This is an approximation of a talk I gave for ECR Day in July 2023 for a panel called ‘The Uneven Sector’. Huge thank you to the organisers and especially to Alison Garden and Ciara McAllister. I was grateful to get the opportunity to talk about my experiences, especially at the beginning of Disability Pride Month. I’ve included some resources and testimonies here. If you’d like to talk about any of this more or ask questions, please do contact me: we can only combat the ableism of academia and the mystification of support structures by talking to each other.

My talk will be in three parts:

1. Tell you about myself and my disabilities
2. Talk about some of the challenges I’ve encountered
3. Share things that have helped

Before I start, a couple of things to acknowledge:

I am not a disability studies or crip studies scholar. I’m a theatre historian who works with early modern material culture. Today I’m speaking from my lived experience of being a PhD student with disabilities. I’m also a PhD student on the cusp of submitting, so my experience of academic careers is limited and I have a lot more to learn.

My default position on this topic is that everyone has access requirements regardless of whether you identify as or are labelled as disabled, neurodivergent, or live with chronic conditions.

I’m talking today about my personal experiences, because that is the only authority I have to speak from. Everyone is different but I still believe it is important to hear about individual stories. I am grateful that when I’ve said I would be speaking on this topic, other people have shared their own experiences with me: so what I say today is informed by other individuals’ lived experiences. Thank you to them for the generosity and trust they have shown in opening up to me.

Speaking today is a privilege: not everyone can or should have to disclose their disabilities in a public space. My lived experience of disability is inextricable from the way it intersects with my identity as a cis white woman. I am going to speak today about disclosure and advocacy, and I need to begin by saying how much more straightforward my individual experience has been because of the privilege I have grown up with. I am studying in the country I was born in, in my native language, and I went to a private school. It is simpler for me to ask for support and expect to receive a positive response because of this privilege. It is never easy, but this makes things easier for me.

I'm going to share a lot of personal information today because that is where my authority on this topic comes from: and again, I am privileged that I can share. There aren't the same risks or emotional labour for me that there may be for other people. So as I'm sharing I need you to know: I don't need sympathy.

About me: I'm 33 and in the fifth year of my full-time PhD. I finished school at 18, and of the last 15 years, since leaving school, I've spent 10 years in education, 5 years working, and pretty much all of them managing a health condition of some kind.

When I left school, I wouldn't have identified as disabled. It wasn't until the second year of my BA at the University of Oxford that I was diagnosed with depression and anxiety. I took a year out of university in order to begin the process of learning how to manage my mental health. I had some therapy through the NHS and through my university, and unofficial support through tutors and friends, but no official support. I didn't know I could or should ask for support, or what that support might look like.

By the time I started my MA with UCL, I identified as disabled because of my mental health. At this point I applied for support via the Disabled Students' Allowance: this gave me a mentor, taxi journeys, and assistive software and equipment. My mental health was at its worst at this point and that wasn't helped by the fact that I was discouraged from pursuing higher

education because of my depression. But, I did finish my degree, and then had two years working before I started my PhD.

After nearly a decade of various types of therapy, I reached a point where I was managing my mental health in such a way that it no longer had a negative impact on my daily life. In 2017 I started experiencing chronic pain and fatigue, and eventually this was diagnosed as fibromyalgia. It's a weird diagnosis to receive: it basically means 'we've done all the tests and we still don't know what's wrong, so we're going to call it fibro'. I received the diagnosis in the second year of my PhD, and thankfully at this point I knew who to approach and the processes of receiving support - but it still took a long time to arrange and was rarely straightforward.

I'll talk about the specific support I've received but first I want to acknowledge some of the challenges.

Any academic job asks a lot of you in terms of time, energy, and finances, and this is exacerbated if you have particular health requirements. For me that looks like attending appointments, filling in endless paperwork, and building in lots of breaks and rest time. I feel like I have to do the same job as everyone else, but in less time.

I have had an additional year extension due to mitigating circumstances on top of my writing up year, but even if you are given more time you are not necessarily given more money. I've been lucky enough to receive financial support from the University of Roehampton and Funds for Women Graduates, but more than a year of my PhD has been unfunded. I've had a few jobs while finishing up edits to my thesis, and the mental and physical energy they require cancel out the benefits of an extension. What is the point to an extension to your thesis deadlines if you cannot use that time to actually work on your thesis.

So even when the support exists, it is not always straightforward. Many of the structures in place are too universal to be useful, particularly to postgraduate researchers. The diminishing levels of support as you

progress through undergraduate to PhD into postdoctoral work gives the impression that either we no longer require accommodations, or that disabled people are not studying at doctoral level, or that they should not be.

Academia operates on ableist structures and expectations, and I want to acknowledge how that is compounded for migrants who have to deal with attendance monitoring, even more paperwork, even more expenses, and even less structural support.

One of the biggest burdens on my time and energy is the constant need to disclose and advocate for myself. I have been lucky in that I have had a number of people willing to advocate for me, but you can spend all of your time advocating for yourself and finding other people to help and still not get what you need. If indeed you know what you need or who to ask. I have to make decisions about when to tell people about my access requirements, particularly as someone with a hidden disability. I have to decide when I feel well enough to share that personal information, and conversely, when I feel bad enough that I can't *not* disclose that information. On one occasion I wrote to student reps at my university about something related to my disability, and because they didn't know the answer to my question, they forwarded my email, with the personal information I disclosed, to all of the other student reps. Although I'm comfortable disclosing a lot of the time, I still like to be in control of who I tell when. I think this is symptomatic of a lack of education and awareness on the topic of disability and how to deal with confidential information.

Academia is deeply personal – that's not to say that we're all explicitly writing from our lived experience. As I said, I'm not a disability studies scholar. But we do what we do because we care about our subjects, our students, and our colleagues. We give of ourselves to academia and don't draw the traditional Monday to Friday, 9-5 boundaries. But not all identities are welcomed in academia. The ableist structures and expectations mean that people with disabilities have to constantly fight in order to belong. There is a disconnect between academia as personal and the experience of packaging yourself in a way that the world will find acceptable. Having to

deny or work around or fight for part of who you are is a diminishing experience. This is true for any identities that are marginalised – and the intersection of different marginalised identities with disability compound these difficulties.

One thing that came up in conversation a lot while preparing this talk was imposter syndrome. Alongside the feelings of ‘should I be doing a PhD’, ‘is my work good enough’, I have also experienced ‘am I disabled enough’. ‘I have it so much better than other people’. ‘Do I deserve to ask for support’. ‘If I receive support or funding or awards, am I only getting it because I’m disabled, and not because of the quality of my work’. We need to be saying to ourselves and to each other: ‘you are enough. You are disabled enough. You deserve to ask for and receive whatever you need in order to do your work and also be a whole and stable human being. You are more than good enough for an industry that thrives on telling you that you are *not* enough.’

A few specific and general things that have helped me:

In some ways I was lucky to receive this diagnosis while studying for a PhD - in what other job would I have the flexibility to take days off whenever I need to or create my own schedule. Make the most of the flexible schedules. Take days off whenever you need to. No PhD student, regardless of their access needs, should be working on their thesis 9-5. You simply cannot concentrate for that amount of time.

There is a balance we have not yet achieved between universal processes/procedures and individual needs. Where possible, we can help to combat this by communicating our needs and our experiences.

For UK students, apply for the Disabled Students’ Allowance – and get official support in place as soon as possible even if you think you won’t need it.

We need better education of people responsible for meeting access requirements.

Make your conferences accessible. More breaks, more hybrid options, more quiet spaces, less alcohol.

Talk to librarians: their job is to get you access to the books that will improve your life - there are no better people than librarians.

I've found referencing software helps me increase my productivity, and you can sign up to a disabled account with archive.org for access to books online: I couldn't have completed my thesis without this.

This is easier said than done, but it's important to find people to advocate for you – this might be friends, family, partners, mentors, supervisors, union reps, therapists, student and staff disability reps. You might not always know what it is you need to ask for or what support is available. Have discussions with people, if you can, to help you find out what you need and then ask for it. Nothing is sufficiently centralised in academia for us to know exactly where to go for our intellectual and personal needs – we're reliant on other people sharing their knowledge.

During the pandemic we learnt that it is far more possible than anyone had been saying to make academic spaces more accessible. One thing to come out of the pandemic for me was a network for other postgraduate researchers in my field. I met Sierra Carter at the University of York, and we established an online network called the Revels Office. In the height of the pandemic we were meeting online a couple of times a week, and although we don't meet as regularly now those are still the first people I turn to when I have concerns about my PhD. We shouldn't have to establish networks to find support, of course, but there are groups of wonderful people – and if you feel able, please do reach out to them.

Finally, supervisors and managers need to take responsibility for regularly checking in with all of their students about what will make their lives easier. In my current non-academic job, I meet with my line manager once a month and she asks how my pain management is going at work. I might not have anything to say, or I might not feel comfortable sharing it on that day, but I know that the conversation is welcomed. Of course the flip side of that is

how problematic it is to ask overworked people to take responsibility for others' wellbeing when the institution does not look after them. If our supervisors and managers are taking care of us, who is taking care of them?

Thank you for listening (or reading). As I was writing this I had a sentence that I couldn't find a home for because it belonged at once everywhere and nowhere. I think it underpins much of what I've been trying to say, so I'll use it to finish: in an industry where overwork, burnout, isolation and competition are the norm, kindness to yourself and to others is an act of resistance.