



ROMAN KELLENBERGER

Challenge assumptions about your disability, says Kelsey Byers.

## ACADEMIA'S ABLEIST CULTURE LAID BARE

Four group leaders with disabilities share their thoughts on how to make laboratories and fieldwork more accessible and inclusive.

**B**etween 15% and 25% of the world's population lives with one or more forms of disability. Despite some progress on disability rights, for many disabled scientists academic-research spaces and career pathways remain out of reach, both literally and figuratively.

Many nations legally require institutions to make 'reasonable accommodations' to ensure

accessibility, but disabled researchers think that a corresponding shift in the attitudes of many co-workers is needed.

They say that ableism – beliefs or practices that devalue and discriminate against people with disabilities (whether physical conditions, mental-health issues, chronic illnesses or cognitive differences) – has excluded them from classrooms, laboratories, fieldwork and

conferences. Not only are disabled researchers under-represented in science, technology, engineering and mathematics (STEM) fields, but both visible and invisible disabilities are often missing from discussions of diversity and inclusion, they say.

"If we designed physical spaces and classes in a way that suits the common denominator of humans – such as always having a ramp, always

## Work / Careers

teaching in ways that are inclusive of neurodiversity – then we make the system work for everyone,” says Kelsey Byers, an evolutionary chemical ecologist at the John Innes Centre in Norwich, UK.

At the same time, many disabled scientists point out that the COVID-19 pandemic has eased access, thanks to virtual conferences, remote working, and telehealth appointments – and they fervently hope these options will remain available after the pandemic.

To mark National Disability Employment Awareness Month in the United States (October; a similar UK event, Disability History Month, runs from 18 November to 18 December), four academics with disabilities share tips for coping with daily professional challenges, when to seek resources and support, and how to let colleagues know the best ways to help.

### **KELSEY BYERS** **CONTRIBUTING SCIENCE WHILE SITTING ON MY BACKSIDE**

I started having problems with my joints in 1998, when I was 13. But it took until 2009, when I was in graduate school, for me to be diagnosed with Ehlers–Danlos syndromes. I also developed postural orthostatic tachycardia syndrome, which meant that I couldn't lift heavy objects or stand for long periods of time.

What worked for me was being really open with my graduate advisers, who made informal accommodations for me. For example, I designed the layout for our experimental array of monkey flower (*Mimulus*) plants, and the rest of the team carried them out to be planted at the field site.

A lot of the how and when of disclosure is based on trust. I had already built a good personal relationship with my PhD adviser by the time I was diagnosed. In that lab, naps on the couch were normal; everyone took them. So although I would sometimes have to lie down to work or attend a lab meeting, it wasn't considered weird behaviour.

My biggest barrier is other people's assumptions about what I can and can't do. While I was doing postdoctoral fieldwork in Panama, our team needed to collect female butterflies from the rainforest. There was some scepticism about my taking part, because I wouldn't be able to hike. I convinced them to drop me off by a river with a stool and some nets, and I parked myself by plants that I knew the butterflies like. I caught two females. The hikers caught only one – and were bitten by chigger mites and mosquitos. It was a great moment to flip life a middle finger.

It was important that I was able to do my share even while sitting on my arse. Just because I'm disabled doesn't mean I can't contribute very



VIVIANE MORCELLE

Show more empathy for people with disabilities, says Viviane Morcelle.

positively to our results: I can drive to a lot of field sites, I can process samples while sitting and there are adaptive wheelchairs for fieldwork. And I give my team a set of instructions in case of any medical trouble in the field.

As a scientist, your job is to think. Hiring someone else to be the hands, ears, or eyes is a totally reasonable accommodation – and legally should be treated as such – where the financial resources exist to do so.

When I was doing a postdoc at the University of Cambridge, UK, the old buildings were sometimes inaccessible. I had to go through one particularly heavy door to get to the toilet, the tea room or lab meetings. It was exhausting and it wore me down.

At teatime, my colleagues would leave me at the elevator while they took the stairs, even if we were mid-conversation. That was emotionally painful. My colleagues didn't have bad intentions, they just didn't think.

I used a mobility scooter when I was interviewed for my current position. The director of the institute asked me about going through a difficult door, watched me do it and then took it on himself to talk to facilities management to fix it. He identified a problem and didn't act on my behalf without first checking with me. That was huge.

Often, the student and the staff disability offices on campuses are focused on documentation. In my opinion, these “gatekeeping

offices” are set up so that universities can avoid liability. In one instance, my privacy was violated when my condition was disclosed without my consent. So many universities treat their official, restrictive processes as the only way to make provision for people with disabilities. That is a real problem.

Finally, I identify as asexual and agender. At conferences there might be an LGBT+ evening meet-up for people from sexual and gender minorities, but the space won't always be accessible. Intersectionality – how different aspects of an individual's identity can combine and intersect in life in both positive and negative ways – is key when pinpointing and addressing challenges.

**Kelsey Byers** is an evolutionary chemical ecologist who studies the evolution of floral scent at the John Innes Centre in Norwich, UK.

### **VIVIANE MORCELLE** **PEOPLE WILL GOSSIP. PERSIST ANYWAY**

In 2015, one year after becoming a professor at the Federal Rural University of Rio de Janeiro, Brazil, where I taught physics, I developed a pain in my left foot that was caused by a loss of cartilage in my ankle. Two surgeries left me

disabled and on crutches. I looked for a local research partnership to get back into nuclear physics while on sick leave.

The prejudice that I experienced as a woman was reinforced after I developed my disability. One researcher accused me of “nursing at the tits of the state”, a common expression in Brazil, suggesting I was using my disability to try to get a special exemption from teaching classes. This was to my face, but it can be even worse for your disability to be talked about behind your back.

People often do not respect the rights that disabled people are guaranteed by the government. All the time, you have to fight for parking spaces or events to be accessible.

In 2019, I attended an international conference held in Brazil on diversity, gender and ethnic equity in STEM. To access both the poster presentations and the coffee breaks, I had to use stairs, with my crutches. Disabled researchers seem to be invisible in these discussions.

There should be equity in awarding scholarships and grants – such as Brazil’s major CNPq research productivity grant – to researchers with disabilities. To compete for public grants here, you must have the same productivity as a person without disabilities, and that is almost impossible in many fields. My research is possible only because my collaborators understand my limitations, and know that they do not affect my intellectual capacity. Without them including me, I would have quit by now.

People with disabilities are not incompetent, less committed or less knowledgeable about their research field. They don’t fake illness to not work. We want respect and to work in partnerships. Have a little more empathy.

**Viviane Morcelle** is a nuclear physicist at the Federal Rural University of Rio de Janeiro (UFRRJ) in Seropédica, Brazil.

## HANNAH MUMBY DISCLOSE, SPEAK UP, BE VISIBLE WHEN YOU CAN

The negative messaging around disability that we are all exposed to can make people resistant to identifying as disabled. For example, this could be the case with thousands of people who are experiencing long COVID – the persistence of symptoms after recovering from COVID-19. Such reluctance means that people can’t then seek the support they need. In Hong Kong, where I live and work, many people do not get formally diagnosed as having a disability, particularly with regard to learning disabilities and mental-health issues, because of the stigma around the subject.

Fear of being seen as incompetent in our jobs prevents people from speaking openly

about disability at all. When I do so, it is usually met with a very awkward silence. But I’m more vocal than some other group leaders about the fact that I’m disabled, in the hope that my students and colleagues won’t feel they have to mask their own disability.

I was 29 when I was diagnosed with a genetic, life-altering condition that has no treatment or cure. It has affected where I choose to do fieldwork: I need to be near hospitals.

When I moved from the United Kingdom to Hong Kong in 2019 to become an assistant professor, I wanted to be able to see the same doctor regularly, a person who knows my history. To see my specialist whenever I need to has been an amazing positive for me here.

Other things make my professional life challenging. For instance, how do we, as disabled principal investigators, manage our lab groups? I don’t want to burden my team members or hold them back, but I want my group to be aware of the issues that accompany my disability because, occasionally, I do have to drop everything and go to hospital.

I asked the #DisabledinSTEM Twitter community how group leaders with a lot of medical appointments make time for regular student meetings. People suggested taking phone calls or typing e-mails (but not doing video calls) while in waiting rooms, and blocking out unavailable times on a shared calendar without specifying why.

Whether or not you have a disability yourself, if someone wants to talk about their own condition or diagnosis, just listen. That’s the best thing to begin with. Often, the initial reaction that we get is one of shock, sadness or wanting to fix things. Just listen.

When someone discloses an invisible disability, try to hold back any surprise you might feel and instead think, how can I help this person? Remember, people aren’t what you can see all the time. When I disclosed my disability to a colleague here, he said something really great: “I have no experience of this, but I want to be a good mentor. Just tell me when you need something and I’ll do my best.”

The scientific community needs to go beyond the legal requirements and normalize accommodating disabled people. If someone makes such a request, and you, as a group leader, have a knee-jerk reaction of “that’s not fair to others”, please take a moment to reconsider. Think about how hard it was for them to ask, and then think of ways to remove that barrier. Principal investigators should proactively state that they are open to making adjustments for those with disabilities, and should be as understanding as possible when asked to do so.

After all, does it really hurt us to lean on the side of being accommodating to people?

**Hannah Mumby** is a conservation scientist at the University of Hong Kong.

## VIVIAN CHEUNG OPEN THE GATE FOR THOSE BEHIND YOU

By the time I realized that I had a rare connective-tissue disease in 2014, I was already a full professor at the University of Michigan. As my condition progressed, I reached a point where I needed a service dog for peripheral vision and for mobility support, and I got Opie at the end of 2014. I take her to meetings, which has been eye-opening for me, because a lot of students with chronic diseases started to contact me about careers in research.

One of their main questions is, at what point do you disclose your disability to a graduate supervisor or programme, and how much do you disclose? We need people with disabilities to be visible in our community, but disclosure is a difficult issue, so it can be tough to counsel them.

I always tell early-career researchers that their supervisor should not be the first person they disclose to. Instead, disclose first to people you trust at work. If they respond negatively, take time to understand their reactions and ask for suggestions on how best to break the news. Hear a range of views before you give the big talk on the big stage of your supervisor’s office.

I also tell them: the more successful you are, the more pressure you will feel as a disabled researcher. You might face disapproval because you challenge your peers’ normative view of what a successful scientist should look like. But to change the norm, we need more disabled scientists as role models.

When I started using a wheelchair, my laboratory building was not very wheelchair-friendly. With the help of colleagues and administrators, we decluttered the entrance and hallways, and made it more accessible for all.

We need more online forums for professors who are disabled to reach out to young researchers with disabilities, because it’s impossible to aspire to become a person you have never seen. We also need better diversity training at institutions, to give people tools – such as vocabularies for describing disabilities with inclusive, non-ableist language – so that they don’t feel awkward around us. (An example would be ‘wheelchair user’ instead of ‘wheelchair-bound person’.)

My goal now is to give visibility to people with disabilities, by nominating them to talk about their discoveries at seminars and conferences.

**Vivian Cheung** is an RNA biologist and paediatric neurologist at the University of Michigan in Ann Arbor and the US National Institutes of Health in Bethesda, Maryland.

### Interviews by Kendall Powell.

These interviews have been edited for length and clarity.

**Clarification**

Hannah Mumby's interview has been amended to use identity-first language.