Disability Lecture 2020, University of Oxford 27 May 2020

SARAH STEPHENSON-HUNTER, STAFF DISABILITY ADVISOR, UNIVERSITY OF OXFORD:

Good evening, everybody. My name is Sarah Stephenson-Hunter and I'm the Staff Disability Advisor at the University of Oxford. And I'd really, really, really like to welcome you all to our annual lecture this evening. Bear with me… As you will see, this world of Zoom Webinars is something that is quite new to us. Obviously, in the current situation, we're all quite used to them, but we're still learning about this. Before I just say a few more general points, I just want to go through some housekeeping. So this is a Zoom Webinar, so all of your audio and video is turned off by default: there will be no capacity for that during the session. But you will see there is a chat box, which – if you can put general comments in the chat box, if you're having problems during the event, then one of our moderators will try and help you out. You can raise your hand in there as well, if you have a problem. In terms of questions for the Q&A, which will happen after Dr West has given her speech, there is the Q&A box, that if you put questions in there, we will not mention names, but we will ask those questions anonymously, and we will try our best to get through all of the questions, but it just depends on timing. We are going to try to keep this to schedule, and I think those are the main things. The only other thing to say is that for those of you that need captioning, there is captioning available; if you click the Closed Captioning option on your Zoom screen, then you should be able to access that. That is live captioning, so hopefully that should give you a better experience. And just a final housekeeping point is if you select Gallery View instead of Speaker View, then you should have a better experience of accessing the lecture.

So that's the housekeeping out of the way. As I said, we usually held this annual lecture physically, around this time of year. Every year, it's hosted by one of our wonderful Colleges, a wonderful setting to have the lecture. That in itself comes with some physical challenges around accessibility that we've got quite used to dealing with, and indeed in holding the lectures, I think, is a great learning experience for our Colleges and our University community to learn about accessibility issues. In deciding to obviously switch the lecture to online, we realised that it wasn't just going to be 'Well, we can just stick a camera and off we go'. We realised there were going to be some other accessibility issues, which we hope we've addressed. If not, then please do give us feedback, there will be a poll at the end where you can give us some of your experience, where you're coming from, perhaps any issues you have experienced. Do bear with us. None of us are Zoom experts but we are becoming so. So really without any further ado I just want now to hand over to Professor Louise Richardson, our Vice Chancellor, who's going to introduce the speaker and say a bit more. Over to you.

PROFESSOR LOUISE RICHARDSON, VICE CHANCELLOR OF THE UNIVERSITY OF OXFORD:

Thank you Sarah, good evening everyone, and welcome to the 2020 Disability Lecture. The sixth annual lecture organised by the Equality and Diversity Unit and the staff Disability Advisory Group. This evening's lecture is entitled '#WhyDisabledPeopleDropOut: A Neurodivergent Student-Turned-Academic on the Neurotypical University'. I am delighted to introduce our guest this evening, Dr Kate West, who is going to be giving the lecture. Kate is Senior Lecturer in Visual Criminology at Oxford Brookes University. She began her academic life as a lawyer, and later criminologist, before developing a particular interest in art history. Kate researches the art history and visual culture of crime and punishment in the late modern period. Her first book, ‘What was Criminology?: An Unlikely Art History’ recovers the role of fine art in 19th-century criminology. Kate obtained a research council funded DPhil from Green Templeton College and the Law Faculty here in Oxford, having previously obtained a research council funded MSc at Hertford as well as an LLB at the University of Edinburgh. Kate has been a Visiting Student at the Faculty of Law in the University of Copenhagen and was awarded a Visiting Fellowship at the Faculty of Law in the University of Melbourne.

In this lecture, Kate, a neurodivergent autistic and dyslexic student turned academic, will use the social model of disability to frame the different and myriad ways in which the neurotypical University disables students and academics. Borrowing the viral hash tag #WhyDisabledPeopleDropOut, created by Queer and Deaf activist Christine Marshall, Kate will draw on her own and others’ lived experience, to reflect on one of the neurotypical university’s most profound and still too common disabling effect: dropping out. Please join me in welcoming Kate West. Over to you, Kate.

DR KATE WEST:

Hi everyone, I am just checking that you can hear me.

Hi everyone, good evening, I am hoping you can hear me, I am guessing you can see me because my camera has started.

Great, fantastic that’s amazing, thank you.

I am certainly no expert at Zoom webinars, so you’ll have to bear with me while I participate in my first ever one. So I'm just going to start by sharing the slides and then I will get going with the talk. So bear with me while I share my screen. OK, so, now you should be able to see the power point. I am just going to put it into slideshow function. Talking aloud actually helps me go through these motions, so thanks for bearing with me. OK, so, current slide… Great, we can begin.

I would like to start with a content warning. I know that there will be many people watching this who may be nervous about what is going to come up in terms of if whether the content might be triggering for them, especially because it tackles a topic, a difficult topic for those of us who identify as disabled or who identify as having a disability. So broadly speaking, I am going to be speaking about disablism, I am also going to be speaking about what’s called and I will explain what this is in a moment when I get into the talk, because I’m aware there may be people in the audience who don’t know what this is, but I will be talking about the medical model of disability as well, and finally, I’m going to be talking about bullying and harassment. If I get onto those topics, I’ll try and flag them up, and if you want to mute your microphone or take some time out, then that’s fine.

Just in terms of how I’m going to present: I’m actually going to read the alt-text, the alternative text that visually describes what I’m showing in the slide, for unsighted or partially sighted audience members.

So I'm just going to start by really describing the first slide. And also just to manage your expectations – as an autistic person, I like to have my expectations managed – there are fourteen slides, so you can get a sense of how far we are along with the lecture.

OK. I'm just going to bring up the chat box so I can make sure I'm not just going off on a whim and somebody's trying to tell me something. I can find it… where is it.. OK, here we go.

OK, so Slide 1 of 14 is the title slide of the lecture. There's a backdrop of candy pink. It's overlaid with a blue triangle. It's offset to the right to leave a strip of pink running down the left-hand side from top to bottom. It reads, 'The University of Oxford Disability Lecture 2020', below which it reads my name, Dr Kate West, my job title, Senior Lecturer in Visual Criminology, and my place of employment, Oxford Brookes University.

For those of you who don't know, Oxford Brookes University is the other University in the city of Oxford. There are two universities here, so although I am a graduate of the older university, I am now a very proud faculty member at the newer University.

So the title of the lecture is '#WhyDisabledPeopleDropOut'. This sits at the top of the blue square, and under that, the subtitle reads 'A Neurodivergent Student-Turned-Academic'. Finally, the Oxford Brookes logo and the Oxford University logos are in the bottom right-hand corner.

Just a word about speaking to you as well: I haven't quite worked out whether I'm going to look at what I have thought to myself as theoretically a thousand eyes – so this camera that is looking at me. One thing about my being autistic, at least, is that my preference is not to look at people in the eye. Of course I've spent my life masking, of course, so I'll do it. I'll try.

I will expend some energy doing that for the neurotypicals, although I should really stop doing that!

OK, so to get going with the talk: moving onto the next slide, briefly describing it visually, it shows two images side-by-side, of two villages in Scotland's north-east coast: Sinine is on the left and Crovey is on the right. The north-facing gable ends of approximately thirty buildings in each village – they're roughly the same size – hug the harbours, while the south-gables face or are built into the cliffs and hillside.

I was 17 the first time I dropped out. I was about a third of the way through the equivalent of the second year of sixth form England and Wales and Northern Ireland, at a large low-performing co-educational state secondary school, five hours north-east of the border between England and Scotland. Its catchment was 33 miles long, along the north-facing Moray Firth coast, drawing a predominantly rural and industrial working class, fishing and faming working class, cohort into its student body. These villages are characteristic of the Moray Firth coast. They're historic Highland Clearance settlements, and they scatter the whole catchment of the school area that I'm from. The village on the right, Crovey, is near Gardenstown, which is where my family is from.

The third slide of 14: it shows two cover art works side by side. On the left is Robin Jenkins' The Cone Gatherers. It features a mid-twentieth century grenade with a military green body, silver fuse. On the right is Lewis Grassic Gibbon's Sunset Song. It features a yellow ochre sun at its centre. It's surrounded by wheat and thistles, and the landscape below is comprised of scorched brown hillside and a green and red field. A labourer can be seen working the plough behind their horse.

I dropped out when I was assigned Thomas Hardy's late 19th century novel The Mayor of Casterbridge. I'd of course been assigned novels throughout my secondary education, including the ones that I spoke about on the slide, but I'd never actually read a novel by the time I was 17. I didn't know it then, but I was dyslexic, attention deficit disordered and autistic.

Pre-Hardy, as I'll call that stage of my life, my go-around, my coping strategy, as neurotypicals call it, was to learn about assigned prose through consolidated teaching, the kind of special close teaching that was on offer in the earlier stages that pre-date the equivalent of A-levels in England. So I had kind of developed these coping strategies; and specifically, I'd learn, for example, the lesson about a discrete passage, so I could take it and apply it to different contexts. It's something I tell my students now. It's not necessarily the content that matters when I'm teaching you: it's the lesson that can be derived from the content, so that you can apply that lesson to other contexts.

So I was doing that throughout my schooling. So by then, I have developed what neurotypicals call, as I just said, coping mechanisms: but I like to think of these as formidably dynamic resistance strategies to neurotypical teaching and learning.

But resistance was futile, to use that social script that neurotypicals use: in the face of Hardy. By then I was in the equivalent of my A-level year; consolidated teaching has ended, and I could no longer camouflage by pretending I could read when I couldn't. Class sizes had diminished from 30 to 5, and I could no longer hide physically either. What did I do? I dropped out.

My being undiagnosed as a dyslexic, attention deficit disordered and autistic student met with my first-generation student status – first-generation meaning here that, with my two brothers, I was part of the first generation of my industrial working class family to go to university. First-generation students enter university for utilitarian, that is, kind of instrumental reasons. I entered university for a vocation, specifically to practise law, not for an education. I stumbled on the latter, thank goodness. I didn't ask my teachers for help then. I didn't ask them for help to read, because I didn't need an education, or so I thought.

A footnote here is that in Scottish secondary education, University entrants, can theoretically, like myself, hold unconditional offers to University at 17 years old, because we do our entrance exams for university before the A-level. So I was actually holding several unconditional offers to my universities of choice in Scotland, and England was never a consideration, of course: for those outside the UK, home students in Scotland, we don't pay tuition fees, so it would never have crossed my mind to study in England. In terms of this dropping out, I do know it then, but, …

(Just making sure you're still with me! It's quite strange doing this because you kind of feel like you might be speaking with yourself. I'm not speaking with myself… Yes, great, thank you, Lydia Townsend, thank you! OK, I'm going back in. That will be the last time I do it, I'm confident now!)

I didn't know it but this would be the first of two calendar year long intermissions during my undergraduate degree; possibly more than a handful of intermissions totalling three academic years during my doctoral degree, and finally post-student life, an almost intermission last year from my career. It was with each additional intermission, or dropout, and most of all that latter example, precisely because I had worked so hard to begin my academic career, that I started to feel quite strongly that this was continuing to happen.

And I stopped thinking at this point of my dropouts as personal failures, results of my impairments and my deficits, as the medical model of disability would tell me. And instead I saw them for what I truly think they are, namely the effect of structural disableism. In this lecture, then, I'm going to weave the ways in which what I call the neurotypical University, that is, a University not designed for neurodivergent students. When I say neurodivergent, historically at least, that has pertained to autists, but also now the paradigm or way of thinking has expanded to include dyslexia, dyspraxia, attention deficit disorder, Tourette's and so on. So it's a much broader way of thinking about neurological diversity now. So this is not a place that's designed for people like me and, I'm sure, many people who are watching. So I'm going to be, as I've said, weaving some of my lived experiences – sometimes anonymously, to protect mine and others' identities, through participant lived experiences, again sometimes anonymous, depending on what participants wished for.

OK, next slide. Slide 4 of 14, it features a title noting that in the UK, and just to note, this is a figure about home students, UK students in universities in the UK. 16.2% of students report disabilities. For a disability to be recorded it has to be reported in the first instance. Under the title, there is a table adapted from Hubble and Bolton 2020, which breaks down the types of disabilities that students in the UK report. Specific learning difficulty is highlighted in blue, because I am trying to highlight neurodivergent disabilities. And so is quote, 'social communication / autism spectrum disorder', close quote. You know, I say that in jest, but sometimes I am using the medical language, and some of us will find that quite oppressive, so I think it's important to highlight that I am using the language that's on the table: it might not be my own choice. So I'm just highlighting these.

So of that 16%, the slide describes how there are 5.2% of the 100% of the disabled student population in the UK, all levels, undergraduate through to PhD, doctoral level. 5.2% report a specific learning difficulty. And 0.6, quite a small percentage, report autistic spectrum disorder or ASD.

And I have highlighted in yellow as a point of interest, and that is just because, especially when it comes to neurodivergence, I am not just dyslexic for example, I am not just attention deficit disordered. The thing with neurodivergence is that often these disabilities are co-occurring. So for example, when I historically reported disability when I was a student, I would always tick two or more conditions, so I was not even being picked up into SpLD or into ASD, and certainly not ASD, because I am late diagnosed, so it was towards the end of my doctorate I discovered I was autistic, self-discovered before receiving a psychiatric diagnosis.

And the reason why I'm highlighting these figures is because disabled students overall fare worse in higher education, without even considering intersectional data. So thinking for example about class, for example we know that first-generation students are more likely to drop out etc. And race, and gender. Disabled students are less likely to enter university in the first instance, less likely to continue university, and more likely to drop out. Where they do continue they take longer to graduate. This is really important, because they will inevitably incur extra costs, and one of the areas of organising that I have been involved in is specifically organising around continuation fees that are being charged to disabled students. And I'm working with my own university and with my former Colleges in this regard. I am not going to speak about that in this talk, because I have spoken about it a lot elsewhere.

In terms of the data on academics, because, you know, part of this for me, as I said, is not just about the student experience. I thought once I graduated and I became an academic, everything would be fine, because I thought this experience was unique, naively, unique to being a disabled student. It's not. In fact, I found it more disabling to be an academic than a student in a neurotypical university. The data around disabled academics really is not readily available. So I am collecting it slowly, but some institutions I've got data back from, the numbers are so negligible and I think this says something about academics even reporting their disability in the first place., that they don't record the data. So, that is an issue in itself.

OK, let me just change the slide.

Slide 5 of 14 shows two cover artworks from two books. On the left is 'Disability Discourse', edited by Mairian Corker and Sally French. And on the right is 'Neurodiversity: the Birth of an Idea', by Judy Singer. So on the left, 'Disability Discourse is split kind of vertically from top to bottom into two colours, white and kind of like a neon green on the right. And the book by Judy Singer for me is really not very friendly for me as an autistic, anyway, it's that awful white with a high contrast, blue title, blue author's signature and so on, and there's a word cloud in the middle that says words such as 'neurodiversity, minority, inclusion, autistic, difference, diversity', and so on.

So the lecture is shaped by autistic sociologist Judy Singer's 1997 and 1998 neurodiversity way of thinking, or what academics would call 'paradigm', which (I think I've said that word about five times already, more to abuse!) as the name suggests celebrates the neurological diversity – quote, 'diversity', close quote – within our species, reframing autism in particular within the social model of disability that emerged in the UK in the 1960s and grew through the 70s. However, more than two decades now after Singer coined this ground-breaking term and concept, and it's done amazing work, I am now starting to be a little bit cautious about using the term itself. And this is a natural way that academic models develop, like they become sharper and more pointed as time progresses, and that is a good thing. So instead I tend not to use that word, because calling or describing someone, or something, an organisation like a university, for example, as 'neurodiverse' simply highlights neurological diversity without going as far as to highlight the character of the diversity. It is kind of amorphous, and nebulous, it is a bit of a kind of liberal surrogate, if you like, and kind of just sucks up all the difference. I'm not sure that makes sense, it does in my neurodivergent brain.

So this has allowed me instead to talk about neurotypical social structures: so two social groups, neurotypicals and neurodivergents. And that's really important to me, because it gives us the language – I'm not the first, lots of people, especially neurodivergent people, do this: we're all speaking in that language. I notice that it now seems to be neurotypical people who tend to use the word 'neurodiverse' as an adjective or noun. But I think it is important to have these two social groups emphasised, because it allows me for example to talk about a neurotypical University: a university, the structure of which is for neurotypicals, to the exclusion of neurodivergence. And importantly then, it's not about sneaking neurodivergents in through the back door in the neurotypical university because the social structure remains the same; it’s about dismantling the structures, to use a metaphor, don’t want to get too radical and pull the universities down, dismantling the neurotypical structures that perpetuate disabling neurodivergent students and academics.

OK. Moving on, slide 6 of 14... (I am just going to check my time. We’re good, back in.) Slide 6 of 14 shows a screenshot of a tweet by Chrissy, rainbow emoji, clapperboard emoji, purple heart emoji. With the Twitter handle @EssentialSign_. The tweet has 439 retweets and 970 likes. I’m going to read out what the tweet says when I talk through the slide, so I won't read out the visual detail of the slide. And also I’d like to say I’m a sighted person, so this is new to me, so if there are things you want to call me in or out on, I really welcome that if I'm doing something wrong.

So the hashtag #WhyDisabledPeopleDropOut was created by Chrissy Marshall, a Deaf activist and student. In Marshall’s words, and this is what the tweet says, ‘#WhyDisabledPeopleDropOut was created to expose the frustration and challenges disabled students face daily in public institutions.’ They continue, ‘Becoming exhausted from advocating for yourself is valid af’ (I know there are children in the audience, so I will leave it at that) ‘and the educational system wasn't developed for disabled people to succeed’. So you can see here that again what Marshall is speaking about is that social model of disability, where the educational system is disabling people. So, if you are not familiar with Chrissy's work I would check it out, it is really important. They have actually gone viral on TikTok for an amazing TikTok video about deafness and access, and actually, and that video got 5.5 million views. It is to do with the #WhyDisabledPeopleDropOut hashtag as well.

So notice the language that Marshall uses, they use the word ‘disabled’ as a prefix for people and students as opposed to people or students ‘with disabilities’. This is how I and many others choose to identify. I am disabled because society disables me, and not because the medical model of disability tells me that I am somehow lacking, that I am impaired and that consequently I am in need of treatment. Relatedly then, it has allowed disabled people to share how outside factors nothing to do with themselves, outside factors beyond their control are excluding them, with the effect that they drop out.

Slide 7 of 14 is a screenshot of a tweet. The author is Ellen Fraser Barbour. Thank you, Ellen, for participating and letting me share your tweet. Twitter handle is @ellenffb. It reads: ‘#WhyDisabledPeopleDropOut. What people don’t get is that for many of us with disability, it is not one experience leading to dropout: there’s a whole accumulation of internalised comments, belittling, low expectation, and discriminatory behaviour in education which goes way back’. The tweet has 21 retweets and 60 likes. The hundreds of tweets and sub-tweets to Marshall's viral hashtag by both students and academics illustrate the numerous and myriad reasons why disabled students and academics drop out. As PhD candidate who authored the tweet, PhD candidate Ellen Fraser Barbour highlights in her use of the hashtag, these are experienced simultaneously and cumulatively over long periods of time. And it is, as she puts it, accumulation of internalised comments, and I’ve just read that, the ‘belittling, low expectation, discriminatory behaviour in education which goes way back’. And you can see that that makes, moves me quite a lot.it will resonate with a lot of this audience, I am sure, and really since we were children, of course.

OK. Others have spoken about how disabled academics, as teachers and colleagues, doubt their students and colleagues being disabled on some occasions. One student said they felt their neurodivergence was in question when their professor continually asked them ‘Why do you frame your experience through your dyslexia, autism etc.?’ – as though they could, to use the extremely online cultural idiom, cancel themselves. On other occasions the same student said that the same professor felt that the neurodivergent student was too autistic or too dyslexic to even continue in their programme, and suggested they drop out themselves. When I asked that student how they fared in the end, they graduated almost at the very top of a cohort that was over 200 people strong. ‘Low expectation’, as Ellen Fraser Barbour said, indeed.

OK, slide 8 of 14 is a grey scale but for a blue scroll and those kinds of ‘Help’ points you can click on at various points. It is a greyscale image of a piece of legislation familiar to many of us, the Equality Act, a section familiar to many of us, Section 20, The Duty to Make Adjustments. I’ve highlighted that in yellow just to draw attention to it. The Government crest is on the top left-hand corner and the National Archives logo is in the top right.

When it comes to why we neurodivergent people drop out of the neurotypical University, I want to focus on one reason, time constraints but also, this gets to the heart of something I am trying to develop for my eventual book, as I call it. I want to focus on one reason. I always tell my students to avoid hyperbolic language, but I am going to excuse myself on this occasion, because I think it reflects the empirical reality qute well: what I call the vast chasm between the section 20 duty for HEIs, that is, Higher Education Institutions, and Government funders working in partnership to make adjustments for their disabled students, and academics in their employment under the Equality Act 2010. So this gap between that and what is happening on the ground to be a little bit sharper and more blunt about it, I want to talk about the failure of public sector organisations to implement the duty. It is mandated by law.

This next slide I am aware it might be distressing, actually I will take it off for a second. The next slide might be distressing for people, it might give you sensory overload. So just to let you know that is coming up if you want to dim the screen etc., just you can hear my voice. But it is kinda designed that way on purpose to demonstrate what new words look like to me when I am reading as a dyslexic reader. So I'm just going to put that screen back up on the screen now.

Slide 9 of 14 It is a series of dyslexic misspellings of the word ‘anachronism’. And I've included – these are my own dyslexic misspellings, by the way. I’ve included them left to right, and they kind of cover the whole page; it kind of makes it look like it’s endless and ongoing. Students have to provide evidence of their neurodivergence in order to access reasonable adjustments, a problem in itself. This is another theme in the wider #WhyDoDisabledPeopleDropOut hashtag. First, students have to at least suspect that they are neurodivergent.

‘Is the death penalty an anachronism?’ – change of tack! This was the question that was the precursor to my dyslexia diagnosis, and also the precursor to the suggestion that I was attention deficit disordered, and also that I might need to get checked out for sensory processing disorder and Irlen Syndrome. Anyway, so it kind of started the journey. I was a law student, so this was the question that was being posed to us. ‘Anachronism’ appeared to me as you see it here on the screen, in this now digitally on-trend and thereby comforting single-spaced formation. When I read a new word and when I read that new word, I sucked up each letter with my eyes, left to right; as right to left, they would dissolve into nothingness.

Below my first-class mark there was an observation about how frequently ‘anachronism’ appeared and that I had spelt it differently and incorrectly every time, complete with a randomised flourish of capital and lower case A. I now know that my doing so, and I do it in my scholarship now, before I do what I call ‘neurotypical proof’ my writing, and kind of fix it for the neurotypicals, is a kind of dyslexic verbal stimming. ‘Stimming’ is a shortened word to describe stimulatory behaviour that I do as an autist. Many autistic people self-regulate through stimming, maybe it is through playing with your hair, it can be anything like biting your nails, it can be doing this. Stimming is great, I encourage it. And actually since I obtained my psychiatric diagnosis, I am an unapologetic stimmer, especially in public, so watch out! So I understood that I was kind of repeating and writing this word, almost to kind of to try and capture it, to make it comforting to me, so I could feel comfortable because I’d never seen it before. And actually, this happened to me recently, just a couple of weeks ago, when a new book arrived in the post for someone I’m living with. And they opened the book and I looked at it, and I read it, and I looked at the word and I was like... ‘Ira, Ira, Ira, Irad, Iradated, Irrigated, Irrer, Irrer...’. Eventually I went through the house (as is a Scottish colloquialism which means ‘into the next room’), and I asked my brother ‘What does the word say?’ ‘Irradiated.’ ‘Ah, irradiated!’ So for the rest of the day, and even in the coming weeks, I would just occasionally , I would be like, ‘Irradiated’; I would just say because it was kind of soothing to do that.

OK. Next slide, we are 10 of 14. (I’m just going to check the time and come out for a moment. OK, I'm going to speak just until, just before 7 o'clock. I was told 45 minutes, but I was anticipating starting at quarter past, so we can push that a bit. I am just going to go back into the slides, current. Excuse the beeping outside there seems to be some building, of course.)

Slide 10 of 14 shows a computer-generated aerial view of the University of Edinburgh’s Old College. A North South East and West Wing hermetically sealed, which means kind of sealed all the way around a quadrangle, which is kind of like a square space for those who are not familiar with quadrangles. I mean, I wasn’t familiar with quadrangles until I arrived Oxford, even though I’d been to a university with a quadrangle, I didn’t know it was called that. There’s a quadrangle. It’s green with grass, as is tradition, I am led to believe, but there’s a lot of concrete around it.

This is the Law School of the University of Edinburgh, where I did my undergraduate degree in Law. For those outside of the UK, and especially those in North America, some of you may not know, but you can study vocational degrees such as medicine and law as an undergraduate degree. Different subject about whether that is good or bad, so I shall not digress into that.

So, although, this eventually, my teacher highlighting this, eventually led to my dyslexia diagnosis. And I actually conveyed ease with which I got that diagnosis, there are so many routes that rely on a lot of self-advocacy, a lot of, a good executive function. When I say ‘executive function’, I mean organising, processing, memory, all the things that neurodivergent people struggle with to obtain that diagnosis. So I don’t want to actually undermine how difficult that was. And the theme of the hashtag is that obtaining, jumping through those hoops was another reason why people dropped out: getting the diagnosis was too hard, and in my position as a teacher I have certainly witnessed that in the short time I have been an academic and it is heartbreaking.

So here is a reason #WhyDisabledPeopleDropOut: trauma. I have a vivid memory of when my essay was returned to me in class. Like many autists I am constantly aware of my body in space, I am always constantly reflecting on proprioceptive – I hadn't heard that word until I was diagnosed – proprioceptive relationship. Kind of the relationship of my body to this chair, to this wall, to touch, to feel, for example. So my body in space is important to me and I was conscious of that from a young age, long before I was diagnosed; and always people have always noticed it, my family of course.

So I remember my body in space. When I think about my body in space, even day-to-day, when during lockdown and I have been going for walks in woodland. I am always thinking of myself in space aerially, that is from the sky. I guess we kind of compare it to Google Earth, that is the way I visualise my body in space, generally. And that is how I remember this experience at the University of Edinburgh. I was sat in the east wing of the University of Edinburgh's Old College, where that the yellow square… (To describe the slide, I don't think I did that, in the north west side of the quad there is a yellow square and about... three floors up, one floor down was where the classroom was. And I sat in that classroom with my back to the north wall of the college, I was sat in the north east corner of a boardroom style setup classroom. So that is a classroom where the tables are kind of set up, like around in a boardroom, I suppose. It's the best way I can describe it, I'm afraid.)

I remember the trauma in that space and the difficulty I had returning to class. I held it in my body. In her 2014 post about being a dyslexic early career academic, and thank you so much to the historian and lecturer Lucinda Matthews Jones, who has allowed me to share her experience, how she was traumatised for two years when a reviewer questioned her mis-capitalisation of C in church.

Next slide: Slide 11 0f 14 shows a screenshot of AQ-10, or Autism Spectrum… I can't say this word, I'm not going to try, quote, quotie, quotient [middle t pronounced as 't']. This'll be my stim for the next few weeks, 'quotient' [standard pronunciation], that sounds good!

Under the title there's a sentence explaining that it's 'a quick referral guide for adults with suspected autism who do not have a learning disability'. Autism can co-occur with learning disability, which is why that sentence is included in there. Below the title, there are ten statements, adjacent to which are the options to go definitely agree, slightly agree, slightly disagree and definitely disagree. Below this is an explanation for how to score the test, how to generate the score, and at what score a referral should be made.

Access, or lack thereof, to self- and/or psychiatric diagnosis is frequently cited under the #WhyDisabledPeopleDropOut hashtag. Many will never be diagnosed, especially when considering, for example, how class, race, gender intersect in social capital. In fact the hashtag #AutismTooWhite was created by Timothy S. Gordon, Jr, to highlight how structural racism operates to exclude people of colour, and especially Black people, from self-, let alone psychiatric, diagnosis for autism. Gender matters too: take the Autism Spectrum – Thing – or AQ-10 Test, the diagnostic screening tool for autism. Look at Question 8. I've highlighted this question in yellow, apologies for not mentioning that in the visual descriptor of the slide. It says that you have to, definitely, slightly, agree, or slightly, definitely disagree with Question 8 (it's not a question, by the way): 'I like to collect information about categories of things. Types of car, types of bird, types of train, types of plant etc.'. Car, bird, train, plant... So these are [known] infamously, at least I think by now, in the autistic community as being gendered. And actually, there is a lot of research being generated into the late diagnosis of women autists for the way in which diagnostic criteria are tailored to men.

I'm a cisgender woman, that's how I identify. But my systems of knowledge – and I have lots of special interests – and I like to know how things are, why things are typologised in the way they are, right? And actually, my system interests don't align with my gender identity, but this is all contextual, it's totally contextual, so there are many, for example, cis women autists who I know who have a lot of systems knowledge about for example cosmetics. I also by the way have a lot of systems knowledge about shampoo, conditioner ingredients etc.: don't really care about shampoo and conditioner, I just want to understand the way in which ingredients manifest, the way you do. I can imagine people are really like "Wow! OK." And it is contextual. I spent a lot of time driving in the car from the north-east of Scotland to the south-west of England, to visit my mother's parents, my grandparents: they're English. The journey took fourteen hours without breaks, and so I'd a lot of time to get interested in the systems underpinning vehicles, and especially heavy haulage vehicles, which I'm still fascinated by. Equally because my dad, my grandad, my great-grandfather were trawlermen, as children we spent a lot of time in industrial fishing ports. This is Fraserburgh Harbour; in the slide, sorry, there's also an image of Fraserburgh Harbour in the north of Scotland. There are two trawling boats in the harbour; one is a kind of turquoise blue and the other is a kind of more royal blue. The boat registrations are FR285, standing for Fraserburgh 285, and BF27, Banff 27. And this is the harbour, the port that my dad fished from, and as a child I have vivid memories of going to this port at the weekend, when the boats came in on a Friday, and left again, early, sometimes on a Sunday night, early on a Monday morning, and generally being from a fishing community and having a dad who's a trawlerman, and your whole family being involved in fishing, you get to know a lot about fishing boats. So I have these quite gendered, actually, systems of knowledge.

The point is though, access to psychiatric diagnosis is key to keep neurodivergent students in education. So long as this barrier remains in place, and I don't think it should, let's be clear, normatively, meaning ideally speaking, self-diagnosis ought to be valid for the reasons that that I've mentioned. Privilege plays in to diagnosis, right, and we need to start recognising that. And it's required, because this is the requirement to access reasonable adjustments.

(Just coming out to check the time, OK, I've got five minutes, which is perfect.)

Slide 12 of 14 is a screenshot of Manchester University, a university in England, by the way, for those overseas. StaffNet pages, and specifically the Disability Advisory Support Service Staff Service. The colourways are the University of Manchester's colours, which are purple on a grey scale, a darker grey and a lighter grey in turn from the bottom up. On that page – and I wonder if there are other disabled academics here looking at this, well, and if they're not at Manchester, who think 'Wow, this is quite something'. When I became an academic I just assumed that there would be a disabled staff service. To my discovery, that's actually an exceptional thing in the UK. Whereas for students, it's very kind of standard to have a disability service for students, it doesn't exist for staff. Curiously, as an academic I have never need to show my diagnosis. So it's different for academics about this evidence of psychiatric diagnoses to anyone. I have never had to show them, which is kind of baffling as I went through my student days having to show them, and I'm sure everyone feels the repeated trauma of being asked to disclose the documents you see from psychiatric diagnosis for various things. And for various reasons. You think, why is once not enough? Why do I have to keep proving to you that I am disabled, and in my case neurodivergent? So I didn't have to do that as a academic. Including – and this is the thing that baffles me most – the Department of Work and Pensions, which is a branch of government and they provides state social support, whose Access to Work scheme fills the space of Disabled Students Allowance in the UK. Of course, I don't know if this is an exception, since disability provision for employees as opposed to students is so ad hoc in my experience in the Higher Education sector, there simply is not enough information out there what the standard procedures ought to be. I only have my own experience in this regard. I would be interested to know what others are experiencing. Notwithstanding their privilege as professionals and PhD holders, disability provision in my experience is much worse for academics than it is for students. It's almost as if – and I think there is also a hierarchy, even within student experience, from undergraduate and when you get to PhD, the provision in my experience at PhD for disabled students – it was bad. And again, a sector-wide issue, and I was quite shocked by that. And then once I became an academic it became even worse. It is almost as if there's this idea that if you progress through [inaudible], you can't be disabled. The further you get you're less likely to be disabled and therefore you don't need the services and more. It's completely baffling.

So for example, very few Higher Education institutions have a dedicated Staff Disability service, whereas this is standard for students. I should say Oxford has one as well, the old University. So In my and many of my disabled colleagues' view, occupational health is not fit for our purposes because it is premised on the medical model of disability, and there's not enough knowledge about the social model. One academic told me that their occupational health advisor laughed at them, and thought they were joking when they requested reasonable adjustments for Specific Learning Difficulties and Autism in relation to their communications: so asking for neurotypical or nondisabled colleagues to communicate with them in a way that was more accessible. They were left, then, to rely on the good will of a line manager who did implement the change. And others spoke of changes as well, academics, that they did not request that would have disabled them even further had nothing been done at all. This is about listening to what we ask for, right?

Final slide. Slide 13 of 14: The title page of Volume 1 of Thomas Hardy's 1886 'The Mayor Of Casterbridge: the Life and Death of a Man of Character', as its full title is and was. The author's name sits below the title, together with a list of his previous works, including 'Far from the Madding Crowd', and 'A Pair of Blue Eyes' etc. The publisher Smith Elder and Cole sits at the bottom of the page. And I want to finish up now, starting where I began, with Hardy. I will move on to him in a moment. There's also a quotation on this slide, which I will read out in a moment.

The neurotypical University is designed for neurotypical people. The neurotypical University operates from the premise that we keep structures in place that support naturally neurotypical people, meaning that neurodivergent people have to ask for adjustments when we are let in through the back door. One of the things I have been thinking about, in my role as a teacher and educator, is the way in which written assessment remains the kind of medium par excellence which we ask students to undertake. Take dyslexic students for example. And this is something very personal for me being a scholar and writing my first book at the moment, and writing this book about neurodivergence in the Academy. I'm not writing that book by the way because I have got reasonable adjustments to record it, and someone's going to transcribe the manuscript, which is great. But I'm slightly confused that, for example, that we ask dyslexic, dyspraxic and ADHD students, especially, to complete written assignments. It's almost like 'extra time', which is not extra time at all. It just gives them a bit more time to allow them to get somewhere close to their non-dyslexic et cetera counterparts. So it is not even, I think, that they get anywhere close. We are still asking them to cancel themselves, to not do what they are actually naturally capable of. And that really disturbs me.

The issue with retaining neurotypical structures is that reasonable adjustments become individualised, and that's important to the extent that, of course, not all disabled people are the same. Not all neurodivergent people are the same. Not all autistic people are the same. Not all autistic people are the same. I will repeat that! We are a 'diverse' bunch. And I think retaining these structures and requiring structures to be individualised is good because we're unique. But equally, it places a huge burden on us, and in my view there has to be a larger structural shift to accommodate us, to move towards an academy that is truly neurodivergent, or some semblance thereof, at least would be a start.

I want to end where I began, with Thomas Hardy. Hardy, which is cited in the Penguin edition of his work, the 1985 edition, in the introduction by Seymour Smith, Seymour Smith says, 'The business of the poet and novelist is to show the sorriness underlying the grandest things, and the grandeur underlying the sorriest things'.

The sorriness underlying the grandest things for me are those neurotypical structures that prop up the University, especially these elite places of grandeur. We look to activist work, not just in the area of disability, thinking intersectionally with race, gender, class and other social struggles. These are grand places, but there is a sorriness to them that quickly needs to be addressed. And belatedly, the grandeur underlying the sorriest things meanwhile, is that of neurodivergent students, academics and people everywhere.

DR CATHERINE WALTER

Thank you very much Kate, you have given us a lot of food for thought here.

I have some questions for the audience, so if you do not mind taking those?

The first question is: As an autistic professor, how do you deal with everything you say or do being interpreted through the lens of disability? Our skills become personalised.

KATE WEST: Thank you Catherine and thank you to whoever asked that question.

I am just going to read it, short-term memory, dyslexic. I am just going to let it sit in my brain again.

Catherine would you mind rereading it for me.

DR CATHERINE WALTER: As an autistic professor, how do you deal with everything you say or do being interpreted through the lens of disability? Our skills become personalised.

DR KATE WEST: I understand. I think there are two answers to my interpretation of that question.

If people, if my audience, whether it's my organisation, whether it's my employer, whether it's my friends, family, the audience here today, view me through that lens of the social model of disability, then I'm with them. They understand, and that's important for me, you know I self-identify as disabled. Disabled is not a problematic word to me, it is something to be celebrated, and I understand in the community that is somewhat controversial and there are other views on that.

If people are viewing me or interacting with me thinking about the medical paradigm or way of thinking about disability, and they see my being dyslexic, autistic, attention deficit disordered, being at the same time, of course, because of the disabling nature of neurotypical society and disabling society, often our disabilities co-occur with mental health conditions as well. So I am diagnosed OCD as well, you know, chuck them all in there. I am diagnosed with generalised anxiety disorder. And it's funny, if people see me in that deficit model, then that is when it becomes personal. I have to say, my students are just, they are just wonderful. Students are always wonderful and I am very lucky to have such a wonderful team Oxford Brookes. My head of Department, Joanne Begiato, has been extremely supportive, as has Brian Rivers, if he's watching. Other people who have made a difference, my team in Criminology is just perfect. I am very lucky in that regard. And I am safe, which is important. I have privilege to be safe, I think.

DR CATHERINE WALTER: The next question I'm going to summarise, because it is quite long. It is from someone who was badly treated at one university and indeed bullied, and who later went to another university – I'll say it, it's Oxford – where they're doing an MSc in teacher education and has had to recover from the emotional turmoil of late diagnosis. How long did it take you to recalculate your late diagnosis in a positive way?

DR KATE WEST:

That is a really just fantastic question, it's a really moving question I think as well. There absolutely is trauma in that process. I think other late diagnosed people will agree. Because there absolutely is trauma in that process, and I think other late-diagnosed people will agree that in that process there is first the period of surprise if you self-discover, which is often the case, and then even if you self-discover: I self-discovered during my doctorate and I ignored it. I'm avoidant because I'm autistic, that's one of my character profiles and I had a really difficult time during the doctorate, not intellectually ever, by the way. I've never had difficulty intellectually, it's always with the structures and things in place etc. There was a difference for me between, there was a gap between self-discovery and then... I can't remember the scholar who's called it this, but self-acceptance. So we can be self-diagnosed and even psychiatric diagnosed but we might not self-accept. And acceptance for me is still an ongoing journey, definitely. Especially because I only discovered autism a few years ago, and I never told anyone: I was a secret autist, apart from another late-diagnosed autistic cis woman, and late-diagnosed non-binary person, we all sort of self-discovered around the same time, actually. We all knew about each other, but we did not tell anyone else. So, for me it is very new, and I imagine it will take me a bit longer time, but at the same time, I think it is important to stress, how good it feels to be diagnosed when you spend the lifetime feeling lonely. I feel so less lonely; it's amazing. You know, I have hope for the future, but solidarity with the people who are still on that journey. I guess I'm there with you.

DR CATHERINE WALTER:

Again, I expect you would prefer me to summarise long questions.

This is a question from someone who is concerned about the fact that in universities, while attention is paid to the issues we have been talking about, it is rare that people, that neurodivergent people are in the places where they can help actually make the decisions: so that the principle of 'Nothing about us without us' does not get played out.

DR KATE WEST:

That is a really important point. Thank you for making that point, whoever asked it, really great point. And I agree, and It is also why I tend to not use neurodiversity language because I think it is important for me to keep the distinction between a social group that is neurodivergent and a group that is neurotypical. Because we are not there yet, so we need to highlight and stress the differences. I think... In my experience it has been very difficult working with neurotypical people. And you know, all minoritised and marginalised and multiply-marginalised people will say this. I carry a lot of privilege in my whiteness, I am socially mobile, so I just feel a fraction of this, right. I am a cis woman etc. I do not have to navigate some of those other difficulties and it is still so difficult to work with neurotypical people. I think I said... Neurodivergent people, we need them in our institutions and we need them to have platforms, we need them to be present, we need them to present, we need them to be listened to, we need them to not be constructed as problems. I think that is the most important thing. And absolutely, that hashtag #NothingAboutUsWithoutUs is so important, especially with people in the audience who are much more well versed in autism, and the problems around the way that the autism discourse has played out historically.

DR CATHERINE WALTER:

Here's another one: 'I'm curious about the comment you made about neurotypicalsing at your writing, I was wondering if you could expand on this, and I am also wondering what neurodivergent writing might look like in the Academy'.

19:10:18 DR KATE WEST:

I love that question! It's so good! All these questions are great, but this one is really close to my heart. Because it was the impetus and the thing that started me on this journey, was that when I became a so-called professional scholar and I was confronted with turning my PhD into a book, and I thought, you know, oh God, I wrote that thing, and now I have to make it into a book, and I thought, I really consciously thought, I am never doing that again, I will not allow people to make me do that again. I will publish books. If you want the book, an object, I will make it, but I am not going to write it in the way you want me to write it. The first one, yes, because I'm an early career scholar, I need to establish a profile, I guess that isn't particularly resistance motivated, but I will let off the hook for that one. I have a plug, I am still slightly culturally Presbyterian in my ways, so I shamefully plug the web platform I have, which is called DyslexicAcademic.com, and in there I talk about neurotypical writing, especially how it follows this linear pattern. It's actually something that the theologian Dan Holloway as spoken about more than me, and who actually drew my attention to it, when they actually talked about how this linear form of prose has a history in the early modern period in particular and it endures today in 2020 oddly.

What does neurodivergent writing look like? It looks like a kind of practice, at least from my perspective, that is far more typical in the arts, for example, poetry, drama, which has always been accessible literary form to me. I said that at 17 I had never read a novel, but I had read so much drama, so much poetry, and consumed so much art, music etc. But linear prose, for me is not helpful. Yes, check out that website, and check out – there are a couple of posts that kind of explain maybe what a neurodivergent literary form could look like.

DR CATHERINE WALTER:

Lovely. OK, there are lots of good questions here. Here's a good one: 'What are your top five tips for creating a more inclusive teaching environment where individual adjustments for neurodivergent students are not needed?'

DR KATE WEST:

Brilliant question. People are great, people ask great questions!

This is something I think about all the time. I love my job as a teacher, I love my job as a scholar too, but teaching is something I absolutely adore, and it's something I think about all the time. For me as an autist and with sensory processing disorder, lighting has been one of the biggest things for me. And even if you don't have SPD, you may have Irlen Syndrome, and bright lighting… I try and dim the lights as much as possible, work with natural light, my students are extremely tolerant – tolerand isn't the word: they are so generous, they really understand that that is a productive learning space. Light low and off, natural light is really important, so that people are not compelled to disclose and ask, or even come out to their teacher, which is a very unsafe thing to do.

Number 2: For me changing for... Giving students an option how they are assessed. If they were to complete written assignments that are linear prose and that is fine, but if they want to do alternative – I hesitate to call them alternative, different kinds of assessment, then I encourage that as well. And I've actually taken my cue here from Lucy Matthews Jones, at Liverpool John Moores University, who really writes some great stuff on pedagogy dyslexia, dyspraxia etc. Number 2.

Number 3: For me, the classroom is a space where I would never expect someone to speak. I never call on students, I want students to have the time to think about the questions that I might pose. If they want is a question then I develop mechanisms for doing that, I used to pass a kind of tombola box around the room, so people could kind of anonymously pose questions and we kind of do it like this, back and forth.

I do a lot of movement in the classroom as well. (I think this might be 4, maybe 5 – I'm not very numerate!) I do a lot of movement in the classroom, especially with first years. Of course, I suppose that presents its own problems for access if people are unable to move, so I'm mindful of that as well.

I guess in sum, I'm trying to think about access all the time for neurodivergents, because the classroom was such an unhappy place for me as a student in 2010 through 2016.

DR CATHERINE WALTER:

There are several other very good questions, but I'm afraid that we've got to the end of our question time. I'd now like to call on Tiri Hughes, who is the Co-Chair of the Oxford University student Disability Campaign, to give the vote of thanks. Tiri?

TIRI HUGHES:

Hi, can everyone hear me. Yeah. Zooming is very much a new thing for everyone. Also, an ambulance just went past, so I'm hoping that will me there is a gap for a while. So, I am Tiri Hughes. I am Chair of the Oxford Student Union Disability Campaign, which we abbreviate to DisCam, and I'm also a medical student at Trinity College Oxford, coming to the end of my second year, and I'm here to give the vote of thanks.

Firstly I would like to thank the Vice Chancellor, Professor Louise Richardson, for giving the introduction. And I would like to thank everyone at the Oxford Disability Group for ensuring that this year's Disability Lecture actually happened, despite all of the current adverse circumstances, and also for making sure that accessibility remained a priority throughout, despite all of the changes compared to how the lectures normally run.

And now, I want to say thanks to Dr Kate West for her incredible lecture. Personally, I identify with so many of the things that Kate has discussed. Despite my not identifying as neurodivergent, I do identify as disabled, having both visual and physical impairments as well as obsessive-compulsive disorder. And there is certainly a lot of crossover in terms of experiences and adjustments required, as well as clear differences across [inaudible] different disabilities. Sometimes these can even be contradictory. I'm acutely aware, after that conversation about lighting, that my lighting requirements as a visually impaired person may be very different to those of a person with sensory processing disorder, but that doesn't concern me: I just find it a really interesting thing, to see how would we adjust for that in a learning environment? That is something I would love to try and see how that works.

The activist in me could easily talk about the topics discussed all day, especially things like the importance of phrases like #NothingAboutUsWithoutUs and #DisabledIsNotABadWord. But now isn't the time to talk about those – although we do have DisCam badges with various quotes on that I just found as they were being discussed. They might be inverted, but I thought I would… I am just showing badges, they are pale blue with a DisCam logo, and we have one that says 'Nothing about us without us', one that says 'Disabled is not a bad word'. We also have 'The future is accessible', and 'Disability looks like this', with an upwards arrow, and we like to give them out at Freshers' Fairs and things.

So instead of me ranting on, as the activist in me wants to, I will briefly explain why having lectures like this and academics like Kate is so important to disabled students. I know that there have been many times in my schooling where only a few more instances of disablism would have pushed me to drop out of school. Never mind University, this actually started when I was about 11 years old and it culminated in a disability tribunal by the time I was 15. In fact, the only way I could do my A-levels was by leaving my discriminatory state secondary school and attending a specialist college for visually impaired people, which, although it was a brilliant experience, was only necessary due to the failure of mainstream education to provide basic adaptations.

The word inspirational is so often misused around disabled people, usually by non-disabled people who mean 'I am surprised that you can do that normal activity because I am ignorant of how disabled people function'. For example when someone tells me I'm inspirational for getting on a bus with my guide dog, and they ask me how I know how to get on a bus, like I don't do it every day.

But I hope Kate will allow me to say, as a fellow disabled person and being able to identify with many experiences she discussed, that I've found this lecture inspirational, and I know many disabled students who watch this, especially those who have hopes to enter further academia, will be similarly inspired.

And as a visually impaired person I would like to additionally thank Kate for her consideration in describing the visual aspects of the site in such detail.

Finally I would like to thank all of the attendees who signed up to this webinar lecture, as well as those who have decided to access it later by the podcast.

Thank you.

DR CATHERINE WALTER:

Thank you very much, and we are sorry about the technical glitches, we will be processing the podcast; it will be out early next week.

We will send out again the link on all our media.

Thank you all for coming, many, many, many thanks to Kate. It's been a wonderful experience, and goodbye everyone.