

**Dr Hamied Haroon:**

***On the intersections of disability, science and academia***

*[All views expressed in this lecture are the speaker's own.]*

**SARAH STEPHENSON-HUNTER:**

Good evening, and welcome to this year's annual Disability Lecture. I still haven't worked out what's more nerve-wracking, doing these lectures in person or doing them virtually. But I think none of us would have imagined a year ago that we would be back here online on Zoom. Hopefully, hopefully, fingers and toes crossed, by next year we can all get together meeting in person again, although obviously we have appreciated the fact that online events do also increase accessibility.

And so we are really pleased that you are here with us this evening. In a moment, I will hand over to our Vice Chancellor, who will introduce our speaker, and then after that, we will have our lecture by Dr Hamied Haroon. We are then going to have a 5-minute break before we get on to the question and answer sessions, and we will finish by 7:30.

Just a few housekeeping announcements before we do begin. We are recording this session this evening, and there will be recordings available. You will all get an email in a week or so telling you where to get that, so you can either watch again, or share it with colleagues or friends who couldn't make it.

This obviously is a Zoom webinar, and so you won't be able to use your cameras or to physically speak in the session, but you can use the chat function to send comments or messages to participants or attendees, or both. If you select the appropriate option in the chat box, then that will happen. If for any reason you have an issue with Zoom during this, if you'd like to raise your hand, then one of our moderators will do their best to assist you.

Also, we do have captioning available for this lecture this evening. It's being provided by 121 Captioning. If you need to find that and you haven't done that already, if you go to the Zoom menu, and select closed captioning, then that should come up with the transcript. Also, as I said, we'll have a question and answer session, so if you would like to put a question either whilst our speaker is speaking or obviously at the end, then you can put that in the question and answer box. Your questions will come up anonymous, and they will be moderated by our moderators, but we will know obviously who they're from.

And finally, our speaker will be describing the slides as he goes through, so for those of you like myself with a visual impairment, that should enable access. If there is any other access issue we haven't covered, please do contact the moderators during the session.

That's all for the housekeeping, so I'll now hand over to our Vice Chancellor, Professor Louise Richardson, who will introduce the speaker. Vice Chancellor, over to you.

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

Thank you very much, Sarah, and good evening everyone. It's such a pleasure to see in the chat so many people tuning in from, it looks like, all over the world: I've seen Nova Scotia and all parts of the UK. As Sarah said, it is a bit of a downer that we have to meet remotely, but the upside is, more people can tune in, so I'm absolutely delighted that so many are doing so.

This is the seventh annual University of Oxford Disability Lecture. And we're coming to you from a very soggy Oxford – hard to believe it is May, it's the wettest May on record, and there's torrential rain outside my window as I speak. Never the less we are absolutely delighted to be here.

So this lecture is organised by the Equality and Diversity Unit, and the Staff Disability Advisory Group. These annual lectures bring together disabled and non-disabled colleagues and students to reflect on how we can advance equality for all our staff and students at the University. Tonight we're delighted that Dr Hamied Haroon from the University of Manchester will speak to us about the intersection of disability, science, and academia. Dr Haroon is a Postdoctoral Research Associate based in the University of Manchester's Department of Neuroscience and Experimental Psychology. His research focuses on using novel and advanced biomedical magnetic resonance scanning, as well as analysis, to study how the human body, especially the brain, works in health; and to look at what changes with ageing, disease, and with treatment.

As a disabled scientist, Dr Haroon became interested in the support available to disabled academics in his own institution and beyond. In 2013 he hit upon the idea of a nationwide super-network of higher education disabled staff networks, to share experiences and to share good practice, as well as to arrange activities and events. With help from colleagues and elsewhere, the result in 2014 was the founding of the National Association of Disabled Staff Networks, NADSN, with Dr Haroon as its chair. Dr Haroon has driven the development of the NADSN as a collective platform for information, communication, and the exploration of challenges and opportunities. With a mailing list, members' forum, a resource bank, and a range of events, the NADSN supports disabled staff and their networks all across higher education. It has partnered with researchers, developed position papers, and contributed to government consultations, exploring issues around disability, and its intersection with other marginalised identities. Tonight Dr Haroon is going to talk to us about the ups and downs of his own life as a disabled scientist and academic, and about the lessons that the work of NADSN has to offer. Please join me in welcoming him. I look forward to his contribution to our thinking, so that we can learn more about how we address the issues posed to our disabled staff and students, for the enrichment of the entire community. So thank you for joining us, Hamied, over to you.

[Note from the organisers: All views expressed in this lecture are the lecturer's own.]

**DR HAMIED HAROON:**

Thank you, very much Professor Richardson. So, Vice Chancellor, friends and colleagues, a very very good evening to you all. I really can't express how honoured I am to be presenting

the annual Disability Lecture at the University of Oxford of all places, the setting of 'His Dark Materials', and scholastic sanctuary. My deepest thanks to Dr Catherine Walter, Dr Jasleen Jolly, Sarah Stephenson-Hunter and Paul Moorhouse for their very kind and generous invitation to talk this evening. As Professor Richardson has already said, this lecture is based on my experiences of how disability, science, and academia intersect. OK, so this slide just shows my name and my job title at the University of Manchester, where I work as a Research Associate in Biomedical Magnetic Resonance Imaging. Of course I told my whole department I was going to be here this evening, made everybody jealous. 'Be here', as if I'm actually in Oxford [laughs], it really does feel like that, but virtually of course.

Let me start my story then. So: my primary school years: this slide just shows the picture of the primary school I attended as a child. My primary school years were spent at a special school in a leafy part of Manchester. The children there had a variety of disabilities, some with complex and severe impairments. And I learnt some of my life's most important lessons there about making the best of being disabled. We did lots of fun things like wheelchair dancing and taking part in fierce sports competitions against other special schools in and around Manchester, winning plenty of trophies and medals - but the academic stimulation I needed just wasn't there. So here is a picture of me in a wheelchair with my friends preparing for a wheelchair dancing competition, no less.

I was very lucky. I was in the right place at the right time to be chosen as one of the first disabled pupils in Manchester to attend the only accessible mainstream high school at the time in the city. This was my introduction to the real world. I absorbed everything high school had to offer. And my favourite subject was science. And my passion for science was fuelled by TV programs like Tomorrow's World. I don't know if anyone remembers – Tomorrow's World was a brilliant program – and Star Trek, another fantastic science fiction. And they did fuel my passion for science. They were portals into the possibilities of the future, some of which have already come to pass. The way Dr McCoy in Star Trek would wave a probe over an ill person, diagnose their illness and then cure them straightaway, without a hitch: that made me think, yes, I want to become a doctor, just like him.

Sadly, though, when it came time for seeking careers advice, I was told that there was no way I could pursue medicine with my disabilities. So that was a setback, and I told my mum, and she said 'Well, never mind, you should become a lawyer instead'. But I had my heart set on science. That's what I wanted, see. So I achieved the best GCSE grades of my year at high school, and went on to study maths, physics and biology at A-level. During a physics class, I spotted a book on the teacher's shelf that was entitled 'Medical Physics'. And I'm showing a picture of the cover of that book. This was like being struck by a divine bolt of lightning - I could enter the medical field, but as a physicist! So I'm showing the crest of the university I attended for physics, and a picture of the place itself.

So while reading physics at University I was elected to the Students' Union as the Disability Access Secretary, and then ended up doing a bungee jump, and I'm showing a picture in a newspaper clip of the said bungee jump, from a crane on the side of the main road, in Manchester, on the University campus. And this was in protest at the lack of access in some of the University's buildings, especially the Students' Union building. So because I was elected to the Council, friends used to have to actually lift me in my wheelchair and carry

me up flights of stairs, to the Council Chamber on the top. It was very dangerous, and the University were not willing to do very much about it at the time. And so this slide shows a snap of me upside down mid-bungee and this picture featured in major newspapers and magazines around the country, and Europe even, and this was the start of my brand of disability activism!

After doing my physics degree, I wanted to do an MSc in Medical Physics, but I had no way to pay for the fees. So at that time, the Snowdon Trust came to my rescue. The Snowdon Trust is a charity that's supporting students with physical disabilities into university. And again, the Snowdon Trust helped me to enter my PhD in medical MR imaging, at the same place, at the Manchester Medical School. So I've put a big green tick on a picture of the Medical School, because I actually got entry at it, not to do medicine *per se*, but to do medical physics, and it was like a dream come true. And I am now an Ambassador for the Snowdon Trust.

I started my PhD at the turn of the century, which was a long time ago now, in developing novel analysis techniques of advanced magnetic resonance imaging in cancer. So in this picture here I'm showing my supervisors, Professor Jackson and Professor Williams, who were my supervisors for my PhD, and extremely supportive throughout the course of my PhD, when I had funding difficulties or difficulties just doing my studies, they both were extremely supportive in coming up with solutions for me. Just great people to work with. And the whole centre was such a buzz at the time, around medical imaging and what we could do with these amazing techniques.

I'm showing a picture here on the left side of liver cancer. This is an MRI image but it's a map of how leaky liver cancer is. So let me tell you about this. I was involved in a European trial of a new anti-cancer drug. So when tumours grow beyond a certain size, they start generating their own blood vessels that deliver the nutrients they need to spread further. This is called angiogenesis. These new blood vessels are very immature, and they've got holes in their walls, so blood plasma can leak out. We can measure this leakiness with MRI and special analysis methods, which allows us to detect the extent and the aggressiveness of cancer. So what I'm showing with this picture here is a map. It's a quantitative measurement map of leakiness and the scale is shown here going from dark colours, from black, all the way through to red, on just how leaky it is. So the more leaky, the more red it is – green and then red. So the patient received the drug, the anti-cancer drug. And the liver metastases actually were suppressed, and the change of colours from the reds and greens to blue in the second picture on the right here signifies substantial reduction in that leakiness, and therefore suppression in that cancer. This was a tremendous result and demonstrated how powerful advanced MRI methods could be, to just to measure this effect. A traditional biopsy would not be able to provide this kind of information, and that is what done usually, is just a biopsy. But you can't get this spatial information from that.

And so while working on this project, I collaborated with some of the best cancer specialists in Manchester. And even trained a qualified medical doctor in how to run the analysis software and understand the physics behind it. That's when I appreciated that the field I had entered was so much more exciting and rewarding than the doctor I originally wanted to be!

I presented my research at major international scientific conferences in some exotic locations like Cannes in the south of France and Honolulu. Which was pretty awesome. What gorgeous places they are! All for the sake of science, of course, and not the most accessible places though. Travel itself is not the most accessible means to cope with. But it was fun at that age anyway to be able to get out there.

The way that my academic abilities were the only thing that mattered, regardless of my physical impairments, convinced me to stay in academia. So I submitted my thesis, and became the doctor I always wanted to be, but not the kind that could save your life. Maybe a better kind.

I was very fortunate to get my first research associate job shortly before I finished my PhD, in the same department, more than 14 years ago. I have worked on successive fixed-term research projects since then. And all the support from my department and line managers over the years have meant I've been able to stay working in Manchester. Many people move from place to place in order to progress their academic careers, but that wasn't practical for me.

So my current research project is on new ways of diagnosing dementia earlier. The brain images over here are showing, on the top row from a healthy older volunteer; and then somebody of the same age at the bottom here, but with advanced Alzheimer's disease. And what these MRI images show, these structural images show, is that in the late stage of dementia there's so much of the brain that's been lost. The black cavities that you see here are the ventricles of the brain, that are filled with fluid, CSF, cerebrospinal fluid. And you can kind of see that the brain is withering away. It's like a tree. In the summer time, in good health, a tree is like full of leaves, lush green leaves. But by the stage of advanced Alzheimer's disease, it's like the leaves have all fallen, and you're left with just branches. It's too late to do anything for somebody at this late stage of Alzheimer's disease, and so we need to catch it much earlier on, if we want a chance of curing it.

So we're using MRI, this beautiful shiny new scanner of ours at Manchester, and we're part of the Dementias Platform UK, which is funded by the Medical Research Council to do advanced MR imaging, PET, which is positron emission tomography, as well as magnetic resonance imaging, in bigger studies, to try and detect those early stages of dementia.

So what I work on is what's called micro-structural imaging, and we're developing cutting-edge MRI to detect the very early microscopic changes in the brain that lead on to this devastating disease. The images on this slide are characterising the micro-structure of the brain by probing the diffusion of water molecules, just pure water, in a human on the left and in a rat on the right. The benefit of using rats is that, I mean, some people like rats, but not everybody is too devoted to rats, so we can take their brains out, cut them out, slice them up, and compare against the kind of images we get, to validate those measurements: make sure what we're looking at on the images are real changes in the brain. So that's the kind of work I'm up to. More recently, I've been working with a start-up company in Manchester who are trying to translate some of that research work to actual patient benefit, which is a real struggle in itself to do that. But it's brilliant to then combine the

imaging work with artificial intelligence as well, to take it into the health care setting, and actually benefit patients by it.

So do I enjoy my job? Heck, yes, I love what I do. I collaborate with all sorts of clever and inspirational people across the globe. I get to teach and engage with bright, young and enthusiastic people. I love being creative, facing new challenges every day, no day is the same, and presenting at international scientific conferences is also a buzz.

But support is crucial. And I bring up the sign for Access to Work here. The integrated support I have is so important to me. It lets me fulfil my potential with independence, and confidence, and dignity. So I need support. Without it, I could not have studied or done my job as a student. I had the Disabled Student's Allowance, which has sadly been restricted for future students in many ways. And additional support from the Snowdon Trust.

On becoming a member of staff, though, I suddenly lost that support. Thankfully, and rather by mistake, my HR contact pointed me to this government scheme, to Access to Work, which he had heard of, supporting disabled people in paid work. But the scheme is still very poorly promoted, like the Government don't want disabled people to know about it. Access to Work allowed me to employ my personal assistant to help me with everyday physical tasks that I can't manage myself and to help me to go to conferences, a vital part of being a researcher. Without this I would literally have to stay at home. Just literally. I couldn't work, I couldn't get to work every day.

But the skills and the perspective that we bring are so important. And so I think it's for every one pound the Government spends for Access to Work, the Exchequer makes back at least £1.20, if not more. So there's a huge benefit in supporting disabled people in academia or any kind of work. And the kind of enthusiasm and passion I have for my work is shared by disabled people in academia in all roles, I believe.

Let me tell you very quickly about the condition I have. I've never actually described this in a public lecture before. But I have something called Charcot-Marie-Tooth disease. It's got nothing to do with dental care. It's also known as hereditary motor and sensory neuropathy. So it's a neurological condition, I've always had it, a genetic condition. It affects the peripheral nervous system. So what happens is the peripheral nervous system, the nerves that carry signal away from the brain and the spinal cord – those nerves have what we call 'myelin', a kind of wrapping around the nerve, but leaving gaps between. So, the signal can progress rapidly from the origin of that signal, all the way down the axons by jumping between those gaps, which is extraordinary, so they just go super speed.

In the condition I have, the myelin is being lost, a demyelinating condition, and so with the loss of that myelin then, it's almost like a frayed wire, a bare frayed wire, and the signal just doesn't travel down the axons fast enough. And in fact the signal gets lost. And this is a degenerating condition, so I could do much more when I was younger than I can do now. And the symptoms are around muscle pain and hand tremors – although I don't get that. Cold hands and feet. Very cold, it's like the heating's on and I'm still cold. Drop foot, because there's no control in the position of the foot. Pain in the nerves. Chronic fatigue – I mean I can fall asleep at any moment: just tell me to go to sleep and I will. Numbness around the

body. Curled fingers, so I don't know if you can see my hands, but they're just floppy hands, and curled as well. Atrophy in the muscles of the legs and the arms, curled-up toes, high arches, breathing difficulties, which is something I'm starting to experience as I'm getting on in years.

So the science and engineering behind understanding the condition also have provided some of the things I depend on: so callipers, being a feat of engineering. For somebody like me, who can't stand on their own feet, my support worker puts my callipers on, and suddenly I can stand up. They're just an incredible thing. And it was in my childhood I was introduced to these, and it was by a professor of bio-engineering who looked just like the Kentucky Fried Chicken man. And of course my powered wheelchair: I can't push a manual wheelchair myself, so having a powered wheelchair just gives me that independence, control, to get around wherever I want to, like everyone else can. And there's so many other pieces of equipment and engineering that give independence, control, and dignity, as well, in life. So these are the intersections with my disability.

Now I want to do a quick exercise with everybody. I'd like you in the chat please, to use a word or two to say how some of these words make you feel. And these words are 'abnormal, invalid, handicapped, spastic, dumb, vulnerable'. So just thinking about those words collectively, how do they make you feel? So just a word or so. And what we're going to do is, Jasleen is going to kindly put those comments together into a word diagram, what do they call it, a word cloud, and we will come back to that later on. And so the words again: 'abnormal invalid, handicapped, spastic, dumb, and vulnerable'. So in the chat just say how these words make you feel.

So, did my disability activism stop at the bungee jump? No way. I had to start up and lead the University's Disabled Staff Network. At the time I had to meet the Vice Chancellor of the University, who was Professor Allen Gilbert, sadly he's passed away now. But he was a great guy, and I met with him having done a SWOT analysis – so strengths, weaknesses, opportunities, and threats – on the experiences of disabled staff. And we were instrumental in making our university one of the first to provide dedicated support for disabled staff. The biggest weakness and the biggest threat was not having that support available for disabled staff. And so we had that arranged alongside the support already there for students. This is shown now on the Disability Advisory and Support Service at our university: there's support available for disabled staff, and staff working with disabled staff. And it was a great moment to have this service provided alongside the students'. It actually helped a whole lot more disabled staff come forward, and... disclose? I don't like the words 'disclose', 'declare'. But they actually shared information about their disability. Because suddenly, there was support available that they had needed for so long. And from a few disabled staff, suddenly, the numbers have shot up to I think 1,000 or so now on the services register. And so it was a brilliant change for the university.

So in June 2014, as the Vice Chancellor kindly talked about in the beginning, in June 2014 we held the first national conference for and about disabled staff in higher education institutions from across the country. And it was called 'What Are We Hiding'? This slide shows our University's President and Vice Chancellor, presenting the inaugural Making a Difference Award to Melanie and I for organising this ground-breaking event. Sorry, I should

have said: the event itself had a double theme of hidden disability, hidden impairment, and the hidden contribution of disabled employees to the nation's economy. So in terms of hidden disabilities, I mean mental health conditions, autism, HIV, all sorts of things we talked about. We had sessions around all of them. And yeah, we were awarded well for doing that conference.

But I used the occasion of that conference to launch the National Association of Disabled Staff Networks, because we saw from that conference, and from contacts before and with other universities that disabled staff in other institutions were having very similar experiences, and were trying to set up their own disabled staff networks. So we thought, why keep everybody in silos? It's always better to bring together people, to bring together colleagues going through similar experiences and to learn from each other. So this is a super-network, connecting and representing disabled staff networks, in the tertiary education sector, for universities and colleges across the UK and beyond, open to any individual or organisation interested in promoting the equality of disabled staff.

And so, who we are: we are focused on universities and colleges, we are open to any individual or organisation interested in promoting the equality of disabled staff. We act as a collective platform to share experiences and good practice and examine challenges and opportunities. We are an unincorporated association, we're non-governmental, got nothing to do with Government, we're independent and self-determining, made up of impassioned people. We are actually looking at changing this set-up into a more formal structure, possibly a charity of some kind, so we can start raising money.

And so, a few facts: we have more than 200 members from over 100 different organisations across the UK and abroad, including 59 universities – probably more by now. And we include colleagues from the BBC, ITV, the Scottish Parliament, quite a few NHS trusts, and the Institute of Physics. And we have a Steering Committee that leads us. So I'm very lucky to be the Chair right now. We have two Vice Chairs, Jacquie Nicholson up in Scotland, and Stuart Moore at NHS England. Our Secretary is Kelly Pickard-Smith, my colleague at Manchester University. Jacquie also fills the role of Fundraiser and Treasurer, although [laughs] we don't have any money just yet. The Engagement and Communications Lead is Peter Collins of Birmingham. And then we have a network of regional leads. You'll note that there are quite a few vacancies in some of the regions, and we are working on trying to fill those. If you know anyone interested, please do let me know. And NADSN's Patron: we're very lucky to have Professor Anna Lawson, who is Co-Director of the Centre for Disability Studies at Leeds University, so she is our first Patron of the National Association. It's great to have her on board. She's a lawyer, and very learned in equality law, so we learn a lot from her and get support.

Okay, some of our aims are around promoting disability equality, and campaigning for disabled staff. The one that I want to highlight is that we challenge stereotypes by endorsing the Social Model of disability, and promoting a positive image of disabled people, eliminating the deficit of the medical model. So let me explain what the Social Model is for those who don't know. The Social Model of disability identifies systemic barriers, negative attitudes and exclusion by society – purposefully or inadvertently – that mean society is the



main contributory factor in disabling people. So it's not us who are disabled, but it's those factors, those systemic barriers that make us disabled. And those barriers include prejudice, ignorance, and stigma; negative attitudes; inaccessible places, transport, conversations, and information: all are barriers and make us disabled. And there's a brilliant video on Scope explaining what the Social Model means to disabled people ourselves, which is a brilliant resource. There are variants to the Social Model now, kind of progressing the arguments around a model of disability, so there's some good scholarly work out there looking at that too.

And of course the UN's Convention on the Rights of Persons with Disabilities – which our country, the UK, does not do well on – the Preamble of that Convention says, 'Disability is an evolving concept, and [...] disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders our full and effective participation in society on an equal basis with others'. And one slogan we love is 'Nothing About Us Without Us'. Disabled people have to be front and centre in anything to do with us. And lived experience is just crucial in getting anything to be better, to improve stuff. Since we're focused on universities and colleges, looking at the experiences of disabled academics is an essential part of what we do in NADSN.

This is a word cloud from Heriot-Watt University, and some work done by a colleague there, around some stereotypes of what makes an ideal academic. Some of the stereotypes around the ideal academic, being that, you know, academics work 24 hours a day. They just work independently, they don't need the toilet, they can easily swap topics, they're mobile, they [don't] have a body, they just do excellent research and teaching all the time, they attract the highest research funding, they are white, they're a man, they like to chat, they can think all the time. So many stereotypes of what an ideal academic is.

This is a brilliant book, I'm showing here the cover of, called Super Hero Scientists, by David Allen and Alex Sinclair, and this book was recently published for primary school children, actually, to promote diversity in science, to let children know that it doesn't matter what your background is, or who you are, science is for you, and this book includes information about all sorts of scientists from all sorts of backgrounds. Somehow I got into this book as well, so my name comes just second after Rosalind Franklin, which is pretty damn good, and this picture here is showing me in my wheelchair with bat wings! – flying through the air and of course the Starship Enterprise drawn just beneath me. Yeah, it kind of hits back at those stereotypes that it's not necessary for being a good academic.

There was a conference back in 2018 around ableism in academia, which brought together disabled academics, pan-impairment, so many impairments were represented, along with neurodiversity and chronic illnesses, and these books have been published by Nicole Brown and colleagues coming out of that conference, with recommendations around how ableism in academia can be addressed – what actions our sector need to take, in terms of institutions, and societies, and funding bodies – to fight back at ableism, and that it has no place in academia. It has no place anywhere.

So these are really great books that have just come out recently, and hopefully will provide a lot of impetus for change. So: disabled academics and researchers in 2018:

- 19% of UK working age population identify as disabled, but only 4% of academic staff are disabled.
- Representation of disabled researchers in STEMM drops by 40% between undergraduate and postgraduate level.
- 10% increase in employment rate of disabled individuals would lead to an extra £12 billion to the Exchequer by 2030.
- And the UK needs an extra 1.2 million engineers by 2025.

Increasing employment of disabled people in STEMM, then, would kill two birds with one stone. And this information is from my very good friend Dr Jessica Boland, and she also says only 25% of disabled researchers apply for research funding. Why? Disabled researchers have a 4% lower success rate than non-disabled researchers for winning grants as PI, and the award amount is also 50% lower for disabled researchers than non-disabled researchers in 2018-19. Incredibly surprising if you assume disabled researchers have increased access costs.

The Royal Society in marking the International Day of Disabled People the last couple of years, that being on the third of December, has been showcasing and celebrating disabled scientists, which is so nice to see. So I made it the first year, and Jessica's in the next year after that. And from this work and these biographies that have been written, somehow I've managed to get onto the Diversity Committee of the Royal Society, which is a huge privilege to be part of, working with incredible colleagues across the board, with such rich experiences in the sector in science here. And there's a subgroup of this Diversity Committee on supporting scientists with disabilities. And right now, we're supporting a project on developing BSL sign language for scientific terminology, and that's going to be focused on environmental sciences, and so it's very exciting to see that kind of work come through.

And on the back of that, because of my membership on the Committee, in NADSN, I set up a club, I called it a club, but it's just a group of people who are interested in STEMM, STEMM being science, technology, engineering, medicine, and math. On the basis of publications and work already out there, so Jessica Boland and TIGERS in STEMM had a report on accessibility in STEMM, and the barriers that disabled scientists face in terms of research funding. We've got a very short communication in *Nature*, around disabled scientists calling for more support; and there is a project at Heriot-Watt University going on right now: Disability-Inclusive Science Careers, looking at the experiences of disabled scientists, and developing virtual reality for managers and PI's of disabled staff so that they can actually experience what we go through [laughs], which is pretty awesome.

So, we want to develop from that STEMM club, we want to develop recommendations and reports that we want to take to Wellcome Trust, to UKRI, in order for their systems to change, and for the barriers to be brought down by those funding bodies.

The Wellcome Trust is already leading re-imagining research and research culture work, which is great, although I haven't yet seen very much on disability in that, so we need to work with them to push that forward.

UKRI: I've met with the new CEO, Professor Dame Ottoline Leyser, and she's very enthusiastic, very keen to move things forward from UKRI's point of view, which is great. And we work with our sister organisations: Chronically Academic, TIGERS in STEMM, and EDIS, which is Equality, Diversity and Inclusion in Science and Health.

So every year NADSN tries to hold a national conference, and the last one we had in person pre-pandemic was a conference around intersectionality: intersectionality of disability and sexuality and gender identity. And it was the first time in the sector, I think, that there had been an intersectional conference of this kind. And it was brilliant for NADSN's work with the LGBT Network of Networks in Higher Education to hold this event. There were some brilliant sessions, workshops, and posters around intersectionality, unearthing the hidden voices in higher education; looking not just at the intersection of disability and sexuality, but looking at faith and race as well, which was just incredible, sharing experiences openly and honestly. And we hope to reignite our conferences as soon as we can, because they have been a brilliant source of bringing our communities together, bringing disabled staff together.

During the pandemic, we published a paper on recommendations post lockdown. We published that last year in May, when we thought that lockdown would be over pretty soon. But of course we went back into lockdown; hopefully that won't happen again. But the paper gave strategies, for universities particularly, twelve recommendations, for universities to support disabled staff and students on returning to campus, and really not losing all the great practice that has been developed during the pandemic in terms of people working from home; flexibility in the way we work; and support of other kinds as well: not to lose all of that as soon as lockdown is over, so there's a paper there from NADSN on that.

And the Black Lives Matter as well: we have a great statement, looking at intersectionality of disability and race too, and how racism, and ableism, have similar issues going on that we need to tackle, systemic issues that we need to look at together.

Sorry, I'm running out of steam a little bit. But I just want to tell you about the Disability and Leadership workshop coming up, an event on new challenges and new possibilities on disability and leadership. So this is an event NADSN is supporting alongside Purple Space, and the University of Birmingham are playing host, the Birmingham Business School, and this is going to take place on Wednesday 2nd of June, from 1:00 to 3:30. And the guest speakers are just some incredible disabled leaders themselves. Kate Nash will be the creator and CEO of purple space – they're all my great friends – Jane Cordell, Director of Results CIC, and Professor Nicola Martin from London South Bank University, the Director of NADP. They will be the special guest speakers, talking on disability and leadership. And I love this little infographic from Professor Martin about what leadership means: supporting people, motivation, having goals, reaching success, contributing and teamwork. And I like these two words [*support* and *teamwork*] best of all in terms of leadership. And so there is a link down there to the Eventbrite . That's going to be in a couple of weeks. I'm really looking forward to that.

So, a brilliant initiative that is just kind of coming – well, it's coming to a peak, I think, is this one, around The Valuable 500. You may or may not have heard of this. It's being led, talking

about leaders, by this marvellous disabled woman, who has incredibly brought together 500 of the biggest businesses, corporations, around the world, on the global stage, to commit to disability being on their board agenda. The Valuable 500 is a global movement, putting disability on the business leadership agenda. So, The Valuable 500 are looking for 500 national and multinational private sector corporations to be the tipping point for change, and to unlock the business, social, and economic value of disabled people across the world. Because, as they say, the potential of 1.3 billion disabled people should not be ignored. Where there's disability inclusion, these companies are going to start on scaling up on leading the charge, and they want companies to join The Valuable 500, and Caroline Casey has been on this mission for the last few years, and just in the last month or so she's actually got 500 companies to sign up, so that is extraordinary.

Just so you know, we're going back to words now. Wow, there it is. I like that one, somebody said they were bored. The biggest words: 'sad', 'angry', yeah, 'othered', 'helpless', 'depressed', 'frustrated'. Exactly, yeah, I couldn't have said it better myself. Those are some of the reactions, exactly, you feel from those words. And those words that I brought up, reactions to which are given here, those words are words used by scientists much of the time to describe disabled people in publications and studies, you know, being abnormal, or being – lost a couple of the words now – but, you know, making us feel like we are othered. We're just outside of the game, the whole time.

So very quickly I just want to end off with just a couple of more slides. I hope we still have the Vice Chancellor's attention. There's been a petition that's going around about a very high ranking, very influential academic at University of Oxford. So Professor Richard Dawkins has made some very worrying remarks recently against women who have Down syndrome babies. And this isn't the first time Professor Dawkins has said such things. Apparently, so I've heard, he's said very derogatory remarks against disabled people more generally before as well. So I have signed this petition, which asks Oxford University to reconsider Professor Dawkins' Emeritus status, which he currently holds at the University, and I would implore the Vice Chancellor to look at this petition, to look at the evidence, and to make a very considered judgment in Professor Dawkins' case. Having read the petition and what Professor Dawkins has said, I would be very strongly suggesting to Oxford that revoking his Emeritus status would be the only right thing to do, and showing disabled people that Oxford University values our lives really – that's what it comes down to. Some of Professor Dawkins' remarks come very close, well, it is ableism, and eugenics as well, frankly speaking, that this encroaches on. And those are very scary areas. You know, disabled people have the right to live, and I implore the Vice Chancellor to look at this.

So these are my children on the right side of this slide here. They've grown up, they're teenagers now. But this is the cutest picture I could find of my son Hamza, here cuddling his baby sister at the time, poking her in the mouth to see what this thing is. So other disabled child in a traditional Pakistani family. My expanded family and community never expected me to amount to much. But definitely my parents refused it for me. And they always pushed me, sometimes literally, to work hard and achieve the best with my abilities. So these are, as I said, the cutest pictures of my family. My wife here, holding me up, is my rock. Her name is Humaira. She keeps me headed in the right direction, stops me falling over – again, literally. We have two children: a son, Hamza, and a daughter, Haya. Hamza is

now a growing teenager, he's got broad shoulders and everything, and Haya doesn't follow too far behind in age, and both are disabled themselves with their own impairments, and I value their lives. I wouldn't ask for anything different at all. Their mum has made them both promise to at least achieve a PhD like I have, and then they can do what they want. So when Hamza was younger, he said that after doing his PhD he wants to be a bus driver, because he likes travelling, and he might get the Nobel prize, if he was up to it. And Haya said she did want to win the X-Factor at some point after doing her PhD. So whatever they aspire to be, we have every confidence that they will achieve their dreams, as long as they have those chances to do that.

And just to end off, this slide shows Professor Stephen Hawking, a brilliant disabled scientist, starring as himself on an episode of *Star Trek: The Next Generation*, playing poker with Einstein and Newton, assisted ably by Commander Data! Professor Hawking made me feel so deeply proud to be disabled and a scientist, as he brought those two parallel universes together. For me he was the epitome of achieving success as a disabled academic and scientist in this century we live.

Thank you very much.

[Break before Q&A]

**CATHERINE WALTER:**

To introduce myself, I'm Catherine Walter. I am a member of the Disabled Staff Network and the Chair of the Disability Advisory Group; and my colleague Paul Moorhouse, who is ably moderating this, was the lead on organising today's webinar. And I thank him for that. I thank Hamied for his wonderful presentation, and all of our colleagues that helped out on this.

We've had a lot of really interesting questions. So I'm going to try to ask Hamied to briefly answer each question, so that we can try to get as many people in as possible. So here is a question. This questioner says:

'I know that Hamied is keen on taking an intersectional approach to his activism. I'd love to hear where he thinks the greatest opportunities and challenges lie in terms of disability and other aspects of marginalisation.'

I'm going to try and copy, paste that into... yes, I've pasted it into the chat as well.

**HAMIED HAROON:**

Great, well, I think... I think the opportunity in terms of intersectionality, is that disability actually gets some exposure. Because otherwise, we're always fighting this, kind of, what do you call it, this hierarchy, and prioritising areas of EDI. And disability always comes at the bottom, in my experience. So race, gender will generally be at the top, and then disability, and perhaps sexuality as well will come at the bottom, in my experience. So intersectionality gives us a great boost in talking about... so gender and disability, for instance, is a big one. Because disabled women and disabled men have very very different experiences. And I know that from my own personal experience: so what my sister who is

also disabled has been through. I have no idea about what she's been through in terms of a woman, becoming a mother even... and stuff like that, I would not know about. And so there is intersectionality, right there at the big issues of EDI if you like.

The challenges are about the people who lead those agendas, taking... wanting to bring disability into the conversation. Many people are kind of, I find, a bit scared around disability. But, you know, I think just having that conversation with disabled people just, will break that kind of barrier down, I think. I don't know if that answers the question very well.

**CATHERINE WALTER:**

That's lovely. Here is a very short question. You can answer it in 10 seconds with a simple yes or no, probably.

'Is the environmental science sign language project with the Scottish Sensory Centre or someone else?'

**HAMIED HAROON:**

I believe it is somebody called Audrey Cameron, I think the BSL lady's name was, not BSL lady... I think it is from the Scottish Centre, yes.

CATHERINE WALTER: OK, thank you. Here's another question.

'Is the climate in academia and STEMM really changing? We see more honesty in a report, and lots of consultations, but will it really improve equity?'

**HAMIED HAROON:**

I'm as sceptical as the questioner is around this. If there is change, it's very slow, and just from us talking about these things, it's clear there is still so much work to do, when it comes to disability equality, or EDI in general. How long have we had things like Athena Swan in the sector, for instance, and still there are issues around gender equality, never mind any other area of EDI. So there's so much to do. When I was talking to the new CEO of UKRI, Professor Dame Ottoline Leyser, she was really enthusiastic, and actually said, what I really believe, which is that the systems are not designed, you know, to include everyone. They're designed around white old males, cis-gendered, and that's how the system is set up, so it's not going to work for people who do not identify in the same way. So the system really needs to be changed. And to do that will take a lot more work to make it better.

**CATHERINE WALTER:**

Thank you very much. Here is a question, I'm going to put the question up, but, I think it's something we need to address after the seminar. The questioner says:

'I'm curious to know about the projections you showed on what increasing the employment rate of disabled people would do for the Exchequer: where do they come from?'

We'll get the references from you Hamied, and we will email out to the attendees when we send the post-seminar email.

**HAMIED HAROON:**

I know my good friend Jessica Boland is on the call, and I and may very well be going to her for some help on that one.

**CATHERINE WALTER:**

Okay, here is another interesting question.

‘Should higher education adopt a compulsory education model of internal support assistants, trained in higher education practice, who can be deployed where the need arises, rather than having to go through Access to Work?’ – which this contributor found was very unsatisfactory.

**HAMIED HAROON:**

Access to Work UK has its plus points and its negatives, but I do see your point. I think if that was going to happen, though, we would need... I don't see universities doing that about staff without the financial input. So these are arguments that we need to take with the likes of URKI and Wellcome and others, to provide the funding to do that kind of thing. I really like that suggestion of having more specialised support available, especially in science, because when you're in a lab or at an MRI scanner or something, then you need people who have more of that basic science knowledge to assist in a more effective way. Although, having said that, my PA is not a scientist, but he's very enthusiastic and very passionate about anything he can get his hands into. And so as I said, there are pluses and minuses in either way. But we need those big bodies to invest in any sort of thing like that. But I think it's a really valid point. I like the idea. Maybe let's try and do something about that.

**CATHERINE WALTER:**

Okay. Our time is drawing to a close. And I apologise to the people whose questions didn't get answered, I'll try to twist Hamied's arm to include answers to some of the more interesting ones or ones that cover more general questions, in our post-webinar communication. But here's one last question:

‘What would be your top tip for a disabled person entering work in higher education, be that in a supporting academic role?’

So what's your top tip?

**HAMIED HAROON:**

My top tip is take no shit. [Laughter] We all have rights. So use the services that the university provides. If they're not good enough, complain. Just make the system work for you, [Laughter] is what I would say. And plug at it. Join NADSN. Be with us, and we can make good things happen. There are people coming into the sector, into STEMM, into academia, and still struggling, and it really annoys me that those struggles are still happening. But, yeah, don't take any shit. Get the university to do what it has to, and should do to support you through that. And yeah, I'm afraid those are the only words I have right now.

**CATHERINE WALTER:**

Okay, find out and don't take any shit.

**HAMIED HAROON:**

That's it.

**CATHERINE WALTER:**

Thank you very much. I'm now going to call on Jasleen Jolly to give the Vote of Thanks.

**JASLEEN JOLLY:**

Thank you so much, Catherine. A huge thank you to Hamied for that fantastic talk. I know certainly how much for me both Hamied and NADSN have been really supportive, and have helped increase disability on the agenda for my Department in Oxford. And so it's always great to hear from him, and his enthusiasm, and his can-do attitude, which I think all of us can take a lot from.

And we can't do a round of applause, but I hope everyone can join me in virtual applause for Hamied for that superb session. I would also like to extend my thanks to the Disability Advisory Group, and particularly Catherine Walter and Paul Moorhouse, who've put a tremendous amount of work in to make today happen. I'm so grateful for all the effort they've put in. And Sarah Stephenson-Hunter, who is the Disability Advisor for staff here. And it's such a wonderful team to work with. So Hamied, Catherine, Sarah, huge thank you for this wonderful event today.

[END]