

Dear Higher Education

LETTERS FROM THE SOCIAL JUSTICE MOUNTAIN

Fighting for Visibility for Disability

ASHLEY SHEW

Dear Higher Education,

I'm probably going to do this incorrectly. Sometimes we can't do it the correct way, or it's extra taxing to do so. And what's correct anyway? Formats and structures should suit the material, the people, the goals that exist in the space between us and the world, not the other way around. People will critique us disabled people for not taking the right path, complaining in the right way, going to the proper committee, but there is never a right way when you are disabled. You are structured to wear us out in search of what we need, to burn us down if we seek justice or even equal treatment, to bleed us dry if we seek to be heard.

I'm writing to you as my disabled self, the face I show mostly to my disabled comrades here. We are here, you know? Maybe you don't. It seems like maybe you don't know, or don't want to know, or maybe think we don't truly belong here. And I get to read another "access statement" or "accommodations inquiries statement" that in no way gives me the information I need to know whether I will need accommodations there or not. Will there be stairs? Will autocaptions be turned on? Will restrooms be accessible? How far is this event from parking? Will I have to focus for hours in a row, or will there be a break? Sometimes we just need a description of how things will be to let us know if an event is accessible to us – and we don't all need the same stuff.

As an aside, I love working alongside autistic colleagues. They are blunt about setting things up in ways that make sense, honest in their assessments of our current situation. You should probably listen to them a lot more than you do. While I'm neurodivergent, I'm not autistic, so please understand that my resting bitch face is not an accident of my neurology, but an actual mean mug for you. For you, dear higher ed. I bring my resting bitch face for you. Resting, because I *need* more rest. Bitching, because you don't even realize how you squeeze us out, push us under, and make being with you a pain. Facing, because where else can I be that will let me do so many things with, despite, and because of my disabilities? I love it and hate it here.

Yes, I'm getting to the part where I introduce myself to you. I've been here – we've been here – always. Disability is a normal and natural part of human life, a social category and a functional assessment, a judgment and a curse, and a source of creativity, community, adaptivity, and joy. We are multitudinous and pulchritudinous. But we are also asked to hide to be with you, or to bend ourselves into impossible shapes, to remain here, unless we want retaliation, dear higher ed.

You don't like the word retaliation. You have lawyers for that. But retaliation for being disabled, for asking for accommodation, is so common here. We talk about it among ourselves; the rare among us actually file a complaint. We know that complaints can also bring retaliation. Better for many to remain silent or continue contorting – to continue passing as nondisabled.

I can't exactly hide what I'm working with. I'm a hard-of-hearing chemo brained amputee with Crohn's disease and tinnitus. The amputee part gives me away easily as disabled, but amputees, especially those of us with prosthetics, don't often receive the harshest treatment here. People tend to believe us when we state our needs

when we are literally missing a chunk of our bodies. It's trickier for my friends with non-apparent and more variable disabilities – or for me to even broach the topic of my other disabilities. I started writing about being an amputee long before I felt like I could talk about my cognitive impairments due to the year of intense chemotherapy I endured. You remember my medical leave, right?

We sometimes need to ask – have to ask – for accommodations, but this opens us up to scrutiny.

And it's a lot of paperwork to exist here as “officially” disabled, and it doesn't end. New boss. New chair. New symptom. New administrator. Updated paperwork. Sometimes the interactive process is far too much interaction when what we need is simple, and we could just be believed.

Administrators, chairs, the registrar, etc. may push back. Have we gone through the appropriate channels? Do we really need a classroom with good acoustics/near a bathroom/on the first floor/near the one accessible entrance/convenient to parking/without fluorescent lights? Have we been properly documented by an MD who is willing to spend extra time filling out our forms? Have we met with the ADA coordinator and our boss as part of the ADA-required interactive process? Of course, we'll need to be periodically reassessed. Or we'll have to remind people that we have accommodations - *over and over* - just to get what we need to be here. It's given grudgingly. We are told #ThisIsHome by a PR campaign, but how can this be home if we are never truly at home here? If things are hostile to us by design? If people regard our inclusion as a concession? If our inclusion is supposed to indicate how nice everyone else is, rather than actually make it possible for us to be here on equal terms?

Sorry, I started talking about accommodations, but there are so many structural barriers here. It's hard not to jump (and also hard to jump – the literal physical action is something I can't actually do; hopping on one leg is what I've got). **Things become necessary as accommodations only when the state of things is inaccessible.** No accommodations are needed where things are built to include more people and flexible from the start and planned with access in mind. But higher education is built for exclusion.

These places, your campuses and perfect walled gardens and arbitrary expectations and deeply held norms, dear higher ed, are built for nondisabled people. And then disabled people are treated as a burden, regarded as expensive to include, and labeled as risky to exist here. We don't “fit the image of the university” – a thing that was literally said to a multiply-marginalized disabled person I know when her desk was moved to a less visible spot. Usually, they don't say it that loudly, and they never say it quite like that to me because I'm white and hetero and sort of otherwise look like other people here. I'm only here by accident and luck and a good supervisor or two, but, still, I've never been ushered to a less visible place due to how I look. I have, however, not been able to serve in some roles – being a faculty usher at graduation, filing up and down stairs at graduation seems impossible. Disabled students sometimes mention not going to graduation exactly because they are made to stand out in the processions and offered confusing routing. Some of them also worry about how overstimulating big events like these are, or how long events are problematic for them. Especially since the Provost outlawed departmental graduations, which were less big, less long, and more possible for some of us. I want all the joy and celebration for all of us – but that's a tall order when so many what-should-be-joyous-things require extra labor and energy to participate in and attend.

And yet we are supposed to be grateful for being here at all. We name it to ourselves – academic ableism. People are so uncreative and inflexible in their planning – for classes, for campus life, and for events. My community works overtime in offering advice, sending links to guidance, sharing our experiences, bleeding out before the people in power in hopes that they will be moved to new action. We absolutely exhausted ourselves in advocacy around covid policies with nothing to show for it except our own burn out, a couple of google docs, and absolute disgust for witnessing the two-faced faces around us. Your face, dear higher ed.

Ableism is the logic that often undergirds things like anti-immigration policy and sexism and white supremacy – by talking about which human beings are “more fit” or productive or intelligent. TL Lewis offers this definition of ableism (2022):

A system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness. These constructed ideas are deeply rooted in eugenics, anti-Blackness, misogyny, colonialism, imperialism, and capitalism. This systemic oppression that leads to people and society determining people's value based on their culture, age, language, appearance, religion, birth or living place, "health/wellness", and/or their ability to satisfactorily re/produce, "excel" and "behave." You do not have to be disabled to experience ableism.

A system of assigning value becomes almost irresistible to put into action, and such systems are part and parcel of higher education. I love the work of my former student Joshua Earle who did some archival work where land-grant institutions promoted eugenic ideology among high school teacher trainees in the 1940s and 1950s; Earle connects this to the modern work of universities and transhumanist ideology. The connections to white supremacy are not lost in this narrative nor time period either.

I get to work with amazing students here though, dear higher ed: my former PhD student Damien Williams works on the way in which AI re-instantiates existing biases and makes them worse – worse because we think AI is impartial and fair; my former student Alice Fox works on harms and harassment enabled through technologies and online spaces; my current PhD student Hanna Herdegen studies the historical development of diagnostic technologies in the context of dysautonomia, medical sexism, and changing diagnoses. I serve on some of the most interesting committees. It's amazing to be in this position – studying bias as a disabled person and learning from elite scholars and colleagues. This is part of the love/hate I feel here.

While I have not experienced the worst of ableism at its intersection with other identity factors (and still get to be here at all), I have been moved downstairs and into an area away from my entire department – which of course is in a three-story building without an elevator. I was so weak from chemotherapy when that happened that a kind graduate student packed up my office for the movers. My department was good to think ahead – my amputation was coming. I don't even know if anyone told the ADA Office or filled out any forms. Some people in the disability community sometimes express how lucky people with cancer are – not because cancer is great, but because doctors and colleagues and family members take cancer diagnoses seriously.

I benefit from being disabled due to cancer. I helped a friend through a major surgery, and I could see her hurt as I told her how my colleagues set up a meal train and delivered meals for my family several times a week for months while I was too sick to function. Everyone knew she was getting a major surgery and would be on medical leave for weeks, but no one was so moved.

I stray off topic, but I want to tell you that it's okay, dear higher ed, to stray sometimes. It's the way the chemo brain goes. My colleagues with ADHD understand this too. Sometimes you just have to take a side quest, or interrupt one thought with another. The thing is: we are good here. Work life is much more possible here where we can pursue trajectories of research and teaching and outreach that fire us up, where we can change topics and pursue new lines of thought, and where these are often value-adds to our disciplines. Work life is also much more possible where schedules can be (should be) flexible - so that scheduling a doctor's appointment or physical therapy doesn't require a conversation with someone else who controls your schedule. And of course, at your large state universities, the insurance plans are often enviable. I know disabled people who have

strategically gotten jobs at universities in order to survive for longer in the workforce (and just survive longer, as we are in a system that links insurance to employment), dear higher ed.

Dear Higher Ed, I would rather not be addressing you at all. I know you cannot hear me, cannot hear us. **Colleges and universities would never make themselves more inclusive on their own. They bill themselves as elite, and the ranks of the elite are supposed to exclude us.**

Even when you let us in, you seek to burn us out. As a tactic. To show how we don't have it in us to overcome, a terrible narrative that requires nothing on your part except to fail to clear the way, to fail to move, to fail me and us. If it's up to us – our persistence, our bravery, our whatever word you describe us by when you sing our praises while holding us back – this work could be flexible and fun and make meaning beyond this place.

But it's time to email the ombuddy again to give him the heads up that the nondisabled faculty member who is trying to grub some grants about autism and dance thinks I have a personal grudge against her and is acting like she's being persecuted because my autistic colleague suggested, and I backed her up, that we wouldn't advertise her research study ad in our community group listserv. She yelled at a disabled graduate student about it, too. I hate it here when nondisabled people make themselves the victim when you don't praise them for briefly considering disabled people (and often without asking us what we'd want).

We have to vet everything we send out because research preys on us. It distorts us so often. And we're expected to be grateful and often unpaid when they "include" us in their study. **But inclusion as an object is not inclusion.** And they get all the categories wrong. They don't know how to recruit. They want autistic people, but only those who can speak, and only those who are a certain level, and who have documentation to share, and none with other disabilities. They don't realize they are asking for something so few are: most of us disabled people are multiply disabled.

I'm a hard of hearing chemo brained rotationplasty amputee with Crohn's disease and tinnitus. I am asked on the form where a university has asked me to fill out my demographic information and what my primary disability is. To pick one to be labeled, but so much depends on context, and, if I'm currently at risk of shitting myself from Crohn's or if my hearing aids can hear only the hiss of air and none of the voices around me, then one or the other might be primary in that moment. Some of these things are highly variable day to day. And none of them are half as frustrating as our campus and classrooms and the provost's mandate for the return to in person.

I'm on immunosuppressants, I've had two lung surgeries. I'm told in early 2022 that the provost isn't granting online or hybrid modalities. Even for classes that have always been online or can be easily zoomed. Oh, and we can no longer ask students to mask. Oh, and even though there's a special team working on air quality in classrooms, we can't have that data. And hey the Covid tracker is going down, and the CDC will stop reporting too.

I know you don't care about me. About disabled people. Even when you play pretend for outreach or some self-congratulations. You make it so unsafe to be here, to be disabled here.

The building I work in has no elevator. I was moved downstairs when I became disabled.

My friend was told he didn't have to attend faculty meetings if he couldn't hear well. Even though he wants to hear people. God forbid they book a different room.

My other friend is forced by her dept to redocument her disabilities every semester, and the admin who books her classrooms forgets every semester, so then she has to scramble every semester to have a classroom. She's been teaching in a computer lab without anyone using the computers this semester, and it was hella weird to guest lecture there.

My other friend is in a lengthy back and forth about disabled parking. She needs a place near her building, not in the parking garage half a mile away. Even if the spot half a mile away is labeled disabled. Parking there doesn't help.

My other friend, and I say friend, but I don't know what to call my fellow disabled faculty and staff, gets advice about how to avoid coming out as disabled because she knows they will doubt her abilities and retaliate against her if she's out. How can she find a workaround? Can she pretend like this is a temporary situation? I tell her to mislead as much as she wants; no one else will protect her but her. They don't want us, we aren't worth small differences in environment, workflow, or, you know, a freaking ramp.

The disability accommodations paperwork is insulting, but I'm lucky to have the healthcare to access the doctor who is trusted more than I am to describe my body and what I need, though he doesn't know my day-to-day life. But I also tell him which disabilities he'll disclose, and which I'd like him to leave out. We can't tell work that I have chemo brain yet. The university can tolerate an amputee, but I'm not sure how they'll look on someone on their teaching and research faculty with a cognitive impairment yet. I will have to win a grant and write a book and be appointed editor of my professional society's journal first. See? I'm doing it all with my cognitive impairment, so it's okay. I have to already be doing it and have accomplishments to get an accommodation. This situation is nearly impossible.

Except why should I have to do so much more just to be accommodated? Not included or celebrated or integrated. Or appreciated.

Here's the thing: **They – you, Dear Higher Ed – pay for stuff that nondisabled people use all the time. Classrooms and stairs and buildings. Why do we get seen as expensive or like an extra when we ask to have the same access? when the problem is how things are made and scheduled and defaulted to always choose nondisabled being in the world?**

I've had students weep in my office, thanking me for how I've built my courses. I've built them with the expectation that I'll have disabled students and plan ahead for that. It's nothing: they deserve this education as much as anyone else and pay more dearly for it too. I care that they learn things about our subject - not about deadlines or format. **I know there are many ways to demonstrate knowledge, communicate, and participate.** Multiple paths, and flexibility. Disability justice says: we move together. Disability rights says: hold up, do you have documentation? I want the former.

My university has a faculty development session on universal design without ever really centering disability. Taught by a nondisabled person to nondisabled people. **But how are they going to get the soul of it aligned? How can they move with us if we aren't there?**

I go to a session on neurodiversity in the workplace, and I wouldn't give it a C. Neurodiversity is so much richer than what they talk about, which only seems to be about autism and maybe ADHD, but autistic people mean neurodiversity to include everyone, and include neurodivergence that maybe HR isn't ready for: from mental health disabilities like schizophrenia to chemo brain like mine to traumatic brain injuries. Autistic people may have theorized neurodiversity, but they built the concept bigger than autism.

And, higher ed, you are stealing neurodiversity – the term, and changing the vibe. The awful autism center conference had ABA therapists – ABA, which autistic advocates decry as abusive. It's time to send another heads up to the ombuddy before emailing my diversity officer to ask if she could please explain to them why they shouldn't be using the term out of one side of their mouth while dishonoring autistic voices. I don't want to talk to the director: she will also view this as a personal attack. And then want to meet with me to discuss. And I'm tired. It's not about her in the least, or what donors she wants to court, and that's the point. Can the diversity officers please handle this? No.

They can't. I'm not sure anyone ever talks to the conference organizers. We crips discuss protesting the conference at our community meeting, but we're all too busy with the end of the semester and this isn't worth the energy right now.

We burnt ourselves crispy offering disability informed Covid policy recommendations, which were ignored. The president mentioned us in a state of the university speech where he said he met with us and announced the very opposite of what we recommended to him.

We understood after that incident that **people want to say they met with us, that you'd say you spoke with us, at the same time that you, Dear Higher Ed, push us out the door.** Here to be objects of design and invention and fundraising, but somehow also never considered experts, agents, and worth the price of inclusion, worth a little adjustment. The price is so low for you, and so high for us, higher ed.

Please just let us be here – or not here if what we need is a work from home accommodation.

Thanks,
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About the author

Ashley Shew is an associate professor of Science, Technology, and Society at Virginia Tech. Her current research sits at the intersection of technology studies, biotech ethics, and disability studies. She is recipient of an NSF CAREER Award for work on disability narrative about technology ([#1750260, Disability, Experience, and Technological Imagination](#), 2018-2023), and a principal investigator of an Andrew W. Mellon Foundation-funded Higher Learning project that supports the creation of a regional [Disability Community Technology \(DisCoTec\) Center](#) providing guidance for developing disabled-led technology and disability-forward technological futures through humanities-based scholarship and disability justice education, arts, and outreach (Just Dis Tech Project, 2023-2025). Shew’s recent book *Against Technoableism: Rethinking Who Needs Improvement (2023)* and forthcoming open textbook, co-edited with Hanna Herdegen, *Technology and Disability*, both focus on the stories disabled people tell about technologies that people do not always expect.

Ashley’s past work has been in philosophy of technology with particular interest in technological knowledge, animal studies, and emerging technologies. She is a current co-editor-in-chief (with Kirk Besmer) of [Techné, the journal of the Society for Philosophy and Technology](#). She is sole author of [Technological Knowledge and Animal Constructions \(2017\)](#) and co-editor of three philosophy of technology volumes: [Spaces for the Future \(with Joe Pitt, 2017\)](#), [Feedback Loops \(with Andrew Garnar, 2020\)](#), and [Reimagining Philosophy and Technology, Reinventing Ihde \(with Glen Miller, 2020\)](#).

Shew believes in cross-disciplinary, cross-disability, and public-facing scholarship: she has written for *IEEE Technology & Society*, *Nursing Clio*, *Nature*, *The Chronicle of Higher Education*, and *Inside Higher Ed*. She is a

grateful participant with her local disability advocacy and activist community in the Disability Alliance and Caucus at Virginia Tech and the New River Valley Disability Resource Center.

At Virginia Tech, Shew participates as a faculty member in the STS PhD program, Medicine & Society minor, and Disability Studies minor; she's also the current director of the Bioethics graduate certificate, and a longtime executive committee member with the Integrative Graduate Education Program on Regenerative Medicine.