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Gut Issues: Applying a Disability Lens

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Introduction

Some models of disability attempt to define disability and determine how to distinguish between disability and non-disability. This paper does not pursue that project, but instead explores what emerges when we apply a disability lens to an embodied phenomenon, without necessarily making a determination about whether that phenomenon “is” a disability or not.

I’m going to be talking about gut issues – which I’ll explain momentarily – but much of what I’m going to say in this paper could apply to a range of different conditions. I think that gut issues are particularly interesting and important, but if it is helpful, they can also be taken as a case study of a larger issue: how can we make use of some of the insights of disability theory to better understand embodied experiences and how our world could be changed to be more accessible and inclusive.

So. The term “gut issues” can refer generally to any condition that affects our digestive systems and which causes pain or discomfort. The term points to the experience of our gut *being an issue* for us – interfering with our plans, undermining our bodily self-control, threatening our well-being. The Canadian Digestive Health Foundation lists nineteen different “digestive conditions” on their website, including chronic illnesses and bacterial infections. If we are interested in the experience of unruly guts, we can also include conditions or bodily phenomena which often have gut-related effects, such as anxiety, migraines, or menstruation. Gut issues are often invisible or nonapparent to others, and do not tend to occupy the public imagination about disability. However, they are often disruptive, and can affect a person’s ability to carry out their intended plans and goals, depending on context and severity. They can create urgent and often unpredictable needs – to sit or lie down, to find a bathroom, to go to a hospital. Despite their significance and frequency, however, it is often perceived as awkward, improper, embarrassing, or rude to admit to them. Their invisibility and unpredictability can also mean they are not taken seriously by employers, instructors, or healthcare

professionals. The silence around gut issues exacerbates the physical problems they present, by creating barriers to requesting or receiving accommodation or help, as well as obscuring them as conditions to be considered when planning for accessibility.

Looking through a list of gut-relevant conditions, some might seem to “count” as disability, and others not. Exactly where one draws the line would have to do with the particular conception of disability one is working with. Cindy LaCom points out that there is uncertainty about how her Crohn’s disease fits within the category of “disability,” particularly during those periods between flare-ups. As she notes with respect to her participation in Disability Studies,

But I cannot identify either as “PWD” or as a “TAB” (person who is temporarily able-bodied). I am neither or both, depending on the moment and my state of health. Do I thus revise and articulate my identity category on an ongoing basis? Like shit, which disturbs so many cultural norms, people with Crohn’s disease (and “disease” is itself a medical and existential category which often resists stable definitions), can disturb identity categories and raise complex questions of power, transgression, and the damning issue of the imposter syndrome which are hard to critically deconstruct (LaCom 2007).

Meanwhile, a condition like IBS, which has no clear biomarkers,¹ might be a challenge to categorize – despite rarely being mentioned as a ‘paradigmatic’ or ‘obvious’ case of disability, it can be very disruptive. People with IBS experience a high degree of stigma from family members, work colleagues, and health care professionals – much of which involves not taking the condition seriously, such as nurses judging that IBS patients “waste doctors’ time” or “craved attention” (Hearn, Whorwell, and Vasant 2020, 608-610).

There is a lengthy list of conditions that have been recognized as disabilities for the purpose of anti-discrimination human rights law², since that standard does not require any ontological determination of disability – it is “a physiological state that is involuntary, has some degree of permanence, and impairs the person’s ability, in some measure, to carry out the normal functions of life” which has

¹ There is a list of diagnostic criteria set out by the Rome Foundation, but the nature of IBS is still in dispute, with some, such as Brown 2019, debating whether it exists.

² In addition to Kilfoil, see also Michael Lynk, “Disability and the Duty to Accommodate in the Canadian Workplace” <https://www.addictionconsulting.com/media/ACCOMMODATION.pdf>

given rise to unequal treatment or access, either through someone *having* that physiological state or being *perceived* to have it (Kilfoil). The attention here is to the unequal treatment and access. So, for instance, acne has been recognized as a disability in a context where there were customer complaints about an employee (Kilfoil).³ Height – being 4’9” – was recognized as a disability in a 1992 case in British Columbia where someone was refused employment in a consignment shop since the owner thought she was too short.⁴ It is not surprising that in this context Crohn’s disease has been recognized as a disability in Canadian case law.⁵ Cases involving IBS have had varied results, largely since its causation is so uncertain,⁶ but on the whole, gut issues can be included within this group. Since this group also includes acne and being 4’9”, it’s not clear that it would be a satisfying group for philosophers concerned with *defining* disability. However, it does help focus our attention on barriers and perceptions.

Law professor Jonas-Sébastien Beaudry notes 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” (Beaudry 2016, 219-220). He suggests that the concept is best left open-ended, as an umbrella concept for a range of phenomena (Beaudry 2016, 222), and that “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” (Beaudry 2016, 225).⁷

I’m sympathetic to this. It’s in line, for example, with Susan Wendell’s comments in the first chapter of her 1996 book *The Rejected Body*, when she discusses a range of different purposes the concept of “disability” might be put to and the consequent boundaries and definitions it might have – from political solidarity to qualifying for certain accommodations to diagnoses.⁸

³ From Kilfoil: “Acne (*De Jong and Horlacher Holdings Ltd. Doing business as “Family Tree Restaurant”*) (1984) 10 CHRRD/6283 (BCHRC)); (Note: The BCHRT found that the fact that customers complained about the acne was irrelevant since customer preference cannot justify discrimination.)”

⁴ <https://www.canlii.org/en/bc/bchrt/doc/1992/1992canlii14265/1992canlii14265.html> See also a 1989 case that also recognized shortness of stature as a physical disability:

<https://www.canlii.org/en/bc/bchrt/doc/1989/1989canlii9047/1989canlii9047.html>

⁵ *Lowe v. William L. Rutherford* (B.C.) and another (No. 3), 2007 BCHRT 336

<https://www.canlii.org/en/bc/bchrt/doc/2007/2007bchrt336/2007bchrt336.html>

⁶ Thanks to my research assistant, Caleb Foster, for combing through Canadian law cases surrounding IBS.

⁷ Side note: this is how I feel about the concept of autonomy.

⁸ I’ll talk about disability theory outside philosophy later in the paper, but here’s a useful overview from Melinda Hall’s Stanford Encyclopedia of Philosophy entry on “Critical Disability Theory”: “But, some call for accountability and simultaneously argue that critical disability theory should resist distinctions between disabled and non-disabled subjects.

Saying that I'm not interested in definition, of course, doesn't mean that I'm not interested in theory. I think that it's useful to have theories *guide* us in our ethical work, including the personal and political ways in which we make sense of our lives. How could we make disability theory useful in this way, without getting caught up in the debates around what it *is* or around whether any given condition *counts* as such?

My proposal here will not mean telling everyone with gut issues that they are disabled or that they have a disability – people have many relationships to the word “disability” for a range of reasons, and I am not interested in telling them what it should be. Rather, I want to argue that if we look to theory not merely in terms of *whether* a given gut issue is a disability, but *what we can learn by applying a disability lens* to our understanding of it, we can achieve important philosophical and social insights. What happens when the question we ask of theory changes from “what is disability” to “what does it help us notice?”⁹

A disability lens can provide insight without necessarily claiming that X *is* a disability. A key thread within much disability theory and philosophy involves examining the ways historical, social, and cultural contexts shape the experience of what might otherwise be taken to be a merely biomedical phenomenon. Examining gut issues through a disability lens gives us a theoretical framework for understanding and addressing the silence around them, and helps point us toward social and infrastructural interventions.

Nirmala Erevelles, for example, does not seek to claim “everyone is disabled” but prefers historically-embedded materialist accounts of disability at intersections among multiple categories of analysis, including “race, class, gender, nation, and sexual identity” (2014, cf. Erevelles & Kafer 2010: 219). Similarly, Alison Kafer refuses a “fixed definition” of disability. She favors leaving open the boundaries of the concept of disability and, therefore, does not settle who counts as disabled. She uses Joan W. Scott’s notion of “collective affinity” to describe disability as a wide net, inhering in no particular persons, but rather describing disability as a complex set of features, attributed to individuals, that pathologize and oppress (2013: 11). At root, as Dianne Pothier and Richard Devlin argue, critical disability theory will claim that disability is not fundamentally a question of medicine or health, nor is it just an issue of sensitivity and compassion; rather, it is a question of politics and power(lessness), power over, and power to. (2006: 2, as quoted in Gillies 2014 and Sleeter 2010).” Hall 2019, <https://plato.stanford.edu/entries/disability-critical/>

⁹ Here I want to make a tiny nod to Lévinas and his prioritizing ethics over ontology – what happens when our philosophical reasoning *follows* from our responsibility to the other, rather than generating ethics *out* of our metaphysics? For Lévinas, I don’t need to ask whether someone is the right category of human before I have a responsibility to them. Similarly, in my suggestion here, I don’t need to ask whether a given gut issue meets a certain paradigmatic disability threshold in order to ask how it might be significant to someone, to ask about their access needs.

The social model is one place to start. While “the social model” actually refers to a range of closely related theories, it generally posits that impairment is an anatomical, physiological, or neurological difference (usually defined in a medical context) and that disability is the limitation caused by the interrelation of that difference with the social and lived environment; the British social model specifies more precisely that disability is society’s oppression of those with impairments, whereas other versions describe it as the barriers that arise through the relation between impairment and environment. It is often opposed to what disability theorists call the “medical model”, which doesn’t refer to any particular model within philosophy of medicine but rather the general view that disability is a biomedical problem that an *individual* has. Whereas the medical model would turn to *individualized* medical treatments or solutions, the social model argues for changes within society.

Critics of the social model often argue that in its focus on the social and political aspects of disablement, it neglects the embodied experience of disability, or glosses over the difficulties caused by the impairment itself (e.g. Anastasiou and Kauffman 2013). Another line of criticism is its apparent circularity – that “impairment” is only recognizable because the difference is *already* recognized as the ‘kind’ of difference perceived to be disabling (e.g. Tremain 2001). For what it’s worth, I think the second line of criticism is correct (there are many bodily differences that are not described as impairments, because they fit in with the kinds of things society prizes and values – to be perceived *as* an impairment, a condition must somehow already be devalued).

However we want to resolve these criticisms, if we are not focused on a rigorous *definition* of what disability *is*, but rather on using a disability *lens* to guide our attention, the social model is helpful. As a lens, it directs our attention away from conceiving of the *individual* as the problem (or as individually responsible for their problem) and toward oppressive barriers in the social environment, which are a collective problem. Further, once our attention has been drawn to those barriers, we can then collectively work to dismantle them.¹⁰

This is certainly the case with gut issues. The social model doesn’t attend to the phenomenological details of painful guts, but it draws our attention to relevant features of our social practices and environment such as the availability of bathrooms (in workplaces, in public spaces generally as well

¹⁰ This does indeed seem to have been Oliver’s primary point & emphasis, as exemplified in the chapter “Disability Definitions” of his *The Politics of Disablement* (Basingstoke: The MacMillan Press Ltd., 1990), 1-11.

as in public transportation areas), the need for benches, the need for access to safe foods (and comprehension of this as a priority), and the need for breaks of adequate length and frequency. Organizing to improve these things (particularly if this involves joining with others who are also organizing for them for a range of justice reasons) would already be useful and good.¹¹

Taking the social model as lens does not mean telling individual people with gut issues *not* to pursue treatment, or avoid eating foods that will harm them, but it helps make everything else more accessible. Since many gut issues are difficult to diagnose and unpredictable in their timing, the social focus of the social model is particularly worthwhile; flare-ups are that much more manageable if a workplace allows flex time, or working from home, or avoids rigid rules around breaktimes.

So, it's a start. But we can also think back to the criticisms of the social model. Instead of using them as a reason to revert back to the individualized focus of the medical model, it's worth looking to those lines of theory that explore the phenomenological aspects of disability more thoroughly, as well as the ways in which societal expectations of normalcy (and productivity) shape what we ask of bodies. While I don't have time for a full rundown of the landscape of disability theory, Melinda Hall's "Critical Disability Theory" Stanford Encyclopedia of Philosophy entry provides a useful overview that is worth checking out.

With the time remaining to me, I'll give an example of applying a disability lens to gut issues – using just one tiny bit of disability theory to explore the phenomena and guide our attention – which I think is useful for gut issues and deserve more uptake in philosophical reflection on disability and embodied experiences generally. Basically, this is a teaser.

This is the example of "crip time," a frequently-used expression that is a longstanding part of disability culture¹² which points to a "reorientation to time" (Kafer 2013, 26) – as Kafer writes, crip time "requires reimaging our notions of what can and should happen in time, or recognizing how expectations of 'how long things take' are based on very particular minds and bodies... Rather than

¹¹ Possible objection: if gut issues *are* recognized as disability, can be used to mount legal challenge to barriers. Response to objection: human rights law already on this. Just requires discrimination, not actual analytically-defensible categorization/definition of the thing – see e.g height, acne.

¹² Kafer points to Irving Zola (1988) and Carol Gill's (1995) use of it, with both of them commenting on it already being commonly understood (Kafer 2013, 26).

bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds” (Kafer 2013, 27).¹³ In addition to shaping how we organize things, it can also attune us to how we live as temporal agents. Another component of crip time discussed by Kafer is the importance of anticipatory scheduling and the need to conserve energy, to plan around breaks and meals, in ways that do not fit neatly into expectations of productivity and efficiency (Kafer 2013, 38-39). Ellen Samuels writes,

For *crip time is broken time*. It requires us to break in our bodies and minds to new rhythms, new patterns of thinking and feeling and moving through the world. It forces us to take breaks, even when we don’t want to, even when we want to keep going, to move ahead. It insists that we listen to our bodyminds *so* closely, *so* attentively, in a culture that tells us to divide the two and push the body away from us while also pushing it beyond its limits. Crip time means listening to the broken languages of our bodies, translating them, honoring their words. (Samuels 2017 n.p.)

Regardless of whether people with gut issues want to identify as disabled, or want to “claim crip”, to use Sami Shalk’s phrase (Shalk 2013), the phenomenon explored in disability writing on “crip time” illuminates many of the shared features of gut issues. This experience of time can emerge, for example, when bathroom visits (or even just *searching* for one) makes someone late for an appointment, or the shift in one’s anxiety around time when working from home (as in COVID) vs. an external work environment with limited break access. Within the framework of gut issues, most of which are chronic but episodic, there is much to reflect on considering futurity and how one conceives one one’s life.¹⁴ These shared experiences of different relations to time can be used to explore, describe, and find points of common contact and solidarity. Further, as an exploration of time, a disability lens that allows for the incorporation of ‘crip time’ provides the opportunity to investigate the interweaving of biological and social aspects.

So what?

¹³ She draws on Margaret Price as well, emphasizing the notion of flexibility for arrival at events as well as speed of processing language and the pace of conversation (Price 2011, 62, cited in Kafer 2013, 27).

¹⁴ There is also much to say of the experience of diagnosis as a dividing line in one’s experience of the timeline of one’s life, e.g. with celiac disease.

My focus for this paper was, as I said above, “*what we can learn by applying a disability lens* to our understanding of it, we can achieve important philosophical and social insights. What happens when the question we ask of theory changes from “what is disability” to “what does it help us notice?”

My current project examines gut issues, with the help of a disability lens informed by disability theory, to figure out what we might learn about our conceptions of autonomy and vulnerability. How do they suit us? How are they limited? In interviews conducted in the summer of 2019 and 2020 with adults with gut issues, very few participants named their gut issues as disabilities (note – I didn’t ask explicitly about this, but did ask questions about how they saw themselves in terms of their gut issues). And yet, the issues that came up in terms of self-perception, treatment by friends, family, co-workers and health-care professionals, discrimination, frustration with an unruly body, attitudes toward cure and treatment – all of these are things that can be fruitfully examined with a disability lens.

There is much that a disability lens might help us notice. Learning from the work that is going on within disability theory enriches and reframes our approach; we don’t need a definition in order to shift our attention.