

# University of Oxford Disability Lecture 2024

Beth Kume-Holland

## Changing the disability narrative: from unseen to understood

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### Greeting by Sarah Stephenson-Hunter, University of Oxford Disability Advisor

This is the tenth annual lecture. It's my fifth and it's just fantastic to feel and see the buzz in the room and such a great attendance, especially on such an unusually warm evening. So thank you.

Before I say any more, just a few words of housekeeping: for those of you online, you should have spotted by now that we have live captioning – if you have any issues with that, switching that on, please do put a message in the chat online. You should have also realised by now that we have British Sign Language interpreters online. Again, they should be being pinned for you, but if there are any issues with that, do put a message online. And similarly,

online there is the Q&A box. As I said, there will be the Q&A session later. So please do put your question and answers in there. And if you've got anything else in terms of online, do put something in the chat and one of our moderators will attend to it.

And again, just a word to those of you online and those of you in the room: this session is being recorded and there will be a podcast and vodcast available in roughly ten days. So all of you who are here, who've registered, you will get details of how to view that.

Those of you in the room: as I've been speaking, you should have spotted we've got captioning throughout on all four screens. There is BSL coming through, if you haven't spotted – it's on the side two screens. Again, if you're not aware by now, then the toilets are out... this is where a blind person points... I believe they're at the doors at the back and to the left. But again, we do have stewards around. So if there's any other issues, please do ask. And we really hope we've covered every eventuality with accessibility. But if there are any issues, do raise your hand and a steward should be able to assist.

Before I hand over to the Vice-Chancellor, I do just want to say how fantastic it is to have this event, to have our speaker, and to celebrate what it means to be disabled and to highlight some of the challenges.

So that is enough from me. And I'll hand over to our Vice-Chancellor. (*Applause*)

## **Introduction by Professor Irene Tracey, University of Oxford Vice Chancellor**

Great.

Well thank you, and thanks to the Unit for organising this evening. I think as we were just discussing before we started: you know, this is a great illustration of what we can do and what we should be doing more in terms of creating such an event and facilitating the opportunity to learn from each other. And that's something we can again go forward with and roll out across the University.

So I'm really thrilled that I'm here this evening. As already mentioned, this is the tenth University of Oxford Disability Lecture. And for those who listened to my inaugural lecture as Vice-Chancellor, I talked then about the risks of complacency and the very clear need for us to have the humility to challenge ourselves and to think and act in new ways. And that

includes examining our attitudes towards and provisions for disabled staff and students. We've got approximately 60,000 students and staff; so our community, if you think about it, is the size of a mid-range UK town. And we know that disabled people make up approximately 24% of the UK population. So the number of our disabled colleagues and students is likely to be non-trivial. And the unique life experiences, the daily problem-solving skills of disabled colleagues and students contribute to creativity, productivity, competitive advantage, and profitability. Their ability to innovate and to provide alternative perspectives can be transformative in a research and development environment, and at the level of self-interest, we must maximise the contribution of disabled staff and students and invest in their excellence in order for our organisation to thrive and to flourish. So we must continue to commit ourselves to fostering a culture at Oxford where disability is not viewed as a limitation, but as a facet of human diversity to be celebrated and embraced.

There is much more work to be done, and I always say that when we talk about (*laughs*) what we've achieved or things that we've won et cetera, 'But it's not done yet. We've got to keep going'. There is much more work to be done so that we can assure that all of our staff and students feel their needs are fully supported. The Equality, Diversity and Inclusion strategy being elaborated by the Joint Committee on EDI has a very strong focus on disability, and I'm really pleased to see that.

And there are a number of initiatives already underway to develop a more empathetic and inclusive community in this university, this collegiate university. And I would like to mention just one of those initiatives tonight. Over the last couple of years, through the Digital Transformation Programme, we have been reflecting on our digital accessibility maturity and looking at ways in which we can innovate in this area. The Chief Diversity Officer who is here this evening, Professor Tim Soutphommasane, is spearheading the digital accessibility agenda, and I am pleased to announce that we are currently recruiting for a new role, a Head of Digital Accessibility, who will be tasked with implementing an institution-wide digital accessibility strategy, and with overseeing a programme to embed accessibility in all of our digital activities. I look forward to moving towards a more inclusive digital culture in the University of Oxford.

Understanding the need to reflect on our culture and on our attitudes towards disability, brings us back to this evening. Our colleagues in the Disability Advisory Group and the Equality and Diversity Unit, with support from the Disabled Staff Network, have worked together to bring us tonight's event and for which I, on your behalf, thank them. And we are very, very pleased to warmly welcome back Beth Kume-Holland, a graduate of Pembroke College – we overlapped just a little bit there – and a Harvard University Kennedy Scholar, to deliver this year's tenth Disability Lecture.

Through her lived experience, Beth will explore the topic of less visible disabilities and chronic illness, and she will share a glimpse into her own journey from Oxford undergraduate and researcher to award-winning CEO and international disability rights advocate. With a varied CV working for the disability charity Scope, Oxford University and Citibank, Beth has established herself as an award-winning social entrepreneur who has been named by the Shaw Trust as one of the 100 most influential disabled people in the UK. She is the founder of Patchwork Hub, a disabled-led social enterprise providing an accessible jobs board, bespoke recruitment services and training and consultancy for employers. She is also the co-founder of the Disabled Entrepreneurs Network, and was recently announced as a Commissioner on the UK's Independent Commission on Healthier Working Lives.

Beth, thank you so much for giving us the honour of coming here this evening to speak and a very warm welcome back to Oxford. Thank you. (*Applause*)

## **Changing the disability narrative: from unseen to understood** **by Beth Kume-Holland**

### **Overview**

*(As Beth's support worker helps seat her on a high stool behind the lectern)* So we do the awkward set up.

Great. Hopefully you can all hear me okay. Perfect. So thank you so much for that kind introduction, Vice Chancellor. And thank you all for joining this evening. I really am genuinely honoured to be back in Oxford and with you today. And also special thanks to Dr Catherine Walter and Sarah Stephenson-Hunter for the invite, and the wider EDU's work for

not only organising today's event, but the genuine commitment to the agenda and accessibility that I've got to witness since we connected last year.

So good evening everyone. Before we get going, and in the interest of accessibility, as a visual description of myself, I'm a 29-year-old white woman with long brown hair, brown eyes, wearing a black and pink floral dress. And some ill-advised black heels. And just to add, I will be using slides throughout the lecture, but they will just be capturing the content I'm also speaking. In any places where this isn't the case, I'll just give a quick visual description.

The other thing I like to share is I have a cognitive impairment, which can affect my communication at times and presents all sorts of barriers in an environment like this, alongside the physical. So if at any point my words come out jumbled, or I seem to be looking at my notes more than the average presenter, this is why: true disability inclusion in action.

Being back in Oxford with such an incredible platform to speak about disability inclusion means an awful lot to me. My time as a student at Oxford, trying to deal with confusing and undiagnosed conditions and symptoms, alongside the rigorous academic side of things, wasn't a simple one. But in so many ways, my time at Oxford completely changed my trajectory for the better, and I'm very grateful for the time I spent here and the people here who supported me. But more of that and my story in a sec.

Today I'm honoured to be delivering the 10th Annual Disability Lecture: Changing the Narrative around Disability: From Unseen to Understood. The aim of this evening's lecture is to provide a bit of an insight into some of the key issues around disability and accessibility. I know we're lucky enough to be joined in the audience tonight, in the room and online, with an incredible array of academics, students, staff, professionals, and advocates. And my hope is that regardless of your existing knowledge around disability inclusion, there'll be something by way of insights and takeaways for each of you.

Now, I've been out of academia far too long, but one of the things I do remember is the rule drummed into me by my tutors for all of my essays. Keep it simple, and remember the power of threes. So, with this in mind, today we'll be exploring the who, the why and the how of disability and disability inclusion. So first up, Who? Who are we actually talking

about when we talk about disabled people? And who am I to be talking to you today on such a topic? Next, Why? Why does accessibility and disability inclusion matter across individuals, organisations and wider society? And finally, How? How can we all make a difference to both the disability rights movement generally, but specifically the experiences of students, staff, and beyond at institutions like Oxford? Even at speaking events like this, I don't just want to pontificate. I think it's so important to give everyone some actionable take-aways that you can begin to use in your day-to-day life. So that will be around 50 minutes or so long. And then we'll finish off by handing over to you for a Q&A where I'll try my best to answer any questions you might have.

## Who?

### *Beth's story*

So who am I? So today I'm an entrepreneur and disability advocate, and my day job is spent running my business, Patchwork Hub, which is a social enterprise that helps organisations to become more disability-inclusive and accessible through our jobs board, training, and consultancy services. I also do a range of work focussed on closing the disability employment gap in the UK, creating a more inclusive future of work, and just trying to break down some of those needless barriers that get in the way of so many talented people in this country.

But working in disability inclusion and starting my own business wasn't part of some grand plan. And to be honest, neither was going to Oxford. Growing up, I didn't think that university, no less Oxford or Harvard, were for people like me. My parents didn't go to university, and my school certainly didn't feel equipped to prepare people for Oxbridge. But I got a lucky break at 17, when I was fortunate enough to be accepted into an access program here called the UNIQ Summer School, for people from lower socioeconomic backgrounds. And it was this summer school that convinced me that maybe university could be for me, and maybe somewhere like Oxford was worth a shot. And, well, I'm so very glad I did.

It certainly wasn't an easy journey. I had a host of health complications across teenage years. At the time, we weren't sure what they were. Like so many people living with chronic health conditions, it was a case of a lot of appointments, but very little by way of diagnosis

or answers. Then during my first year at Oxford, I became particularly unwell, caught glandular fever and, to be blunt, never recovered. Combined with an autoimmune condition, over a number of years this caused me to develop fibromyalgia, and subsequently triggered a range of underlying genetic and limiting chronic health conditions. It's a trajectory that will now perhaps sound more familiar, since society has become increasingly aware of how viral illnesses can trigger long term impacts during the Covid 19 pandemic and Long Covid.

So that you have a couple of examples of what that means in terms of symptoms I live with in practice: Fibromyalgia means my brain misinterprets nerve signals as pain signals. And I live with a great deal of chronic pain. ME/CFS gives me intense brain fog and post exertional malaise after physical and mental activities, which I should know will not just fix itself by exercising more. EDS, or Ehlers-Danlos Syndrome, affects my connective tissues and means I regularly and easily dislocate or sublux my joints. And POTS, or Postural Tachycardia Syndrome, means that my blood vessels don't properly pump blood back up my body, and when I stand, I can faint if I have to stand still for long periods. Obviously, each condition I have is wide-ranging and complex, and includes a range of other symptoms, but it's hopefully helpful just to have a couple of examples of what my conditions mean in practice.

I'm also not just telling you so you know more about me. I'm telling you because my experiences of navigating chronic illness at Oxford, then Harvard, and then when I started my own business, serve to contextualise where I'm coming from and what I'm about to put forward. They also hopefully illustrate some of the barriers that at least this disabled person has faced in education and work, as well as support and help I received along the way.

During my time at Oxford, I got very lucky. I'm sure I don't need to tell most of you here that eight-week Oxford terms can be intense, and they just don't leave a lot of scope for fluctuating health conditions and health emergencies. I got lucky because I was fortunate enough to have some tutors and a mentor that just got it. He worked with me to find a sustainable path forward, particularly at points in my second year while I was recovering from an operation and really wasn't well. My tutor that term was flexible, empathetic, and trusted that I would get the work done if he gave me space to do it in a way that worked for me. At the same time, I was lucky that my family were only a short drive away in West

London, and that my friends and those around my college, like the porters, were wonderfully supportive and looked out for me. Even with the support, Oxford was hard and had an impact on my health. But I truly believe that the understanding and support I got from key people was the difference between graduating and having a successful time here, versus having to pause or stop altogether.

I came to realise how lucky I was because unfortunately, things were quite different for me when, after graduating from Oxford, and spending a year working here as a Research Fellow, and some time as a researcher at Citibank, I got a Kennedy scholarship to go to Harvard. At Harvard, suddenly I was an ocean away from my family and wider support network, and unfortunately, I came up against some inflexibility and barriers in both the institutional 'way things are done', and from individuals I was working with. To give one example, at an institutional level: even though I'd registered my conditions and provided medical documentation of my impairments prior to arriving at Harvard Grad School, because I wasn't a primary wheelchair user, I was given a room up eight flights of stairs with no lift and no other suitable alternatives. This meant there were periods of the year through which I was completely confined to my room, because my illness meant I physically couldn't climb the stairs to leave my floor, and I was relying on friends to bring me food. This was hard and had many long-term impacts, something which I'm sure anyone else in the audience with an energy-limiting condition whether ME/CFS, Long COVID or anything else can attest to.

On the academic side of things, I was super excited to have the chance to study film-making as part of my studies, something I'd always wanted to do, with big, grandiose dreams of telling people stories and maybe becoming the next Spielberg. So I secured my place on two film courses, and excitedly rocked up to the film-making department. But when I arrived, it turned out that the standard camera equipment for us to create our films was an extraordinary heavy camera, tripod and separate mic boxes, which, to my horror, we'd be required to take on our own to every shoot. Given I could barely lift the camera to waist height, let alone carry it for hours on end, I quietly asked for a meeting with my professor and assistant, and requested an adjustment to use my own personal camera, which was compatible with all of the software but, crucially, was lightweight. Sadly, I was told that this just wasn't possible, as it wasn't something they'd done before and thought it wouldn't



allow for a level playing field for other people on the course. So I just tried my best to make it work, but it had a real impact on my symptoms, took up so much of my head space trying to manage, and just sucked the enjoyment out of a course I'd been so looking forward to. I used to find it almost comical each week when we presented our footage in class to see how everything was getting on. My professor would remark on how I seemed to be relying on the tripod quite a lot, and how my handheld shots were extremely shaky. Funnily enough, I wasn't actually trying out a new artistic approach to cinematography. I literally just couldn't hold the camera to waist height.

And these are just two examples where adjustments could have easily been made. I could have had a room with far fewer stairs up to it. The whole block was graduate accommodation. It wouldn't have been that difficult. And ultimately, using a lighter camera might have differed from others, but for relatively little impact in real terms, it would have allowed me to focus on my filmmaking, learn more, and develop skills using a piece of equipment I might actually be able to use in the future. To their credit, the Accessibility Office did try their best to help in various ways, as impacts on my mental and physical health became clear across the year. And I know it's something they've made strides on since, but both examples just needed a bit of flexibility, and the lack of it had a profound experience on my time there.

Most of the people I interacted with at Harvard were trying to do what they believed was the right thing to do. The majority of the issues rose from a lack of awareness and understanding of the barriers different disabled people can face, often driven by a lack of exposure to people who had access requirements that differed from the norm.

And I think part of the issue was that the people who I was speaking to had a very traditional view of what a disabled person was, that I didn't fit, because my disabilities were invisible or non-apparent. Despite all of the medical evidence and advocacy and all of the things going on with my health, they kept seeing a seemingly non-disabled young person in front of them, rather than the unseen realities of my chronic illness. They too often framed my requests as wanting some sort of special treatment, rather than just needing help to navigate barriers that most other students weren't having to think about. And just to add a quick visual description on the slide here. On the left is a picture of me smiling at the

camera, while on the right is the same picture with a range of some of my symptoms that I mentioned earlier spelled out around me.

I think reflecting on those different experiences really crystallised for me that you can only go so far relying on individuals to do the right thing, or even know what the right thing is, especially in the face of inaccessible and rigid processes and procedures within organisations or institutions, and that can throw up all sorts of unnecessary barriers. Ultimately, leaving disabled people to navigate adjustments person-to-person leaves them open to individual ignorance and puts a big unfair burden of self-advocacy on them.

However, and as a hopeful point for everyone to take away, I also came to realise the power and impact that individuals can have for disabled people if they're willing to listen and be flexible. My time at Oxford showed that individual allies can genuinely transform a disabled person's experience of otherwise inaccessible situations. My experiences at Harvard did also do one very important thing. Far more so than any time previously, they made me identify as disabled and think about my disability identity. I was forced to advocate for myself to try to get the adjustments I needed in a way I hadn't had to before, and it was facing these assumptions and ignorance and deciding to try to change things for the better that led me to get very involved in wider-reaching disability advocacy work in the States, which eventually took me to Capitol Hill in Washington, D.C. to meet with Congress and Senators.

And it was actually during one of these trips in 2019, where I was sitting around the table listening to the stories of incredible, highly skilled individuals who'd been forced to stop work because of barriers they were facing that I had the initial idea for Patchwork Hub. Across my advocacy efforts, I met so many people like me who were wanting and able to work, but who just faced so many barriers due to inaccessible conventional work practices and cultures. I began thinking about the potential of creating an accessible employment platform, through which users could connect with inclusive employers, access training and support, and facilitate a different way of working that broke down some of the unnecessary barriers they were facing in the world of work. It should be noted, of course, that for many people living with moderate to severe conditions like ME, Long Covid or others, work often isn't an option. So I think we need to be really careful when talking about removing barriers

that we do recognise the fact that some people are too unwell to work, and it really is as simple as that. In support, however, of those who were able to work, the more I thought about this founding idea, the more convinced I became of its potential.

So when I returned to the UK, I started work on Patchwork Hub, and I've been pushing things forward ever since. Through my work at Patchwork Hub I've met so many amazing people, whether it's the job seekers who we connect with inclusive work opportunities; people driving the change around disability inclusion within organisations across the country; or other disabled founders and entrepreneurs who are doing amazing things across so many sectors.

But in my work with employers and jobseekers, I've also really come to appreciate the extent to which unnecessary barriers in the way things are done are holding back so many talented people, either excluding them from the workplace, pushing them into less secure employment, or halting their career progression and their ability to thrive and work in a sustainable way. And whilst the business I built is trying to tackle the persistent barriers within workplaces and society, I still hadn't quite expected, when I broke away to embark on my own vision, the extent to which I would come up against those same barriers in the world of entrepreneurship. First of all, even in 2024, there's still a real macho tech-bro culture around innovation and the start-up space, both from entrepreneurs and investors. There's really quite an ingrained sense that to be a successful entrepreneur, you have to be hustling or burning the candle at both ends – almost to the extent of glorifying concepts like burnout. Now, for someone like me with fluctuating health conditions and chronic fatigue, this can often make me feel like I'm falling behind, or there's pressure to push myself in really detrimental ways. There are, of course, some really amazing inclusive accelerators, investors and funds that are starting to disrupt that a bit. But I think it's worth flagging how exclusionary the current mainstream start-up culture as a whole can be.

And that's not just for disabled entrepreneurs. In many spaces I find myself in, I'm not just the only disabled person, but the only woman in the room, with an equally notable exclusion of people of colour and other marginalised groups. Very much linked to this are attitudinal barriers that get in the way of disabled entrepreneurship: the assumptions that people make about disabled people and the lives they can lead, the skills they can have and

the things they can achieve. For example, far too often people have assumed that because I'm disabled, my business would naturally be some charity style, small-scale lifestyle business, or that because I'm working in disability inclusion that my services and expertise should be provided to them for free. Often when I explain that I run my own business to new people, I'm met with a well-meaning but somewhat patronising 'Oh, good for you, keeping yourself occupied, despite everything', rather than just taking me seriously as an entrepreneur and a business leader. And for many of my disabled peers, there's also a really ingrained assumption that the only thing disabled people can be leaders in is disability inclusion, and that the disabled entrepreneur must be doing something disability related. We need to normalise the idea of disabled people being experts in areas that aren't just disability.

In fundraising as well, I can guarantee that I'll have a completely different level of conversations with investors when they don't realise I'm disabled, compared to if I walk into the room with my stick or in my power chair. And I don't mean in a good way. In the past, potential investors have literally dialled down the amounts we're talking about once they realise I'm personally disabled or the nature of the conditions that I live with. A lot of this is down to ignorance and a lack of awareness, driven by a lack of representation, which can fuel so many stereotypes. But I did just want to highlight these barriers, as I think they're really relevant to thinking about the broader underlying cultural and systemic barriers that pervade all institutions, workplaces, and the general narrative we have around disability in this country.

### ***The disabled community***

What I've gone through so far is very much my own story and some of the barriers I've experienced and witnessed. But something I really want to stress – perhaps obvious, but still something worth saying – is the diversity within the disabled community. The story I know most about is my own, but disability is such a broad umbrella that encompasses a wide variety of lived experiences, all the while intersecting in complex ways with other parts of our identity. So I now want to broaden things out and look at disability in the round: who we mean when we talk about disabled people and what ways we can start to understand

and conceptualise the array of barriers that different disabled people may have to navigate in their daily lives.

When we talk about disabled people, who are we actually talking about? The definition of disability according to the 2010 Equality Act is somebody has a physical or mental impairment which has a substantial and long term negative effect on their ability to do normal daily activities. Now, just because it's interesting to see what people's perceptions are, and also just to check it also with me, can I ask you what percentage of the UK population you think has a disability?

So there's three options on the slide. 15%, 21% or 24%. Not to bring it back to school too much, but if I can ask those in the room to raise your hands or otherwise indicate in whatever way you're able:

A: 15%. B: 21%.

... or C: 24%.

Interesting. I put this before I realised I can't see the Zoom chat to see the responses, but in the room we've got some Bs and some Cs. And actually, C: 24% of the British population are disabled, according to the latest government data published earlier this year, which is over 16 million people. And it's actually a bit of a sneaky trick question for anybody that said B, because it was 21% until a couple of years ago with the census. So now I'd like to ask you to guess what proportion of disabled people you think are wheelchair users.

So we have 7%, 14% or 35%.

So who thinks it's A: 7%? OK, quite a lot.

B: 14%. OK, and C: 35%.

More of a mixed bag. So correct answer is in fact just 7%. And actually, recent studies have shown that fewer than 3% of disabled people are full-time wheelchair users. The remaining 4% are ambulatory wheelchair users like me, meaning they can walk but use a wheelchair some of the time for certain purposes. Now, I think this is really interesting because if I ask you to close your eyes and imagine a disabled person, I think more often than not, your mind might immediately think of somebody with a visible impairment, such as a wheelchair

user. And in fact, the icon of somebody in a wheelchair is the universally recognised symbol of disability. But in fact, as we've just seen, 93% of disabled people are not wheelchair users. According to the WHO's World Report on Disability, over 1.85 billion people globally are living with a disability, and of these, over 80% of disabilities are non-visible, with 450 million living with a mental or neurological condition. So a lot of disabled people might not conform to society's stereotypical view of disabled. And I think this is something to watch out for in your own thinking around approaching disability and access.

It's also important to note that many people with disabilities might not seek medical help. For example, around two thirds of those with a mental or neurological condition are thought not to have done. And this number of people living with a disability is rising as we battle global trends such as an ageing population and most recently, the Covid 19 pandemic.

Something I'd like to do in today's lecture is to highlight that disability might be affecting us all in ways you might not necessarily realise. So nearly 1 in 4 of the British population now live with a disability. And yet repeatedly, results in studies have shown that almost half the population say they don't know a disabled person. There's many systemic reasons for this, with ongoing challenges around disability, poverty and isolation. But another reason for this disconnect is people not necessarily realising or recognising impairments and health conditions as disabilities, or identifying as disabled. And I'm very aware that whilst I now proudly self-identify as disabled, early in my 20s, this was something I had an incredibly complex and personal journey with. Like I said, it was only really after my experiences at Harvard where I came to realise that as a really core part of my identity. And young me is not alone in this: studies have shown that the number of people who meet the Equality Act definition of disabled, but don't self-identify as such, is really sizeable. It's actually a good reason why now surveys often ask about disability tend to ask about disability or long term health conditions. Because although the world is changing and adapting its awareness of disability, neurodiversity and mental health, awareness and representation is still low, even among many people with various health conditions.

The vast majority, 83% of people with disabilities, weren't born with them, but acquired them during their working life. And most of us grow up knowing very little about disability. Sadly, a disabled person's path to becoming disabled is not as simple as being diagnosed. It's

not like you're handed a booklet that says you're disabled now. And then you've got the fact that it can take a long time before that. And I think never has the sentiment had more light shone on it than during the pandemic. Awareness of underlying health conditions and the notion of adapting behaviour to protect your health and the health of loved ones and strangers was introduced in an unprecedented way. Terms like *immunocompromised* suddenly became a part of commonly understood language, and people became acutely aware of being clinically vulnerable from their conditions.

And then, of course, there's Long Covid, impacting an estimated 2 million people in the UK. This has resulted in individuals becoming in some cases severely unwell and disabled almost overnight, and now having to come to terms with a wholly new identity. And then you've got the fact you can take a long time to receive a diagnosis for many chronic health conditions. The average diagnosis time for Ehlers-Danlos Syndrome and POTS, two of my own conditions, is around 14 years, with the number being even higher for under-represented demographics. And unfortunately, diagnosis doesn't equal treatment, with waiting lists for treatment of critical conditions still incredibly long. So again, for me as a disabled person, wanting to take advice and positive steps to at least ease symptoms and improve my situation with things I know would help, I'm still on waiting lists six years on from my original diagnosis, which makes it quite hard to make those sorts of improvements. Ultimately, awareness of disability remains very low and few people identifying as disabled, combined with a lack of authentic representation, helps to fuel misconceptions around what disabled looks like and how we should work to accommodate people.

So far, many of the stats I've quoted have talked about disabled people as one community. But I really want to stress there's very much no one-size-fits-all view of disability. Different health conditions and disabilities can require radically different accommodations, while even people with similar conditions and impairments can have different needs and experiences. My lived experience of my disability is my own, and every disabled person will have a different experience with their disability.

And as with all marginalisations, it's also really important to consider intersectionality and how different parts of people's identities will impact their experience. For example, as a female disabled entrepreneur from a lower socioeconomic background, I'll experience

different barriers than others, whilst being a white woman affords me privileges that people from other backgrounds would not have. Looking at disability without this intersectional lens is a non-starter. But even in 2024, the disability space in the UK is still incredibly white and heteronormative. We need to work as a movement to listen to, platform, and learn about the experiences of ethnic minority disabled people, LGBTQ+ disabled people, and other minorities within the disabled community.

So what does this all mean? Well, it means that when we're trying to be inclusive and provide an accessible environment for people with disabilities, we always have to start with the individual and their specific needs. We need to set up ways to listen to them and ask them, as experts in their own experience. And considering the different aspects of their identity is of paramount importance here. So while there's good general practice you can learn and we'll be discussing, when approaching disability, it's always vital to remember to listen to individuals when they tell you the barriers they're facing and what they need, to capture the complexity of individual circumstances. And I think one useful way to do this is making sure you and your peers understand and utilise a very key principle and approach: the social model of disability.

### ***The social model of disability***

So what is the social model of disability? Traditionally, when people used to think about disability, they would often think in terms of what's called the medical model. The medical model focuses on what's wrong with a person and says that people are disabled by their impairments or differences. In contrast, the social model of disability is a way of viewing the world which has people disabled by barriers in society, not by their impairment or difference. So, for example, a barrier could be being in a wheelchair and unable to get up the stairs because there's no lift. In the traditional medical model, this would focus on there being something wrong with the individual in the wheelchair who can't climb the stairs. But in the social model, the person is disabled by a lack of access, not their condition. When there's a lift put in place, that barrier's removed. Barriers can be physical, but they can also be things like digital accessibility – a real problem across so much of the internet. Or they could be processes and procedures in organisations or cultures and the way of doing things



or just simply people's attitudes to difference: like assuming there are certain lives disabled people can't lead or things they can't achieve.

Now, I'm not going to stand up here and tell you I think that the social model is perfect. Like all advocacy tools, I personally think it can oversimplify disability a bit. Just in terms of my lived experience, it's true that an awful lot of the impacts of my disability could be lessened or mitigated in a society built with disabled people in mind. But even in a world where you removed all of society's barriers, I still have chronic pain, daily dislocations and fatigue.

However, I do think the social model can be and is a very powerful tool for advocacy and for organisational understanding of disability inclusion. And frankly, my life would be an awful lot nicer if all of society's barriers for disabled people were removed, even with my symptoms intact. We can still see the persistent negative impact of the social model of disability in so many aspects of our society and institutions, most obviously in the media or government framing of disabled people as a problem to be solved, rather than as a community living in a society not built with them in mind, and who should be engaged with.

What's always really interesting in all of this is looking back at March 2020. Society in just a few weeks was able to make the adjustments and remove barriers to remote and flexible working that disabled people had been asking for and denied for decades, demonstrating the art of what's possible when the will and desire is there to implement it. So the social model's strength is in placing responsibility on all of us in society, in the workplace or institutions we're part of, to remove these barriers rather than wrongly writing off disabled people as a problem, or broken. And for me it's quite empowering for everyone. Because if the problem is society, it means every one of us can play our role in making things better and pushing for a more equitable and inclusive future.

But – and actually, this is a question that gets put to me far more often than you would like or hope – while we can all play our part to drive change, why is this change actually needed?

### **Why?**

Why is disability inclusion important? Well, first and foremost, this is a basic fairness issue. Like so many other marginalised communities, disabled people are living in a society not built with us in mind, which holds them back, and which stops them from thriving and

contributing in a way they could. And I find it sad that this moral argument is so often sidelined and deprioritised. It often feels like we need to make the case that disability inclusion would be economically beneficial for the majority, or we need to link it to the personal interests of non-disabled people by reminding them that disability is a category that any of us can join at a moment's notice. Fundamentally, I feel really strongly that disability inclusion is a good in and of itself without any of these other justifications.

But having said that, there is a massive cost to society from being so inaccessible. Every day, I'm blown away by the talent in the disabled community. And every day, I'm equally frustrated by the way that that talent is blocked, derailed and marginalised. In other words, there's a massive opportunity cost to our current inaccessible society and inaccessible workplaces. And that's all the amazing things that disabled people would have gone on to be able to do, if they'd just been able to get on and do it in a setup that works for them, rather than having to spend all their time, effort and money navigating a needlessly inaccessible world.

And I think this is something that we can recognise and extend across marginalised communities. Inclusivity and accessibility is not just nice to have, as it feels far too often it's framed as. There's an immense cost to all of us for our lack of inclusivity, and that's all of the insights, creativity and progress we're missing out on because people aren't given the same chances and opportunities as others in our society. And it's the same in organisations and institutions. If you've got barriers that are stopping you from recruiting disabled people or cutting potential disabled students off for application processes, or disrupting their efforts once they're at university, that's a sizeable portion of the population you're missing out on or marginalising. And you're missing out on people that are great problem solvers, compassionate leaders, and innovators who likely bring different and fresh perspectives, tasks, and topics alongside many additional skills honed from navigating an often inaccessible world.

However, in almost all countries there's a large disability employment gap, with the employment rates for disabled people much lower than non-disabled people. In the UK, it's remained relatively stagnant, moving from low 30 percents to high 20 percents over the last decade or so. And that's before we get onto career progression and the disability pay gap,

which we can't even measure properly because the data just isn't being collected in the way it needs to be. Yet it's been repeatedly proven by research and studies that disability-inclusive companies outperform their peers in terms of revenue, retention rates, productivity, and reduced sickness absence. So society as a whole is missing out on excluded disabled talent. But so are organisations and institutions up and down the country. It's costing us all.

And my next point around Why? Well, accessibility and disability inclusion is vital for disabled people. Environments set up in an inclusive and accessible way ultimately benefit everyone. There are so many cohorts beyond disabled people that can benefit from a strong foundation in disability inclusion and accessibility across all parts of society. As a simple start, businesses that know how to support disabled employees effectively will likely be better placed to support people with shorter term illnesses. I'm currently a Commissioner for the Commission for Healthy Working Lives, and I was actually really shocked by the work that the Health Foundation, Resolution Foundation and others feeding into that commission found around the rising ill health across the working age of the UK, but especially among the younger cohorts of the workforce. To me, a really necessary requirement is to get disability inclusion right, with the right systems in place, and use that as a fundamental basis and template for creating a healthy way of working that benefits everyone. It's an issue that's been getting a lot of coverage over the last few weeks, even this week and today. And I probably don't need to clarify that for me, it's clearly really damaging and wrong to continually frame disabled people, and those out of work due to sickness, as the problem, or question the validity of the health and accessibility challenges people face, as the current government narrative seems intent on doing. The problem is the barriers, the inaccessibility, and the practices that amplify ill health, not the people, and I think any serious solutions would address that. Overall for me, workplaces that are truly disability-inclusive are going to understand how to flex around people's needs and circumstances to help them put their best selves forward. And if harnessed, this ultimately unlocks benefits for everyone, whether it's the 5 million unpaid and often unrecognised carers in the UK, parents who need that flexibility for childcare, people who thrive with different communication styles and ways of learning, or just the natural variation of lives that people are balancing outside of the workplace.

Disability inclusion, accessibility, and the lessons they teach are vital for disabled people and neurodivergent people. But I truly believe they benefit everyone. So this means that I really have to bite my tongue sometimes when I speak to employers and organisations around diversity and inclusion, and they tell me they're focusing on addressing other areas such as gender or ethnicity, before getting to disability. And yes, they do say this a lot. The reason for my frustration is because these things are all linked in a way such a siloed view of diversity and inclusion pillars misses. And one key thing to remember is that for all types of demographics, disabled people are part of them all. And it's why intersectionality is so absolutely crucial. Ultimately, disability inclusion is a basic fairness issue, and that alone should be enough to make us care. But it's also a massive benefit for us all across society and organisations. We benefit from harnessing disabled talent and diversity of thought it brings, rather than putting barriers in the way. And we all directly benefit from some of the lessons of accessibility and flexibility that disability inclusion has at its core.

So I've talked a lot about the issues and why they're important. But for me, it's vital when you engage people on issues like disability inclusion, you don't just flag the problems, but you actually start to broach solutions. And I don't just mean long term, complex societal and organisational changes. I mean things that every one of us, across our different walks of life, can start to think about and take action around immediately. Because while I think that ultimately a lot of the change needed does need to happen at that macro level, as I said earlier, I know from my own experiences the power of individuals in lowering barriers for those they manage, those they tutor and educate, and those they interact with. So I'm going to go through a mix of small and slightly larger actions that can really make a difference in creating more disability-inclusive and accessible environments.

### **How?**

My first suggestion is perhaps the simplest. Take the burden of raising adjustments and access requirements off of the disabled individual. Too often, the burden is currently on the disabled person themselves to raise the issue of adjustments or accommodations, which relies on their confidence and personality, and impacts the process for them in getting what they need to thrive. It can take a lot of energy to constantly advocate for and proactively bring up access requirements or adjustments. Disclosing your disability can be a really scary

thing. A study by BUPA found that over 2/5 of those with less visible disabilities hadn't disclosed them to their employers. So it's about creating a culture for disclosure. And not only this, but it's also important that, especially in university settings or early careers, often for many students living with undiagnosed or newly diagnosed conditions, this may well be the first time they've gone through the process and concept of reasonable adjustments. And it may be completely new to them. Yet I can tell you from personal experience and from speaking to countless disabled candidates and job seekers, there's nothing quite like the feeling of relief when someone asks first if there's any adjustments you need, and comes across as just genuinely wanting to help.

So how can we implement this in practice? Well, if you manage people, it's as simple as proactively asking everyone when they start working for you, and at checkpoints throughout your work with them, if they have any access requirements and how you can set them up for success. If you're tutoring students, bringing it up at the start of each term can be really powerful. And if you manage recruitment or even within the interview process for entry to Oxford, proactively asking whether adjustments can be made, and then returning to the question as a standard part of any communication with them throughout the process. Making this part of mainstream communication to all students, applicants, and staff can take a huge burden off of people and will benefit you in turn if you're providing support. Flagging how adjustments can be raised at every stage and signalling clearly that your priority is helping people put their best selves forward isn't costly, but it's a powerful message that your team, organisation, or institution cares about its talent.

My second suggestion is a more organisational one: mandatory disability awareness training for those in positions of management or pastoral responsibility. From my work in organisations across the UK, I've seen the importance of line managers as the people that have the most direct contact with the individual. You can have the most amazing policies and procedures in place, but if someone's line manager just doesn't get it, that's often going to be the biggest problem and can make or break the outcomes for the disabled person. And at educational institutions like Oxford, I'd extend the concept of line manager to include tutors and those in pastoral positions of responsibility across colleges, alongside others. And while I fully acknowledge that training is only one part of the solution, what it

does do is set that baseline of awareness that makes it just that little bit easier to hold people accountable and question unhelpful or even unacceptable attitudes and behaviours.

My third suggestion is something we can all improve on and practice around different aspects of our life: accessible communications. Another one of these things that's essential for some, but useful for all. Whilst this is vital for company, university, or college comms, it's equally important for all of us, even if it's just our social media. Accessible communications could take up a whole discussion of its own. But I thought I'd just leave you with a few priority quick wins that anybody who uses social media can ensure they're implementing from now on.

The first of these is for anything you or your company or society puts out on social media: Please ensure that every image has both alt-text and image descriptions. Alt-text, for anyone unfamiliar, is a simple description of an image and allows users who may be blind or living with low vision to consume your content as it is read aloud by users of screen reader software. However, not everyone who benefits from having an image read aloud to them has access to a screen reader, and this is where image descriptions come in. Rather than just being read just by screen reading users, they're added in the body of text and can be read by anyone, normally containing slightly more information around nuances like moods or emotions. They are added to social media captions, comments, or as the caption to a photo on a web page. Image descriptions aren't just beneficial for those with visual impairments. They benefit people with visual processing differences or different learning styles. For example, autistic or dyslexic people might benefit from having something written in text rather than the image of a text. People with sensory processing differences, like a chronic pain condition or chronic illness or fatigue can also greatly appreciate them.

Next, please ensure that every piece of video content has closed captions. Not only is this essential to allowing deaf and hard of hearing users to consume your content, it can also help people with cognitive dysfunction like me, where I benefit from being able to read and listen at the same time. There's countless other benefits to captioning, too, especially as studies are showing that up to 80% of people now listen or watch their videos with their sound off.

And a final quick point for anyone using hashtags on social media. Make sure you #CamelCase them. By this I mean capitalise the first letter of each word, rather than having everything lower-case, so that screen readers or those with cognitive disabilities can enjoy your content. And again, it's so much easier for everyone to understand. For all of you avid watchers of Love Island, I'm sure there's many in the room, you all know what a revolution it was when, a couple of series ago, they finally started CamelCasing their hashtags – ridiculously long – on their texts.

But the point is that whether it's CamelCasing your hashtags or including image descriptions in your images, these steps might be essential for some disabled people, but they make your content more accessible for everyone. Now, these are by no means comprehensive suggestions, but hopefully they also don't come across as that complex. From my perspective, these are the sorts of things that should be commonplace everywhere. They're completely free and so easy to implement. And yet it's really, really frustrating the number of people, societies and institutions that just don't. Digital accessibility is just as important as physical accessibility. And yet, sadly, 97% of the internet is still inaccessible for assistive technology. And while I don't expect you to be able to solve that on your own, I think we can all do our bit to improve things.

So my fourth and final suggestion, at the individual level and organisational level, is to think about how you can build flexibility into your ways of working with others. As I've said throughout, it's so important to listen to disabled individuals about the specific barriers they face and the adjustments that might be helpful to them; but it can also be really helpful if you've thought in advance through some basic ways that you could be flexible. I've already said what a difference it made to me during my time at Oxford, to have a tutor that was pragmatic and flexible around my essay deadlines and studies while struggling with my health. But there's more to flexibility than just flexing on timelines. There's communication styles. Colleagues, students, or others may have different ways that they process information. Some might thrive in person, while others will do better virtually. Some might find it beneficial for you to verbally explain written instructions, while others might find it easier for you to follow up on any verbal discussions with a written summary. For everyone here, that just requires us to be aware in our own working practices and thinking through how we can adapt and flex them to get the best out of those we're working with. Just like

the flexibility you would show for child pick up or post-pandemic return to work when underlying health conditions came to the fore, it should be no different for supporting disabled staff and students.

And then at the level of things like university courses, just to make things slightly more controversial, flexibility might be around being aware that for some people, particularly those with fluctuating conditions, who need to be able to accommodate a bad day health-wise, time-bound short bursts of exams may be a poor way to assess their progress and competency versus things like coursework; or that spoken word vivas or back and forth verbal entrance interviews might present real hurdles for some disabled people. Or that numerical, spatial, and other reasoning tests could be a really poor proxy for whether some disabled people will thrive on the course.

I'm not saying that these things all have super easy fixes, but I do think it's worth any of us involved in process and decision making taking a step back to think about the potential barriers and possible ways that flexibility and accommodations can be built in, separate and in advance of it being raised as an issue by the individual. Asking ourselves every day, are we really doing everything we can? Are we really being as aware and therefore flexible as we can be?

For the last five years, I've set a personal goal each day to take an action, however big or small, to make the world and the places I work with more accessible and aware than when I found them. And I'd like to wrap up this final section by inviting you to do the same. Accessibility is a journey. You won't always get it right, but what you can do is challenge yourself to keep learning, and do one thing today to make it better for others tomorrow.

### **Closing comment**

Now I think I've said quite enough, and I'm really keen to hear thoughts from the audience and answer any questions. But I did just want to end by reiterating a really key point that I hope's been clear across what I said. It's true that a lot of the barriers that need to be addressed for disabled people are at a societal, organisational or institutional level, baked into processes, procedures and structures. However, I can really attest to the fact that individual allies and support can make a huge difference for disabled people, making a world of difference to our experiences. And it's vital that we all do more on this because it's



simply the right thing to do; because we're currently missing out on and excluding an extraordinary wealth of talent; and because ultimately, a more disability-inclusive and accessible society and world is a better one for everyone. So, all that's left for me to do now is thank you very much for having me here tonight. It's been a real privilege to talk to you all. Thank you. (*Applause*)