

FROM A FIGMENT OF YOUR IMAGINATION: DISABLED MARGINAL CASES AND UNDERTHOUGHT EXPERIMENTS

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Abstract: Philosophers often enroll disabled bodies and minds as objects of thought in their arguments from marginal cases and in thought experiments: for example, arguments for animal ethics use cognitively disabled people as a contrast case, and Merleau-Ponty uses a blind man with a cane as an exemplar of the relationship of technology to the human, of how technology mediates. However, these philosophers enroll disabled people without engaging significantly in any way with disabled people themselves. Instead, disabled people are treated in philosophy as literal objects—and in many cases, as less than human. (This sense of a categorical difference between disabled and nondisabled people is becoming especially clear during the Covid-19 pandemic, as I write this article.) Philosophical reflection thus makes assumptions—often wrong—about disabled people’s lives, experiences, and relationships to technology. Outside of philosophy as well as in, disabled people are not regarded as experts about our own experiences and lives; our testimony is paternalistically written over. We need better consideration of disabled people as people as we consider the future. Lack of disabled people’s points of view in philosophy colors—and sometimes invalidates—views of technological change.

Key words: disability; disability technology; assistive technology; marginal cases; thought experiments.

Introduction

I began writing this essay on 27 March 2020, at night, unable to sleep; I am considered “non-essential personnel,” and I sit on the sidelines as tragedy unfolds, cloistered at home with my fear, grief, and hope. I was asked to pen an essay for this special issue on Philosophical Reflection and Technological Change back in October, which now seems like eons ago in another world. In this new world, it feels like there is no time for philosophical reflection—or maybe only time for reflection. What I originally wanted to write about—and still will, but in a different register—was the image of disability in philosophical literature and the impact on technological change this has created. In short, our imaginations are poor when it comes to thinking about disability and technology because of unrecognized ableist prejudice that flows from philosophical reflections as well as our collective imagination about the role of technology in the future. But the pandemic has added another dimension to this argument,

for it has made it increasingly clear that these philosophical conceptions of disability have also infected the outside world; some hospitals have openly made it policy that when triage is necessary in overwhelmed wards, disabled people go to the back of the line, or are treated as altogether disposable.

This paints a picture of a future without disabled people. But the fact is that our imagination about the future should be about disabled futures. Although science fiction often depicts technology as curing the “problem” of disability, the future will be a disabled one; there will be more disabled people, not fewer. With space flight and travel, we can expect more disabled people will be made, with changes to vision and bone density and Circadian rhythms askew. With environmental disaster, climate change, and pollution, we can expect there to be more people with asthma and chronic illnesses, not to mention fresh psychological and physical trauma. With new diseases and the effects of new viruses like Covid-19, whose long-term effects are not yet certain, but we can expect more disabled people, with new types of fatigue and permanently damaged lungs and organs.

Disability is a political category. My identity as a disabled person is a political one. My body and mind are often subject to extra vetting, extra curiosity, and extra imagination, but without my input; my own testimony is often discounted by those who consider themselves experts, whether about assistive technologies, legal accommodations, medical science, or social welfare. We are not seen as good judges of our own circumstances. Disabled people are more often seen as undesirable, expendable, as either less worthy of care or drains on the systems with needs too great to deserve consideration or care. And the pity shown by many toward disabled people suggests that it would be better to be dead than to be disabled.

I paint a grim picture, but it’s one backed up by the experiences of my community and the past century and a half of history. While one might consider the past roughly 150 years as one of great technological change and success, technological change has a way of throwing certain bodies and lives into chaos and violence. Though eugenicism is rarely labeled so these days, we’re not out of the era of eugenics—particularly for black and indigenous disabled people, who experience disability at a greater level due to structural violence, trauma, and environmental racism.

All this is to say that we should not be treated as objects (of pity, scorn, or dismissiveness); we are human beings with valuable interior lives and perspectives. When philosophy uses us as marginal cases and objects of thought experiments, they too often ignore what disabled people have to say, either not asking people at all or ignoring or denying the response. I’m acutely aware of these issues, being as I am on the inside of medical care, of need, of being vulnerable in ways normal 30-somethings don’t consider: I’ve had two lung surgeries due to the spread of a cancer whose initial treatment involved a leg amputation, chemotherapy-induced hearing loss and tinnitus. When philosophers—often in bioethics, but not only there—use disabled people as marginal cases, as interesting thought experiments, as Other, as interesting problems to work around, they are talking about *my life*. *My goal in writing this is to make my worlds (as both a philosopher and a disability community member) collide, in hopes that this collision will prompt philosophy to reflect about technological change in ways that take into account the experiences of the disabled people who depend on these technologies.*

Marginal cases & disability simulation

Arguments from marginal cases are most prominent in philosophical debates about animal ethics, in particular about the moral status of nonhuman animals. Arguments from marginal cases usually take some group—whether intellectually disabled people, infants, people with dementia, or people in comas—to argue that because this group has moral status as comprising persons in the rights-bearing sense, despite mental deficiency or incapacity, then we cannot exclude from moral consideration a host of nonhuman animal species who have greater mental capacity. Contemporary philosophers like Peter Singer use this line of reasoning.¹

Philosophers who have countered arguments from marginal cases have also done disservice to those marginalized in the cases: for example, Jeff McMahan (2003) argued for a two-tiered system of personhood positioning some “marginal cases” in the second tier, with the rest of humanity in the first. Philosopher Eva Federer Kittay addressed the problems with this argument (2009). When philosophers make arguments based on the lives of people and communities with whom they have little experience (and whose permission they do not have), it treats the disability community as simply a resource for arguments rather than as people.² But even consultation is not necessarily enough; should a person in these categories be consulted only as case study object in order to prove that they are less capacitated/worthy or less-than-equal? There are many built-in assumptions in the use of marginal cases for argumentation that are unethical and/or flat-out ignorant of the actual conditions and value people place on their own lives.

Thought experiments and phenomenological investigations using disability are perhaps less inflammatory than marginal case arguments, but they, too, often bulldoze over the experiential expertise of disabled people and the social contexts within which our lives unfold. Thought experiments, in general, are not problematic—we all imagine and work through scenarios, some more fantastical than others—but, when it comes to our collective ability to engage imagination, worn-out tropes about disability often color these imaginative explorations.

This is very clear in recent sociological literature about disability simulation, and the problems of these simulations are relevant to how philosophers should reconsider disability in their technological imaginations. Disability simulation became popular about twenty years ago as a way to promote disability awareness; examples of these simulations are wearing a blindfold to perform tasks as a way of finding out what it’s like to be blind, being given text that’s rearranged to show what it’s like to be dyslexic, or wheeling around a campus or urban area to find out what it’s like to be a wheelchair user. On their face, these simulations may seem innocuous. They are often promoted as experiential learning and are popular for

¹ There is actually a wide range of disability community writing taking issue with Singer’s work; see Johnson, 2003, Weise, 2010, Taylor, 2017, for a small sampling.

² Some may object that “not all marginal cases,” like infants and babies, deserve this scrutiny. However, and thanks to Heath Sledge for pointing this out: Human infant development studies have found that they are actually smarter than we often think, signing as early as 6 months, expressing preferences and opinions (about, for instance, sleeping on their backs or fronts), etc. I suspect that even when infants and babies are taken as marginal cases, they are often done an injustice. We’ve often been stereotyping about infancy and childhood in poor ways.

training techniques for disability professionals, designers, and students.³ As Michelle Nario-Redmond, Dobromir Gospodinov, and Angela Cobb explain,

The primary goal when administering disability simulations is to grant nondisabled people an opportunity to improve understanding and acceptance of people with disabilities [. . .] simulations allow people to role-play through personal experience. This kind of perspective taking is built on the assumption that people cannot fully understand the circumstances facing disabled people unless they know first-hand how disabled people seem to do what they do (2017, p. 325).

But disability activists have long decried such practices: disability simulation strips disabled people of the chance to speak with authority, as the participants then see themselves as experts about the disability from the simulation. Participants may feel that they know enough to speak about access, possibly without ever talking to a person with the disability they just simulated. These simulations give people a snapshot in time, a brief experience that might emulate first becoming disabled, but cannot capture the experience of living with a disability. Being blinded and going out for the first time is surely disorienting, but most blind people learn to navigate and manage their lives over time. The first day of being a manual wheelchair user taxes your arm muscles and shows you all the inaccessible ruts in pavement, so the first day is pure frustration and confinement, but many wheelchair users come to see their wheelchairs as “chariots of liberation” that let them participate in their communities and go about their lives—as empowering technology or as a useful tool, not as a burden or a problem. The first day is not the experience, and it certainly doesn’t run up against the social context of long-term disabled life, with all its paperwork to prove yourself disabled, with social stigma and disappointment, with existing in a world where ableism colors your everyday, with success in learning to do old things in new ways, and sometimes with defiant crip pride and radical community.

Nario-Redmond et al. add that, part of the problem here is that “Simulating the experience of any minority group is problematic, particularly when the imagined target is portrayed in stereotypical terms” (2017, p. 325). Too often, philosophers, and educators more generally, don’t recognize disabled people as a minority group. *By thinking about disabled people as impaired or deficient people, disabled people are further marginalized.* The “perspective taking” of these thought experiments, simulations, and marginal cases is an actual taking, a ripping away of experience, a stereotyping and collapse of experience, a willful ignorance of the real people whose lives are being subsumed and used.

Often people using disability simulation and similar imaginaries⁴—and, similarly, those employing disability as an imaginary in their thought experiments and phenomenological

³ Age simulators, similar “awareness” exercises aimed at getting people to “take the perspective” of elderly people, also exist, using virtual reality, weighted suits, goggles to lower vision and mufflers for the ears. While these are newer developments, we should be similarly wary of the results of such exercises. Recent virtual reality and computer-assisted experiences meant to simulate the experiences of other people should be similarly reconsidered.

⁴ “Sociotechnical Imaginaries” is a term often used in academic Science and Technology Studies, associated with the work of Sheila Jasanoff, that refers to frames of thought that guide and inform policy making and the management of dissent (Jasanoff & Kim, 2009). There are a few narrative

explorations—ignore the experiences of the disability community. They often don't even understand disability as a community connection and belonging, which means they often don't know that disabled people find the practice harmful, as an active silencing and talking over of disabled people.

Disability simulation events are still widespread, despite additional sociological data about the outcomes of these events, which bolsters the argument that they do not produce the intended outcomes and should be stopped. Nario-Redmond et al. found in their study, about various types of simulation:

[a]fter completing all three simulation activities, people expressed more pity and discomfort about meeting someone with a disability, and felt more vulnerable about becoming disabled themselves. Although empathetic concern (warmth) toward disabled people increased, willingness to volunteer to increase campus access did not (2017, p. 330).

Similarly, Arielle Silverman (Silverman, 2015, Silverman et al. 2015), focusing on blindness simulations, found that simulation participants actually had more negative perceptions of blindness after completing the simulations, thinking of blind people as less capable than before the simulation. This casts a new light on the ways that blindness is used in philosophical literature—as a referent for exploring different phenomenologies and the use of technologies, used by philosophers such as Merleau-Ponty. However, as Joel Michael Reynolds has pointed out, Merleau-Ponty's conclusions cannot be correct because he does not get blindness right: “Merleau-Ponty's famous reading of the blind man's cane is problematic insofar as it omits the social dimensions of disabled experiences, misconstrues the radicality of blindness as a world creating disability, and operates via an able-bodied simulation that *conflates object annexation or extension with incorporation*” (2017, p. 419, my emphasis).

Technological change can produce wonderful things for both disabled and abled people. Disabled people have used the internet as a place in which to come together as a community and participate, and to meet peers with their rare types of disability; the internet serves as a place to collect and share advice, camaraderie, and lifehacks.⁵ Technology can also offer new kinds of accessibility: braille (and now laptops that have Braille readouts), text-to-voice and voice-to-text software, eye tracking; likewise, non-digital technologies, such as my favorite rolling walker. There are indeed technological wonders and skillful hacks here. There are also technologies of access that can be built into the physical and digital public environment: curb cuts, large print signage, elevators, better acoustics, fire alarms with both audio and visual cues, captions, image description, etc.

tropes or ways of imagining disabled people that seem to guide all thought about disability policy and ethics concerning (but not with) disabled people. Often, when disabled people disagree with the tropes about them, their testimony is actively discounted and written over.

⁵ There are many disability-specific and disability culture facebook groups, and disabled people communicate through twitter, blogs, youtube, and, indeed, all social media. For instance, Alice Wong of the Disability Visibility Project often discusses how online life means so much to many in our community and promotes the use of #DisabilityTwitter, fostering live chats and crip world building, see: <https://disabilityvisibilityproject.com/about/>

When I teach my class on Technology & Disability, which has readings mostly from the disability community, some students are surprised by the narratives they encounter, for many of them come in expecting to learn about new technologies that are “fixing” the lives of disabled people. This is the aim of many technological developments designed “for” disabled people by nondisabled people. But these designs take disabled people as imaginaries to be designed on, instead of people. Students are surprised to find out that the disability community itself is much less enthusiastic about exoskeletons and sign language gloves than the media and the Silicon Valley disruptors are (sometimes it’s not even clear what problem design teams think they are solving). In my class, we also talk a lot about technologies designed not *for* but *against* disabled people—technologies of eugenics, such as sterilization procedures, selective breeding, and gas chambers. These are the two poles of thought about disabled people: but neither eugenic thought nor ideas about normalizing disabled people take us seriously as people with rich, full lives, who do not need fixing, through technological change or anything else.

Given these imaginaries about disability, it’s no surprise that some philosophers use disabled bodies and minds as examples as they frame problems and push agendas. But philosophers (of all people!) must be thoughtful and careful that in “taking on” a thought problem we do not “take away” disabled people’s voices and full humanity. We should be equally careful as we think about technological futures in relation to disability. Too often, disabled bodies and minds are used to justify the development of new technologies by developers who are imagining a future where disabled people do not exist—are “fixed” or never born at all. To understand the inhabitants of the future—about what it is like to be a cyborg (Wong, 2019)—requires more than simply imagining or simulating what it is like to be us.

Cyborgs and the disability community

People in the disability community have long decried the co-opting of cyborgs by philosophers. Jillian Weise and Alison Kafer have written powerfully about the traces left by Donna Haraway’s cyborg visions in which disability is invisible or absent (Weise, 2016; Kafer, 2013). In urging us to become cyborgs, Haraway forgets that some of us already are: people on ventilators, prosthetized amputees, wheelchair users, diabetics with insulin pumps, etc. For us, our politicized cyborg identity doesn’t come from defying conventional binaries; we are forgotten in both binaries (and in between). It does not come from the desire to become super- or transhuman; transhumanists seek to eliminate disability (Istvan, 2015; Kurzweil, 2013; see also Ladau, 2015 for a disability community reply to Istvan, 2015), envisioning futures where we are transformed into abled and super-abled people.

There are few things I feel certain about saying about the future. But I am certain about this: in the future, we can expect more disabled people, not fewer. Environmental catastrophe—climate change and pollution, pandemics such as Covid-19—mean that more people will be disabled. Even if we were to meet our wildest dreams of Martian colonization, the physical effects of space travel and of different gravities would disrupt human bodies, and we would find ourselves in new environmental niches that we are not evolved to master; we would thus face pervasive disability.

Rather than think about the nondisabled futures imagined by nondisabled tech enthusiasts, we should work within the framework of narratives from disabled people, who grapple with technologies on and in their bodies every day—disabled crippborg-cyborgs (Nelson et al., 2019). We know what cyborg maintenance and being requires (Earle, 2019; Jackson, 2018); we know that disability (which is not always deficiency—it can mean superior performance under particular conditions, and instills a creativity and adaptability like no other) is mere-difference, rather than bad-difference (Barnes, 2016); and we know that all human bodies and minds are good bodies and minds from the work of artists and activists collectives like Sins Invalid, the Deaf Poets Society, and Disability Visibility Project. We philosophers of technology should attend to Aimi Hamraie and Kelly Fritsch’s notion of Crip Technoscience as a way to better consider disability and technology (2019).

Covid-19 & conclusion

As these scholars and others have shown, the disability community offers better ways to think about the future than the ways we do now. Despite cyborg-enthusiasts who forget we exist (Weise, 2016), disabled people offer different thinking about time with Crip Time (Kafer, 2013; Samuels, 2017), produce better plans and designs for distributed education and research (Shew, 2020), and offer a lens for thinking critically about marginalization in technology. But just as we are learning these lessons, the Covid-19 pandemic of 2020 is showing us that disabled life is valued less; disability is and must remain a political and politicized category, not a physical or essential one.

As a disabled cyborg philosopher of technology, I think a lot about whose stories get told. Philosophical reflection is too often done in isolation, alone with your own thoughts and a few books. This makes it easy to forget that the people you are imagining might not think what you think they think, might not even agree to being enlisted in the thought journey you want to take. They might actually want to be thought about as real people, not as imagined avatars. Thought experiments, phenomenologies of other people’s lives, and arguments from marginal cases represent three types of philosophical reflection that are at great risk of getting their imagined stories wrong. I worry that it’s too easy for technological futures to be motivated by false images. Rather than philosophical reflection performed alone, philosophers need rich engagement with the communities—stakeholders in political and technological decision-making, and others—impacted by technological change. Disabled people are more than justifications for the development of technology, especially technology that we didn’t ask for and weren’t asked about.

This is made all the more salient today in the face of the pandemic, whose impacts fall disproportionately on indigenous, black, and disabled people. For a long time, the “solution” to those perceived as undesirable, including disabled people, has been institutionalization, and this pandemic has been felt most by people living in nursing homes, residential mental health facilities, and homes for developmentally and intellectually disabled people—especially people of color in these institutions. During this time, it’s hard not to see our failures of imagination, especially about those whose bodies and minds are cast as different or risky. This amounts to a failure of humanity, our lack of care for those we see as others: not only chronically and permanently disabled people, but also our elders (who we will one

day become, if we're lucky) and the acutely ill. People on ventilators are disabled cyborgs, after all. We are, sadly, seeing what happens when eugenic dreams come true.

Transhumanists, techno-progressivists, and others who describe technological change as linear and progressive and on a course to eliminate disabled people, all while marveling at technology for disability, do us a grave disservice. Our existence—our political will and organizing—produces a better world. “The Curb Cut” effect is but one example: curb cuts, often fought for by disability campaigners and regulated on sidewalks, are used by package delivery people, people with strollers, anyone making a move, and bicycles. The same applies for other things like captions, which are turned on in bars and in airports (and are probably very handy if you are on lockdown and want to watch a show while someone you live with is working). Building a world for disability inclusion—in both infrastructure and in how we think/approach people with different bodies and minds—builds a better world, period.

With every death of a stranger from Covid-19, people inquire whether the person was old, sick, or disabled—to explain to themselves and tidy away the world: to justify a death and make one feel more at ease. “Phew, I don’t have to worry about that because I’m not,” people say in their heads, and sometimes, terribly, aloud, filling in the blank with the reason the “pre-existing condition” that makes a death dismissible. Dismissed in life as we are in death. Marginal as cases and as people. Philosophy can do better in its reflections, and in how it imagines the future.

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