

What Disabled Culture Teaches On Life Post-Pandemic



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Before the vaccines are completely rolled out, people have already begun speculating about what they want life to look like post-pandemic. Fantasies about our new world abound: leisurely eating at restaurants, maskless workplaces, in-person learning, hugs. This is a return to before, usually phrased as a “return to normal”. Such fantasies not only ignore the public health wisdom we’ve learned, but also disregard just how inaccessible the old normal was. Returning to normal ostracizes the very group whose wisdom, culture, and experience allowed them to foresee many of the problems we faced, a group that rarely receives credit for anything: the disabled.

Let’s face it. This worldwide encounter with a pandemic is a worldwide encounter with disability. Activists and scholars make a distinction between impairment and disability. Impairment is what happens to or in the body and mind. Disability is what happens when impairment has social and material consequences. That is,

disability is created by social, cultural, legal, and physical structures. A person who is hard of hearing has an impairment. They become disabled when the telecommute software does not have accurate closed captioning or the software company makes captioning prohibitively expensive, or their company makes its use optional. I'm looking at Zoom, Microsoft Teams, and everyone else.

Social responses to the novel coronavirus are textbook examples of disability and impairment. We haven't just been dealing with a disease. We've been experiencing the social effects of that disease given our current structures. Large numbers of infections occurred because officials prioritized profit over people. The disproportionate effects on the poor and people of color comes from established public health disparities. Further, a culture that prioritizes individual desire over collective need catapulted us into dangerous territory. In these examples and many others, coronavirus is the impairment; the response to it makes it a disability.

Over the course of the pandemic, folks deployed coping strategies that disabled communities know all too well. For instance, work from home was not helpful for everyone, but it became clear that the need to create work-from-home access was going to be one of many solutions that allowed people to tend to their rapidly changing needs. Disabled activist, Imani Barbarin, like many of us, had requested work-from-home as an accommodation, only to be told it could not be done or that the company in question relied on

in-person offices as the ideal business model. The March/April 2021 issue of *Harvard Business Review* rethinks an in-person only model, suggesting the utility of a hybrid model that allows for impromptu in-person interaction, while optimizing the utility of work-from-home access. The lesson is this: this new COVID-19 reality allowed some of us to benefit from the long advocacy of disabled people for the right to work in spaces that honor specific needs.

Those with disabilities and chronic illness were uniquely prepared to cope with the pandemic because our realities in non-pandemic years dovetail most neatly with what others understood as new. We have become accustomed to fighting for sensible accommodations for ourselves, dealing with warped senses of time, coping with isolation, deploying other behaviors required to stay healthy, and navigating grief.

One might suggest that marginalized communities were least prepared for the pandemic because they could not control their environments and became more susceptible to infection and death. That is certainly true, but that understands the pandemic primarily through the lens of class. Class did and does govern the way people have been able to weather COVID-19. However, class does not shape pandemic responses on its own.

Ableism — the pervasive belief that able bodies and minds are superior — shapes all facets of life, including access to upward

mobility, and health care. For example, ableism allows for a loophole in the Fair Labor Standards Act that makes it acceptable to pay the disabled below minimum wage. Along the same logics, the government can require that social security income recipients' resources remain under \$2000 in order for them to qualify for benefits which makes it impossible for them to marry or cohabitate. In addition, the perception of disability as lack can lock us out of jobs altogether. From a health care perspective, thinking of disabled lives as unlivable makes us the viable candidates for discontinuing life support. The list goes on. These policies have a long history that constitutes the structures under which the disabled operate. Because these policies have also disproportionately have affected Black and Brown people, it is important to note that the disabled community includes a large amount of people of color. Our histories are shaped by interlocking structural inequalities such that we possess knowledges and cultures all our own. Since we know the structures will change slowly if they change at all, why not turn to the cultural wisdom of those who know?

Leah Lakshi Piepzna-Samarasinha, author of *Care Work: Dreaming Disability Justice*, writes about the learned flexibility of disabled communities of color both with themselves and each other. Part of that flexibility is the ability to deal with grief. This historical moment, while unique, is not singular as part of disability history. Given the confluence of structural ableism and the reality of some impairments, the disabled understand grief intimately. In fact,

people shy away from disabled histories and cultures because it appears as though our lives are a relentless battering of grief.

What people do not realize is that out of that experience comes creative possibility. Disability history and cultures allow us to navigate this time and many others with the seriousness that grief commands, the dark humor it engenders, and the honesty of conversations about hospitalization and death. That creative possibility is not merely cultural: it includes the new structures created or innovatively used as a result of living with the novel coronavirus.

During the pandemic, the disabled were not seduced into believing that happy endings were possible, though we hoped for them. Our happy endings also looked a little different than a “return to normal”. Our happy endings included the possibility that health care professionals might prioritize us and our lives rather than decide that our lives were not worth saving. Our happy endings also allowed for COVID-19 long haulers who would be newly-welcomed members of our community. Our happy endings gave us the opportunity to say goodbye when necessary.

For some, it will be anathema to understand disability as a culture of creation and agility rather than an individual lack or deficiency. The able-bodied are all too accustomed to understanding disability based on what someone can't do. In truth, that is how we have generally understood the pandemic: We can't go places. We can't

eat out. We can't. We can't. We can't. What if we had accepted the limitations of the virus? What if we had worked within them to create beneficial structures for most people? What if? What if? What if?

As people clamor to return to a so-called normal, I cannot help but think about how terrible pre-pandemic life was for some of us. While I will not laud forced isolation, restricted physical movements and socialization, and all-encompassing grief, all of these allowed for certain forms of access to open up possibilities: teleconferencing permitted some people to speak more to loved ones, access to certain forms of entertainment became more readily available, people began to pay more attention to the limited bandwidth of the human body and mind. These were not universal truisms, but the fact is they were more possible. Disability wisdom tells us that access is for everybody.

COVID-19 has taught us all that the current structures we have — including the Americans with Disabilities Act — do not go far enough in creating an accessible atmosphere that includes and learns from people with disabilities. And, that exclusion has been done deliberately. Knowing that our future is uncertain with regard to the pandemic's lingering after-effects, we have to rely on the wisdom of people with disabilities. They know what is necessary in creating an inclusive space: one that we will all need in order to survive.

I do not intend to minimize the actuality of coronavirus as an impairment, but rather to poke a hole in how we understand disability writ large. In addition to wrongly understanding it as an individual problem, we also tend to understand it through the lens of overcoming. That is also how people think about the pandemic: soon this will be a memory of a bad chapter in our history or it will be over soon. Once we all are vaccinated, we'll be cured and done with this.

But the disabled know better.

Learn from us and our lives. Refuse to discard us and our wisdom. We know that the future will not be back to normal, but rather the constitution of a new reality. This reality has to take the lessons learned from an encounter with disability — access is for everyone, grief is real, isolation is sometimes a painful necessity — and use those ideas to better create the world we now encounter. The idea of overcoming won't serve us well since it asks us to individualize a collective problem.

Our way forward is not back. It is through.