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Disabling Bioethics Futures

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Article abstract

Relationships between disability and bioethics are often fraught, particularly when we are concerned with imagining possible futures. The futures imagined for disabled people are often futures without disabled people, utopias where disability has been cured, defeated, or overcome. How might we build better disability futures in a discipline so often committed to futures without disability? Here, I call for more creative inquiries into disability through research, representation, education, and engagement with disabled expertise.

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TÉMOIGNAGE / PERSPECTIVE

Disabling Bioethics Futures

C. Dalrymple-Fraser[a]

Résumé
Les relations entre le handicap et la bioéthique sont souvent délicates, en particulier lorsqu'il s'agit d'imaginer des avenirs possibles. Les avenirs imaginés pour les personnes handicapées sont souvent des avenirs sans personnes handicapées, des utopies où le handicap a été guéri, vaincu ou surmonté. Comment pouvons-nous construire de meilleurs avenirs pour les personnes handicapées dans une discipline si souvent engagée dans des avenirs sans handicap? Ici, j'appelle à des enquêtes plus créatives sur le handicap à travers la recherche, la représentation, l'éducation et l'engagement avec l'expertise des personnes handicapées.

Mots-clés
handicap, bioéthique, justice, ableisme, handicapisme, accessibilité, éducation à la bioéthique, COVID-19

Abstract
Relationships between disability and bioethics are often fraught, particularly when we are concerned with imagining possible futures. The futures imagined for disabled people are often futures without disabled people, utopias where disability has been cured, defeated, or overcome. How might we build better disability futures in a discipline so often committed to futures without disability? Here, I call for more creative inquiries into disability through research, representation, education, and engagement with disabled expertise.

Keywords
disability, bioethics, justice, ableism, disableism, accessibility, bioethics education, COVID-19

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What might a future for disability and bioethics look like? Relationships between disability and bioethics are often fraught, particularly when we are concerned with imagining possible futures. As disabled scholars have regularly noted, the futures imagined for disabled people are often futures *without* disabled people, utopias where disability has been cured, defeated, or overcome (1). Debates concerning disability in bioethics similarly tend to focus on disability in terms of who should survive into the future. I am interested in exploring futures of disabling bioethics – better understanding the processes by which *bioethics disables* by constructing and disavowing disabilities, and the ways we might *disable bioethics* by more critically centring and attending to disability. This article offers brief remarks toward the latter: how might we build better disability futures in a discipline so often committed to futures without disability?

ON "DISABILITY"

For sake of scope, I use the term "disability" to gloss across all those who are excluded or oppressed based on their apparent abilities and disabilities. But such generalizations can obscure important differences among disabled people, such as competing needs and capacities, different cultural and historical constructions of disability, or the privileged attention some disabilities receive over others. Moreover, there are questions about whether any definition of "disability" could possibly apply to all peoples, or what "disability" properly picks out (2-3). Even in policy and legislation, there is no singular sense of "disability" across Canada: different offices and levels of government use competing definitions.

Meanwhile, to talk generally of disability can further obscure the ways disability intermeshes with other social locations. While 22% of Canadians are estimated to be disabled, this statistic obscures the fact that disability occurs at far higher rates for those who are Black, Indigenous, transgender, poor, or unhoused. And it would be inappropriate to identify differences in disability prevalence without also attending to the social structures and policies that influence those rates and experiences. For example, Indigenous disability rates cannot be adequately explained without discussing ongoing legacies of residential schools, forced adoption, land dispossession, environmental violence, and racism in medical education and practice. Calls against disableism in bioethics must be read alongside calls against broader ableism, colonialism, racism, cissexism, and classism, among other structures of inequality.

Uses of "disability" in bioethics infrequently go this far. Rather, there is a tendency to conceptualize disabilities as pre-theoretical, individualized, naturalized, undesirable bodies or minds (2). Consider the convention of measuring global disease burden or triaging in terms of "disability-adjusted life years" (DALYs). DALYs rhetorically equivocate disability with morbidity and presume that disabilities can be located within individual bodies, that they necessarily make a life undesirably worse off, and that they are objectively measurable and applicable across people and contexts. These presumptions are not self-evidently true, and a more critical approach to bioethics requires we interrogate what our concepts and rhetorics of "disability" reveal or obscure.

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DISABILITY BIOETHICS BEYOND SURVIVAL

When disability appears in bioethics, it is primarily in debates over who should live and who must die: how we should select or modify embryos; who should be eligible for medical assistance in dying (MAID); what triage protocols we should adopt during critical resource shortages, and thus which lives we should prioritize for the future. Outside of questions of survival, disability is often relegated to the background, unless to ask whether disabled people have the autonomy or personhood to even count in these debates.

Overemphasis on matters of survival obscures the complexities of disabled lives and forecloses opportunities for more creative inquiries. Disabling bioethics calls us to consider: What new inquiries unfold when we step away from questions of survivorship or accessibility? What would it mean to ask questions that start from the position that disability does not alone make a life less valuable? How can we measure quality of life in ways that do not reduce the myriad experiences of disability to ableist norms of desire? How can we introduce disability into other bioethical projects and debates where it has been excluded or deemed irrelevant? In the past two years, *The Journal of Philosophy of Disability* and *The Disability Bioethics Reader* have made good moves in these directions (4); we can continue to push further.

Consider a further example. There is growing interest in architecture for public health: how principles of “active design” can nudge people toward desired behaviours like increased exercise. Common examples include replacing park benches with leaning bars, rerouting public transportation to create pedestrian-only spaces, and restricting elevators in favour of stair use. Many of these interventions disadvantage disabled people. Meanwhile, these designs are frequently evaluated on metrics of “walkability” and increased staircase use, tacitly or explicitly excluding disabled people from study design and outcomes. What do we foreclose by equating activity with certain kinds of movement, and health with certain kinds of bodies? Whose health counts in public health research? Disabling bioethics demands that we interrogate and reimagine the norms, metrics, and questions taken for granted.

“NOTHING ABOUT US WITHOUT US”

These narrower approaches to disability in bioethics are partially explained by the underrepresentation of disabled people in bioethics. Indeed, many leading scholars of disability bioethics are nondisabled, and while one need not be disabled to contribute to disability research, we should be concerned about the social, professional, and epistemic harms associated with the underrepresentation and displacement of disabled expertise. For example, it is well established that nondisabled health professionals rate the quality of life for disabled people lower than disabled people self-rate. These concerns echo in debates over DALYs and COVID-19 triaging, such as through online protests using the hashtags #NoBodyIsDisposable and #ICUgenics, and in disability justice’s calls of “nothing about us without us” in debates over MAID legislation. While these data are heuristic, they raise caution for scholarship that is produced *about* or even *for* disabled people, but *without* us. Similarly, merely consulting disabled stakeholders does not necessarily lend to better disability inclusion in research or practice. It is one thing to consult disabled expertise, and another to engage it productively. Disabling bioethics requires addressing the dearth of disabled representation among researchers and professionals, and that disabled people are more often treated as collaborators rather than mere consultants, stakeholders, or objects of study.

DISABILITY AND BIOETHICS EDUCATION

In turn, the dearth of disabled representation in bioethics is informed by the underrepresentation of disabled people in higher education. While figures vary by location, disabled undergraduate students graduate at slower and lower rates than nondisabled peers. Further, Canadian studies suggest that fewer than 7% of university faculty are disabled, and fewer than 12% of medical students – rates appear even lower in the USA – despite at least 22% of the general population experiencing disability (5). These figures are even lower in related disciplines like philosophy, where fewer than 1% of Canadian faculty report disabilities (2).

Many factors contribute to these statistics, including inaccessible campus buildings, insufficient financial support, course infrastructure and accommodations. Even among disability-positive instructors, lack of training and institutional support can make it difficult to design accessible materials on one’s own, or to navigate competing accommodations in increasingly large courses. In my own teaching experience, disabled students often report that inadequate disability representation inclines them away from bioethics and toward disciplines like disability studies, or toward non-academic pursuits altogether. Reports of inadequate representation range from the absence of disability content to the centring of disableist debates and readings. The latter of these seems particularly common in philosophical bioethics courses, where it is more common to include decades-old literature with antiquated language and science. These experiences are further exacerbated for students who experience further discrimination and disadvantages on the basis of other identities. As one student offered, “It’s hard to feel at home in disciplines that regularly argue against your existence.”

Looking to the future, disabling bioethics requires not only local reform in how we conduct research, develop policies, or teach bioethics, but also requires institutional commitments to accessibility and representation in higher education and professional settings.

ACCESSING PROFESSIONAL ACTIVITIES

Beyond calls to better reflect disability in bioethics research, education, and professionalization, we should attend to barriers of representation and retention in professional activities like conferences. For example, the 2019 meeting of the Canadian Bioethics Society (CBS-SCB) was held in Banff, Alberta. Not only was the conference held in a relatively inaccessible venue, but matters of conference accessibility did not appear anywhere on the registration materials, nor the conference app. Rather, the most explicit documented mention of accessibility appeared in the conference exit survey. And where disabled people experience higher unemployment and poverty rates than nondisabled people, public registration rates for preceding CBS-SCB conferences routinely exceeded the average monthly rent for a single-bedroom apartment in the hosting cities. To be clear, this is not meant to single out CBS-SCB programming in particular, but rather to provide one local example of broader systemic inattention to disability and accessibility in professional activities (6). And while digital programming during the coronavirus pandemic has alleviated some of these barriers, digital spaces are not necessarily more accessible than physical spaces, and too few digital venues meet minimum industry standards like the Web Content Accessibility Guidelines (WCAG).

Whereas our professional activities increasingly centre themes concerning exclusions and systemic injustices in bioethics, it is an unfortunate irony that those activities regularly present barriers to inclusion. A more inclusive future for disabled bioethics requires better enabling disabled community participation and engagement.

DISABLED EXPERTISE, ELSEWHERE

Bioethics cannot merely rely on strategies of inclusion that bring disabled people into the discipline and professions. We must look also to those places where disabled expertise has already flourished. This will include more frequently turning to other academic disciplines, like disability studies and mad studies. But recognizing the present inaccessibility and uninhabitability of higher education also requires that we look further outside of academic spaces.

The COVID-19 pandemic helps make this clear. Many of the lifestyle changes associated with the “new normal” had been part of an “old normal” for many disabled people, and disabled communities generally have a wealth of knowledge in navigating public and personal health matters (7-8). Wearing masks, social isolating, not being able to shop or dine out, reliance on telecommunications, housing and employment precarity, are all things that many disabled people lived with long before the pandemic. Similarly, many recent moves toward increased accessibility with telehealth, online working, safer public spaces, captioning services, available and affordable protective equipment, for example, have each benefitted from decades of activism from disabled communities. Rarely are academic publications the primary way of sharing and communicating these skills and knowledge.

And while many disabled people have been working from their chairs and beds to create new knowledge, resources, and public actions throughout the pandemic, others of us have had to prioritize simply surviving a pandemic that disproportionately affects disabled communities. Those focused on survival are less likely to participate in conferences, or to have the luxury of authoring academic articles. Still, knowledge is not constrained to journals and conferences; it also appears in spreadsheets, social media, music, zines, blogs, podcasts, fiction, and many other spaces. Attending to disability requires that we engage in creative explorations into existing sources of knowledge. What, for example, might we learn through disabled speculative fiction, where writers have long been imagining different disabled healthcare and futures?

DOING DISABILITY, DIFFERENTLY

The fraught relationships between disability and bioethics call on us to think creatively about different bioethics futures, and this in turn calls attention to sources of disability exclusions in bioethics. Ultimately, this article provides only brief notes, highlighting the need for more creative inquiries and accessible, engaged collaboration with disabled expertise. This is no small task, requiring structural interventions on bioethics education, concepts, and professional practices, as well as individual changes in how we teach, research, and engage with disabled peoples and expertise. Still, together, these changes and conversations may serve as further steps, limps, and rolls toward better disabled bioethics futures.

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