

RUNT OF THE LITTER: DISABILITY IN THE AGE OF PANDEMIC

Magda Romanska

Magda Romanska is a writer and theatre and media scholar. A graduate of Stanford and Cornell's doctoral program, she was a founding editor of *Palimpsest: Yale Graduate Literary & Arts Magazine*. Her op-eds and articles appeared in *The LA Review of Books*, *The Boston Globe*, *The Conversation*, *Salon*, *PBS*, and *The Cosmopolitan Review*.

There was a saying in the Eastern Bloc back in the days of the Soviet regime: "You might not want to follow the news, but the news will follow you." It meant that if you're not aware of what's happening in the larger world, you might not be able to escape the next impending catastrophe, be it human- or nature-made. Thus, those of us who grew up in the Eastern Bloc (Poland, in my case) are compulsive readers of news: understanding the world being considered essential to survival. I am explaining this to provide context for why I ordered my first face masks on January 22, 2020. On January 27, four days after China closed the city of Wuhan, I purchased four months' worth of food and supplies, including hand sanitizer. Knowing how centralized governments work, I knew in an instant that China would not close Wuhan in response to the measly 300 cases reported at the time if they didn't have some other internal knowledge of the severity of the epidemic (the combination of its mortality rate and the infection rate). For the next six weeks, I compulsively followed every piece of news and data, from peer-reviewed articles and preprints to local news reports and citizen-journalist social media posts coming out of China. I analyzed both the news and the numbers, calculating the likelihood of being personally caught in the upcoming storm. On February 5, I emailed a close friend from my alma mater Stanford, a computer scientist working in Silicon Valley, to give me his reading on the numbers, not trusting my own humanities-trained mind. His casual response, "Wash your hands," indicated a gulf between us that I didn't immediately understand. For him, it was a potential sniffle. For me, it was the question of life and death.

President Franklin Delano Roosevelt, whose legs were paralyzed from an illness, reportedly had a recurring nightmare about not being able to get out of the [White House in case of a fire](#). Every disabled person, particularly those whose disability is connected to mobility, has a set of such nightmare scenarios: fires, floods, tornadoes, earthquakes. Being in a wheelchair, I choose to live in a state where the usual natural disasters—snowstorms—can be predicted ahead of time, because anything that requires urgent packing and escape would mean my most certain [eventual demise](#). Regardless of whether my choice of residence is warranted or paranoid, it is a part of the broader multi-data analysis that every disabled person must perform daily to survive: a calculation of risk defined by the complex intersection of environmental, political, social, and cultural factors interweaving with the peculiar demands of one's disability. Among the set of my nightmare scenarios, a potential pandemic has always ranked quite high: the chances of someone like me surviving one are slim, and the reasons have as much to do with my own high-risk susceptibility to infections as they do with the historical treatment of the disabled. Understanding this history, I knew that once the healthcare system got overwhelmed, I would be the last one to get the care I need, be it a ventilator, an ECMO machine, or medications. If I were to catch the virus, I would most certainly die. That's what the data, my knowledge of human psychology, and awareness of the historical treatment of the disabled were telling me.

In early February, I emailed my two doctors, sharing with them my concerns. One of them dismissed me, assuring me that the hospital would have enough ventilators for everyone who would need one. "We're ready," he said. The other promised to advocate on my behalf if the worst came to worst. I couldn't tell whether she actually understood what I was saying or whether she was trying to calm me down. Did she know that in case of state or federal guidelines, her advocacy would have no impact? In early February, I also made an ADA request for access to the back elevator at my college to limit my exposure to potential infection. Working in the college environment, one sooner or later develops some form of germophobia, but I knew that my usual precautions (don't touch elevator buttons and door handles, stay away from sick students, wash and sanitize your hands multiple times throughout the day) would not be enough. I sent my HR department a set of data and scientific articles coming out of Asia, together with my doctor's note attesting to my (already clearly visible) condition. Although the back elevator was in constant use by other faculty, my request for assistance with accessing the elevator was refused. In mid-February, when it became clear that we would have a global pandemic, I made another ADA request to teach my courses from home. I supplied our HR with additional articles and more data. By then, the top virologists and epidemiologists on social media (if not on television) were pretty much in agreement that we would have a serious pandemic within the next two to three weeks on US soil. My HR, once again, refused my ADA request, arguing that it posed an "undue burden" on the college to allow me to teach from home. The students paid for in-person classes, and they expected in-person classes. I was told. A few days later, all of our in-person classes were canceled. We were given one week off to prepare for online teaching, all of us.

What I experienced at work, a refusal of ADA-based life-saving accommodations—considered an "undue burden" when applied to me but necessary when applied to others—was not unique. Many disabled Twitter users have been vocal on the topic, pointing out the bittersweet irony of the current pandemic: the requests for remote work or other [ADA accommodations](#) that would make it possible to increase the employment of disabled people to more than the current [19.3%](#), and which are customarily refused when requested by the disabled, are now considered essential to the survival of the greater population. We all suddenly have become disabled, requiring ADA accommodations.

Dr Amy Kavanagh  [@BlondeHistorian](#)

As a disabled person it hurts to see all the adjustments that we've been denied suddenly be made available because non-disabled people might get sick.

But we will remember, we see you & your ableism.

So next time you deny us accommodations, we will say "but during Coronavirus?"

1:50 AM · Mar 7, 2020 · Twitter for iPhone

6.1K Retweets 232 Quote Tweets 25K Likes

Cal Montgomery  [@Cal_Montgomery](#)


Replying to [@BlondeHistorian](#)

Oh yeah.

"Fundamental alteration, can't do it."
"Undue burden, cab't do it."
An abled would benefit.
"Done!"

8:48 AM · Mar 7, 2020 · Twitter for Android

15 Retweets 1 Quote Tweet 174 Likes

Juliana  [@jamjam127](#)

Replying to [@BlondeHistorian](#) and [@al_valentin](#)

Quite honestly, I've been offended by every adjustment I've seen, big & small. Just the panic alone. As someone w/ no immune system on top of my disabilities other people are ALWAYS a threat. Do you think I was ever taken seriously about it?

12:01 PM · Mar 7, 2020 · Twitter for iPhone

6 Retweets 125 Likes

The dissonance I feel right now is difficult to put into words. The raw contradictions that this pandemic has unraveled are playing out in [the public eye](#), on the global stage, and on our bodies: from top-level conversations about the [allocation of ventilators](#) to numerous articles pointing out [the low value](#) that societies [across the globe](#) place on the lives of the disabled, and pleading for [some universal sense of mercy](#), with a mixture of incredulity, pity, and moral outrage. The pandemic made visible what many of us have always known.

Historically, to be a disabled academic has meant to be constantly faced, intellectually, with some potential form of eugenics, whatever your field might be, from [sciences](#) to [humanities](#). This history often informs the present moment. The academic world is fundamentally secular: in extreme interpretations, the utilitarian value of human life can be [calculated](#) and thus subsumed under some other misconstrued "greater good," either social, political, economic, or cultural. A conscious choice to have a disabled child appears to some people as [irrational on multiple levels](#). For those of us caught at the crossroads of this contradiction—having to assign a value to our own lives in multiple discursive contexts—philosophy and ethics don't always provide easy, comforting, or unequivocal answers. And yet, live we must, despite what Hollywood continues to tell us so many times, in no uncertain terms, with the images of [various euthanized cripples populating the yearly Oscar sweeps](#). I don't know a single nondisabled person who has ever felt the urge to justify their existence with the same urgency that the disabled are asked to justify theirs on a daily basis: in brutal, utilitarian, economic terms.

One billion people in the world have some form of disability. This pandemic is cleaning the global gene pool of the "glitches" we [repeatedly hear we are](#). Our collective chances of survival, low in most parts of the world even before the pandemic, are now increasingly precarious.

Under pressure from disability advocacy groups, Massachusetts eventually [revised its guidelines on ICU access and ventilator allocation](#). Being disabled no longer automatically disqualified you from access to care. However, I don't trust these revisions: not with my life. The disabled body stands at the very foundations of human self-perception, like a palimpsest on which centuries of culture have etched their aesthetic, religious, ethical, philosophical, scientific, and technological forces and tensions. How we treat a disabled body is a sign of our times. I won't subject my body to this test.

While I was in grad school, Martha Nussbaum delivered a guest lecture on disability. She was writing her milestone book, *Frontiers of Justice: Disability, Nationality, Species Membership*, and struggling with her own body approaching old age. The project was an attempt to create some sort of ethics of care founded on something other than mercy towards the weak. But there are no good alternatives there, Nussbaum seems to suggest, except the transactional ethics of late capitalism: the disabled should be cared for because they deliver intangible social goods, the nobility and wisdom of suffering, the grace and joy of survival and perseverance, the inspiration of a life lived despite the many costs of living. Kant's categorical imperative of absolute ethics, "you must because it's right," always seems to fail in moments of crisis. The reports that only the elderly and people with underlying health conditions are in danger of dying from Covid-19—repeated over and over on network and cable channels throughout February and March of 2020—are drilled into our collective brains: our lives are *only*, they're a sacrifice society is willing to make.

My doctor—the one who initially dismissed me—eventually emailed me to say that they are doing okay with ventilators, they have enough. If I need one, there will be one for me. In a later video conversation, he emphatically reiterated that if I need any other care, it will be available, looking into my eyes and trying to read me. The fact that he felt the need to email me this, and to stress it again in person, touched me deeply. Yet as much as I trust his intentions, I don't trust his assertions. I don't want to be anyone's ethical choice. It feels like both an indignity and an imposition. To avoid them both, I would have to be the one to make this choice for a strange doctor in the ER stuck with my dying body, and I don't want to. I don't want to make a choice about the worthiness of my life, but I also don't want to be anyone's post-traumatic nightmare. And I don't want to make the choice between these two options.

In academia, your career depends on making others comfortable around you, convincing them you're a safe bet, even with your peculiar social quirks and habits, that you will deliver whatever needs to be delivered: research, grants, publications, or loyalty. This requires a constant maintenance of social life with other academics, admins, and sponsors. I stopped counting the times I was left behind after an academic event as my colleagues cheerfully went for a casual, spur-of-the-moment dinner with the Dean of this or that to a house, building, or restaurant without wheelchair access. The lure of the schmooze is too great for anyone to righteously stay behind—I am tacitly asked to understand that. There will be no solidarity for me, not the kind that requires the sacrifice of a social evening of academic schmoozing. The *professional* response is to accept this state of things with *grace*, absolving my companions of any mental burden of guilt and discomfort. The *grace* always comes at the price of my dignity and professional value; it involves a public acknowledgment that my absence is *not that big a deal*—but what other *professional* choices do I have?


Irony, if I am feeling particularly tired of performing the mental labor. Humor, if I am feeling particularly generous. It's nobody's fault. It's the system that I am part of. I have to believe it to sell it. The awkwardness of these situations is unatched, but the ethical choice of response is always mine.

My various affiliations with Harvard give me access to the library stacks. Since my upper-body strength is virtually nonexistent, making the use of said stacks a physical impossibility, I am technically eligible for ADA access to electronic resources as well. I was reluctant to ask for it, and was making do with my husband's driving and carrying capacities, but the pandemic made me rethink this, so I made an official ADA request for electronic access. My request was denied on account of the vendors' contracts, which limits such access (and which are also subject to ADA law), but I was given an option to become a faux research assistant to one of my Harvard colleagues, which would grant me the desired access, thus subverting the vendors' contracts.

I refused. It would have been so much easier to just accept the faux arrangement. After all, I have always relied on the kindness of friends and strangers. At all the top institutions I have ever taught and studied at, including Stanford, Yale, Harvard, and Cornell, my sheer physical survival was often tied to my network and my social skills: friends who saved my life on more than one occasion. [With their notoriously inaccessible buildings](#), universities, even top ones, frequently fail to comply with ADA. But I could not do it this time. ADA access should not be a function of collegial favors. It should not be a function of our ability to form and leverage our personal and professional networks. It should be a function of equitable access, including for those—especially for those—who don't have friends and family to take care of them. How else will I survive if I ever lose my support network?

Three days after Harvard library refused me ADA access to its electronic resources, *The Boston Globe* reported that [Jeffrey Epstein had his own office and phone line](#) at the university. Harvard had resources to spare for a wealthy man [indicted for sex trafficking](#), but not for a disabled researcher.

At some point in one's academic career, travel becomes a status symbol: the more places you can physically go to in order to deliver the knowledge you produce to a small circle of those with access, be it guest lectures or conferences, the more prestige points you rack up. When I was young, I often traveled alone. Traveling with my husband now is physically easier: he is there to save me when the airlines lose or break my wheelchair, when the hotel room is not wheelchair-accessible as it was supposed to be, when the airport shuttle doesn't show up, when the lift on the bus is broken, when my talk is rescheduled at the last minute in a building without wheelchair access. But my husband's presence is much harder on me psychologically. Watching him witness my usual dose of small and big humiliations, with heroic tenderness and shame in his eyes, is more than I can manage most of the time. I can do without travel. And so I stopped playing the in-person public-speaking game. More often than not, my requests to deliver my lectures via VR were denied, and once again, I was forced to rely on my network of colleagues to deliver my words for me. Being there via VR has always been considered a form of cheating the system: without the obligatory burden of travel and post-lecture schmoozing, the lecture itself is not worth that much, our community seemed to collectively believe, regardless of how damaging conference travel is for the environment or our increasingly shrinking budgets.

Magda Romanska  [@MagdaRomanska](#)

Hey @ASTRtweeps #ASTR2017 folks. I am not there, but @RobinMBerstein bravely stepped in and she is reading my paper on "Bionic Body: Technology, Disability, and Humanism" right now...

10:46 AM · Nov 17, 2017 · Twitter Web Client

5 Likes

Now, with all lectures, conferences, and events being held on Zoom, I move from a place with an ease that was previously unimaginable. Events formerly inaccessible due to extensive travel, a commute, or building inaccessibility are now open and available to me. What's more: when on Zoom, nobody knows I am in the wheelchair, so the entire dynamics of my interactions have changed. The pressure to perform the emotional labor of making other people comfortable around me is gone. This unexpectedly leaves a lot of mental space that I am not used to having. It is a deeply discommodating and bitter experience because it makes me suddenly aware of the previous difference in access and acceptability between me and my colleagues. The social distancing, which appears to be a mental burden for most, is not a particular problem for me either. I am used to loneliness.

Although my chances of surviving this pandemic are statistically so much lower than the average person's, the flattening of access accomplished by Zoom creates a new public space in which we're all on the same playing field. It is strange to relish this newly discovered professional freedom in a virtual world while also facing more acutely one's own mortality in the new public sphere of the real world of the pandemic. Will the changes in how we communicate create a permanent society-wide mental capacity for reimaging access to work, knowledge, and resources for everyone, regardless of their [ability to travel](#), commute, or [communicate](#)? Or will we quickly forget that for one year, we were all temporarily disabled? For those few disabled lucky ones who will survive Covid-19, and for those who will [be left disabled by it](#), will the world be a more welcoming place? Will the sacrifice of so many of our lives be worth it?

