there are things that we cannot do, places we cannot go and special supports that we will always need. When all is said and done, disability is an extraordinarily bad thing that happens to a small group of people. The great shame of it is that medicine cannot fix us.

Parenthetically, my encyclopaedia goes on as follows: The greater shame is that medicine can – and does – define us – and in contexts far beyond the clinical setting. How health law frames disability, how health law approaches the problems of disability – our analysis, frameworks, discourse and judgments – have at their heart certain ideas about the condition of disability that are so pervasive as to be almost invisible. These ideas, which draw their popularity from a simple and stubborn logic, can be reduced to two declarations:

The condition of disability is situated in the body (or mind) of an individual. It is discrete and diagnosable

The problems or limitations experienced by disabled people are a direct consequence of their individual impairments.

Within this paradigm, the problems and difficulties that I experience on a daily basis are understood as unfortunate but inevitable consequences of my impairment. My problem is that I am different, and because of my differences, I don't fit in to the social environment without considerable adaptation.

Well, the truth of it is that meaning number 1 strongly leads at the polls. But at the insistence of our unexpected guest, let's consider an encyclopaedia entry for meaning number 2 – the one about not being taken into account.

Looking at Disability through a Social Lens

Disability is not intrinsic, but rather extrinsic. Disability is situated not in an individual pathology, but in society's failure to embrace diverse ways of being in the world. Disability is not a variant of human physiology, psychology or genotype, but instead the manifested outcome of social barriers and deeply entrenched patterns of discrimination. The problem is not that I cannot walk – the problem is that I find myself living in a social order premised in the most fundamental ways upon the assumption that everyone – or everyone who counts – does walk in that

quaint (if somewhat labourious) biped way. The ideas upon which meaning number 2 is premised are not simple – but they can be stated quite simply:

- The condition of disability is situated not in the body but in the body politic, not in a medical failure, but in a social failure, a failure to take into account the needs and circumstances of a particular category of citizens.
- The problems or limitations experienced by disabled persons are predominantly the result of exclusionary, ablest and arbitrary norms and standards.

What Does Disability Studies Demand?

From the unexpected guest, a bouquet of new meanings, definitions and conceptual tools. And for this, what does the guest demand?

In ten words or less, Disability Studies, or, a critical disability perspective, demands **that we relinquish our comfortable adherence to meaning number 1**. The problem with meaning number 1 is, in the words of Bill Hughes, that it too clearly “absolves social arrangements from both causation of and responsibility for disability.” Meaning number 1 clouds our discernment of the problem of disability and distorts our notions of just outcomes for disabled persons. It sets the category of “disabled” apart from all the other categories. It asserts the centrality of non-disabled experience, and in so doing, subordinates the disabled status. It assigns to me, and to the people who live and breathe the perspectives that Archie and Patty will soon report on – the status of outsider – an outsider who may be invited in and offered all manner of comfortable accommodations – but an outsider nonetheless. Surely meaning number 1 is very much an expected guest, but one whose welcome is long worn out.

It is my hope that meaning number 2 will infuse not just this morning’s panel, but every session of this conference and that the *unexpected* guest will find a place among you for engagement, debate and reflection at every table.

References

- Adrienne Asch, “Critical Race Theory, Feminism, and Disability: Reflections on Social Justice and Personal Identity” (2001) 62 Ohio St. L.J. 391.
- Simi Linton, *Claiming Disability: Knowledge and Identity* (New York: New York University Press, 1998).
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Melanie Panitch, "Disability Studies: A Field Of Study Whose Time Has Come" *Abilities* 44 (Fall 2000) 56.