NADSN STEMM Action Group White Paper Launch Glasgow

Monday 31st May 2025

0:00
JR: Afternoon session, not like many white paper launches, partly because I'm involved, so my most distinctive apologies.

0:08
JR: I'll be constantly allowing people in the room and occasionally reminding everyone online because you keep on accruing numbers that we are recording this.

0:17
JR: So please be aware that we're being recorded.

0:20
JR: We are presenting our white paper today.

0:23
JR: So I'm Jen Remnant and I work in the Business School here at Strathclyde and have had the incredible honour of working with my colleagues here who are invited to introduce themselves momentarily.

0:34
JR: We've written this paper and as a labour of love, we've applied for funding to launch it formally.

0:40
JR: We're launching it here and we're launching it in London.

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JR: As a totally personal and honest reflection, it's been really tough.

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JR: It's really hard getting people in a room when you're going to talk about disability in a way that's consistently depressing, actually, sorry.

0:55
JR: But it is like, yeah, we've, we've been wonderful.

0:58
JR: We've worked really hard.

0:59
JR: It is so depressing that you can run all sorts of events and you can get loads of funding and the funders know that it has value.

1:06
JR: And your disabled colleagues and your colleagues working in equality, diversity and inclusion know it has value.

1:11
JR: And for whatever reason, not many other people know it has value.

1:16
JR: And I keep doing this and I know my colleagues are getting tired of me complaining.

1:19
JR: So I keep on getting funding to run events to bring STEMM experts and disabled people who are also STEMM experts into a room together to get them to talk about how we can make work emancipatory and how we can make STEMM inclusive and accessible.

1:35
JR: And I keep on failing to get STEMM expertise in the room to the point where I'm looking at Jodie, you will remember we got some funding a couple of years ago, huge amount of funding to run a series of events for scientists and disabled people.

1:48
JR: And on one of the events we, we were running over time.

1:52
JR: And so someone said, well, we want to do a lab tour.

1:55
JR: And I said, well, we haven't, we haven't got time.

1:57
JR: We haven't done the social discussion of how to make this emancipation yet.

2:01
JR: And they said, well, let's just have a vote.

2:02
JR: And anyone who wants to do the lab tour, we do the lab tour.

2:04
JR: And anyone who wants to talk about making STEMM accessible can stay.

2:07
JR: And every scientist, and it happens to be every man in the room got up and walked out and every woman and every social scientist stayed sat ready to talk about inclusion.

2:17

JR: And Jodie, our esteemed colleague over there, ran out of the room to hook them back in to say you've misunderstood the point.

2:24
JR: So I just wanted to tell you that to give a bit of context.

2:27
JR: So anyway, firstly, could you just introduce yourselves by name and then we'll go through the after the order and the housekeeping.

2:34
JR: I just would like to meet the esteemed colleagues that wrote this incredible white paper.

2:37
JR: Before I keep on talking.

2:42
JJ: I'm Jasleen Jolly, an associate professor in multidisciplinary vision research.

2:53
FD: Hi, I'm Frankie Doddato from Lancaster University, and I'm a teaching assistant in the physics department.

2:58
JL: Hi, I'm Jennifer Leigh. I'm a reader at the University of Kent and an honorary professor at the University of Liverpool.

3:09
GR: I'm Gayle Brewer. I'm a professor of psychology and education at the University of Liverpool

MMS: I’m Martyn Mahaut-Smith, professor of cellular Physiology at the University of Leicester.

3:25
JR: OK, I'll move to Hamied but he will introduce himself and NADSN in a moment.

3:30
JR: So overall, we're not expecting a fire alarm.

3:33
JR: So please don't worry.

3:34
JR: If an alarm goes off, I suggest you panic travel around in a circle and just shoot out the nearest exit.

3:40

JR: Fortunately for you it's just the 2 so you should be fine, but there's no alarms planned because I'm not very good at this.

3:47
JR: There is a lecture after us at 6:00 so we will be finishing this promptly.

3:51
JR: I've also massively over catered so please take home any food that you would like plus a little bit extra.

3:59
JR: And in terms of accessibility, if you feel like applauding, we do this for applause, so rather than clapping.

4:06
JR: So that's great.

4:07
JR: We have BSL interpretation and provided we have subtitles on the screen, we have a very poor master of ceremonies who's going to really struggle with the technology.

4:17
JR: You just can't get the staff these days.

4:19
JR: And the order of service will be I've just done housekeeping.

4:23
JR: Hamied is going to introduce NADSN, the National Association of Disabled Staff networks.

4:28
JR: We are then going to have an incredible video.

4:30
JR: That's going to be Jennifer.

4:32
JR: Are you introducing Jennifer's going to. Yes, you can pin the BSL interpreter.

4:42
JR: There we go.

4:43
JR: How's that big and on the screen, but sometimes we'll be sharing screen.

4:48

JR: We've got a video to share and then Jasleen is going to present a speech before we then open it up for a panel discussion where you can ask questions about the motivation or content of the report.

4:58
JR: There are also copies of the report, both in easy read and standard version for you to please help yourself too.

5:04
JR: I think that's me done.

5:05
JR: So Hamied, I'm going to hand you the floor and I will stay loitering somewhere helpful to press buttons and do things to share my screen.

5:17
JR: Don't mind.

5:27
HH: Hello, Can you hear me?

5:34
Yeah.

5:34
HH: Can people online hear me?

5:36
Yeah.

5:36
Cool.

5:40
Would you like me to?

5:41
I think I'll be there if that's all right, if I can get in, then.

5:45
HH: Thanks, Jen, You good?

5:54
HH: All right, Good afternoon everybody, and a very, very warm welcome to this wonderful, wonderful launch of our White Paper from the National Association of Disabled Staff Networks.

6:06
HH: What a great, great event this is.

6:08
HH: We're so excited and so looking forward to this.

6:11
HH: Thank you so much Jen Remnant for, for organising everything, especially the food.

6:18
HH: There's loads of food people online.

6:19
HH: Really sorry.

6:20
HH: We, we, we'd love to like package the food and send it to you.

6:24
HH: But yeah, we don't really run Uber Eats, so can't really do that.

6:28
HH: But I'm Hamied Haroon.

6:30
HH: I am very lucky to be chair of the National Association of Disabled Staff Networks.

6:37
HH: We are a super network of disabled staff networks.

6:41
HH: We focus mainly on the tertiary education sector and other organisations in the public sector.

6:49
HH: So we include universities, colleges, NHS trusts and others.

6:55
HH: And our strap line is that we are defining, connecting and representing ourselves.

7:02
HH: And so you're very welcome to visit us on the NASDN website nadsn-uk.org and we're on social media which you can find out how to join us there through Link Tree.

7:18

HH: So we welcome any individual and organisation from any sector committing to committed to advancing the equality, equity, diversity, inclusion and access of disabled staff.

7:37
HH: We act as a collective platform to share experiences and good practice and examine challenges and opportunities together.

7:46
HH: We have nothing to do with the government.

7:48
HH: Thank God we are independent, self determining, intersectional and a dynamic community of impassioned disabled people.

7:58
HH: We lead ourselves and we are made-up of disabled people.

8:03
HH: So in terms of membership, we have almost 500 members now from more than 200 different organisations across the UK and abroad, including 110 universities in the UK.

8:18
HH: But we include, as I've said before, NHS Trusts, people from the Academy of Medical Sciences, the Scottish Parliament, BBC, ITV and others are amongst our members and we are led by a steering committee and a network of regional leads.

8:37
HH: So as I said, I'm lucky enough to be chair.

8:40
HH: We have two amazing vice chairs, Jacquie Nicholson and Stuart Moore and Jackie looks after all our finance stuff, which is great.

8:49
HH: And then our Co secretaries and then Aden and Yota Dimitriadi, we have an engagement and communications lead who is very busy right now redeveloping our website and social media.

9:02
HH: Rachel Shillock, who has worked incredibly on our web page for for this launch this afternoon on the the NADSN website.

9:10
HH: So please do check that out.

9:13
HH: We are also very keen on intersectionality, looking not just that disability, but how that intersects with other identities and other or other forms of being.

9:25
HH: And that's led for us by Kayla Barram and Fideline, who are incredible leads on that.

9:33
HH: And then we have a network of regional leads across the country.

9:39
HH: So Andy Crosbie is right here.

9:41
HH: Hey, Andy.

9:43
HH: It's nice to see him in person at last.

9:46
HH: So Andy is one of our Co leads for Scotland, for the Scottish region.

9:51
HH: So please do reach out to Andy if you'd like to get involved in nuts and further.

9:56
HH: And we have regional leads all over the country and obviously some vacancies too.

10:02
HH: So if anyone's interested in taking those up, let me know.

10:06
HH: And yeah, we're, we're definitely into global domination through NADSN.

10:11
HH: So we have the wonderful Nancy Hansen, who is on the call, in fact this afternoon, who is our lead in Canada and from North America, although there's a bit of trouble brewing, brewing on that side of the pond right now, of course, which is having influence on us.

10:30
HH: And then we have a colleague in Norway, France Rose Heartland, who is starting up their version of NADSN in Norway.

10:38
HH: So yeah, slowly but surely we will spread and take over the build.

10:43
HH: We also have a number of subgroups developing within NADSN.

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HH: So we have a disabled women in academia network.

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HH: We have a neurodivergence focus group which Andy also leads.

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HH: We have an Access to Work User group that's going to be formed very soon and we have our STEMM Action Group of course who many colleagues from the group are here today.

11:06
HH: We have a new Blind and Visually Impaired Staff and PGRS in Academia Network and the RIDE Higher project, right being Realising Inclusion of Disabled Employees and is a framework we're developing as something akin to a Venus One and the Race Equality Charter Mark, but focused on disability and how disabled employees can be better included in the whole higher education system.

11:40
HH: So yeah, look out for more news on that very soon.

11:43
HH: It's quite exciting work.

11:45
HH: I say it's going to be akin to a Venus One and the Race Equality Charter Mark, but it's going to be much better.

11:52
HH: And we have a patron who we're very proud to have there as our guide and influencer as well.

12:02
HH: Professor Anna Lawson at the University of Leeds, so she is a blind person and a lawyer with her speciality and human rights around disability.

12:16
HH: So it's wonderful to have her as our patron for NADSN.

12:20
HH: And just a couple of years ago, in June 2023, NADSN became a community interest company with Jackie, Stewart and myself as directors of this CIC that allows us to do work that is now able to receive some funding.

12:40
HH: So before we've done everything for free, but being a CIC means that we can now get paid for little projects that we do and to be able to enhance and develop the community that we're making together.

12:56
HH: All right now I want you to have a quick think about some of these words.

13:01
HH: Are we all right for time, Jim?

13:03
HH: Some of these words that I'm going to bring up on the screen I want to make.

13:07
HH: I want you to think about how these words make you feel OK words like handicapped, invalid, spastic, dumb, vulnerable.

13:20
HH: I can't read the top, but what is that is behind the zoom?

13:23
HH: But words like these are words very often used to describe us as disabled people and how they make us feel is inhuman.

13:34
HH: Just like we don't really belong.

13:37
HH: Like we're not meant to be.

13:40
HH: Like we're not normal and we need fixing in order to fit the system better.

13:47
HH: We need curing, we need making better and, and we don't really belong.

13:53
HH: We're not really welcome.

13:55
HH: And these feelings and these whole notions are exactly what as you probably all know, is around the medical model of disability, where we are the problem.

14:10
HH: We as people are the problem.

14:11
HH: We need to be made normal to fit the system, to fit a certain way of being a certain mould.

14:20
HH: But of course that that's well, that is the medical model.

14:26
HH: So the social model of disability is what we from NADSN endorse.

14:32
HH: And this is flipping things on its head.

14:35
HH: This is a different approach, which actually is quite emancipatory for me as a disabled person, for many disabled people.

14:45
HH: And that is that the social model of disability identifies systemic barriers, negative attitudes and exclusion by society, whether that's on purpose or inadvertently, that mean it's society that's the main contributory factor in disabling us as people.

15:06
HH: So in being disabled people, it's because of those structures, because of those attitudes that we are disabled.

15:14
HH: Does that make sense?

15:16
Oh yeah.

15:17
HH: So this includes prejudice, ignorance, stigma, negative attitudes, inaccessible places, transport, conversations and information, and the whole notion of disability.

15:32
HH: The whole concept of disability is forever evolving and newer models are always being proposed and models that include chronic illness and neurodiversity are also out there.

15:48
HH: But it is the social model of disability that we endorse and want to build upon.

15:52
HH: There's a brilliant video by the charity Scope that actually talks about the social model of disability, what it means to us as disabled people.

16:04
HH: So as well as the social model of disability, kind of building on that is the UN Convention on the

Rights of Persons with Disabilities, which says much the same as the social model of disability but taking this in a human rights perspective and giving it that social justice viewpoint as well.

16:27
HH: And so from this convention was established the International Day of Disabled People, or Persons with Disabilities as they like to call it, on the 3rd of December every year, which now actually forms part of the Disability History Month that runs from mid November to mid-december.

16:48
HH: So it's a time for us to raise awareness of what the challenges we face as disabled people, but also to celebrate ourselves.

16:57
HH: And of course, there can be nothing about us without us, that we have to be front and centre in any conversations or campaigns or, or changes that affect us.

17:11
HH: And that is frankly everything.

17:14
HH: So disabled people need to be front and centre in all conversations and be present in the in the room and heard and valued.

17:24
HH: So there's this, this kind of notion, this, this concept in academia, the ideal academic.

17:31
HH: And you'll read a few of these kinds of qualities of what an ideal academic should be.

17:38
HH: This comes from work from Professor Kate Sanger, Heriot Watt University.

17:43
HH: And these concepts like you have to be a man to be an ideal academic.

17:49
HH: You can't go to the toilet.

17:52
HH: You, you have to go to every conference there is.

17:55
HH: There's no way you could have caring responsibilities.

17:58
HH: You can work 24/7.

18:01
HH: All of these, all of these ideals make this kind of model of what an ideal academic should be.

18:08
HH: But this model, this mould is, is a mould that we're forced to kind of fit into.

18:15
HH: But this mould is breaking people and people are leaving academia, taking their talents with them because we don't fit this mould.

18:25
HH: So rather than this mould breaking us, it's time for us to break this mould so these preconceptions don't have to make us the successful academics we want to be.

18:39
HH: And our colleagues in NADSN have published wonderful books exploring ableism and academia by Jen Leigh and Nicole Brown, The Lived Experiences of Ableism in Academia, Disability and Higher Education by Gayle Brewer, just on the table there and talking about investigating those identities and stigma and disclosure amongst academics.

19:07
HH: Some brilliant resources there.

19:09
HH: A book on research for her from the Women in Academia support network too, and superhero scientists.

19:17
HH: So believe it or not, I, I feature in this book, but with wings on my wheelchair, which is great for the kids.

19:23
HH: So there's lots of resources out there trying to break down those stereotypes, break down that that mould that has been created for us.

19:39
HH: So we formed our STEM Action Group in 2020.

19:45
HH: Was it?

19:45
HH: Yeah, I think it was 2020 when we formed our group and but I think it was around the COVID pandemic at that time, wasn't it?

19:54
HH: When we all came together online and we, what we've have always wanted to do from the outset was to form recommendations, first of all, to state what the problems are, what are those barriers that we face as disabled people in STEM and then our recommendations of how to break those barriers down.

20:16
HH: So we did.

20:17
HH: I think I've lost mine.

20:21
HH: There we go.

20:22
HH: So what we did was to look at the three main themes and these barriers that we face within them and systems that we need to change.

20:35
HH: So those themes being enabling inclusive culture and practise, accessible and proactive funding and enhancing the accessible digital and physical environments.

20:50
HH: Was it enhancing?

20:52
HH: Yeah, and that's the word.

20:54
HH: So those are the themes that we kind of brought these experiences under and we went to all sorts of funding bodies and learning societies, welcomed the UKRI World Society, NIHR, many others and worked with our sister organisations like the Equality, Diversity and Inclusion in Science and Healthcare Group that that's housed by Wellcome, the women in academia support.

21:24
HH: Now we're chronically academic and tigers in STEM working with these people going to these funding bodies and presenting our problems statement to them, which we came up with.

21:37
HH: And so, yeah, Jasleen, sat over here also went to Parliament for us with Gayle as well and presented out one of the inquiries there around diversity and inclusion in STEM.

21:49
HH: And we've worked alongside also the Lightyear Foundation, which is trying to make STEM more accessible to disabled children to begin with.

21:58
HH: That's where we need to start these conversations from.

22:02
HH: We've worked, as I said, with the all party parliamentary group on diversity inclusion in STEM.

22:09
HH: EDICa is a framework that's just started up more recently.

22:14
HH: So the EDICa, which Kate leads from Heriot Watt University and we have some some great funding applications going into that, looking at specific barriers.

22:29
HH: So with Catherine Dean who is on the call, we have funding from them to look at accessible laboratories, for example.

22:38
HH: And then at the University of Sheffield, NADSN is a partner on their disability matches projects where disabled people are being put into the driving seat of health and science research instead of being the subject of it.

22:54
HH: And also their welcome anti-ableist research cultures projects again, trying to break down the ableism in our university research systems.

23:06
HH: So today is all about our white paper.

23:10
HH: And we're really, really excited to be presenting this and to be launching this officially today.

23:16
HH: This comes after how many years of work guys, four years of work as it goes into creating this paper.

23:26
HH: And if you have chance to read it, please do read it.

23:30
HH: It's a wonderful kind of collection of the evidence of the arguments of setting the scene of our experiences and then really presenting those recommendations which can make change.

23:44
HH: And those recommendations actually do a great job of bringing together some of the smaller

projects happening out there in terms of accessible laboratories, in terms of those projects like disability matters, anti-ableist projects.

24:02
HH: Actually, those recommendations are bringing all that work together and where we're trying to focus that in making the change we want to see happened in the sector.

24:13
HH: So I am extremely grateful to all the co-authors of this paper, Gayle, Yota, Frankie, Jasleen, Jen Leigh, Martyn, the other Jen and Julia for all working so tireless tirelessly in putting this paper together.

24:28
HH: Our hashtags for today going onwards is #NADSnWhitePaper and #DisabledInSTEMM.

24:39
HH: So please join us on socials with those hashtags to talk about what we're doing here today.

24:45
HH: So towards a fully inclusive environment for disabled people in STEMM is exactly what we want.

24:53
HH: The website is right there at the bottom.

24:55
HH: From there, if you go to the NADSN website and click on the subgroups, you'll come to the STEMM Action Group.

25:02
HH: And on that page, I believe the white paper is also online and ready to share far and wide.

25:10
HH: So please do so we as NADSN, we highly commend this work and hope it will make the change be desperately want to see.

25:23
HH: Thank you.

25:23
JR: Do a screen change over for the video.

25:33
JR: Jennifer, would you like to briefly give an outline of the video while I model my way through this?

25:46
JL: That working.

25:48
JL: So one of the projects that the NADSN STEMN Action Group got involved in was funded through NERC.

25:55
JL: Yoto, who's on the call, was the mastermind of this.

25:58
JL: And there was a bit of money to bring awareness to disability and inclusion in STEM.

26:03
JL: So we decided to make a short documentary which is aimed at provoking discussion and increasing awareness and also hopefully making people think about disability inclusion in STEM a little bit differently.

26:17
JL: And when we were working in the planning for this, it was very much, oh, let's go to a school and see some children doing science, which we did.

26:26
JL: And it was an amazing school, as you'll see.

26:29
JL: But we also wanted to make sure that there was a focus on disabled people doing science and being science professionals, which I think often gets lost in higher education.

26:38
JL: Particularly, we tend to focus on disability in terms of students.

26:41
JL: How do we support students?

26:42
JL: How do we include students and completely neglect that staff are also disabled?

26:48
JL: And by doing that, we're kind of creating more barriers and more obstacles.

26:51
JL: But I think we're ready to go.

26:53
JL: So hopefully I will be quiet and it'll be good to hear thoughts.

27:01
JL: The videos got subtitles throughout, so we said there was no need for interpretation.

39:21
JR: Talk from Jasleen, so let's have the website.

39:33
JJ: Before I start, please come and grab a drink, get some food.

39:39
JJ: There's loads of olives, crisps, chocolate.

39:42
JJ: Next bit is going to be intense, so you'll definitely want to drink.

39:54
JJ: And then we're going to go straight into the panel discussion afterwards.

39:59
JJ: So during the panel discussion, you're welcome to come and get food and drink.

40:10
JJ: OK, then maybe you forget that.

40:16
JJ: It's already described how to get to it, so that'll be fine.

40:21
JJ: And maybe just put the link to it in the chat.

40:46
JJ: Jen, join the table.

40:47
JJ: There's a chair for you at the end, and some water

41:43
Just thank you.

42:37
JJ: OK, we're ready to get going again.

43:05
JJ: OK, so working in healthcare, I see that it's really tempting to treat people with disabilities or chronic illnesses or people who are neurodivergent as patients only, but this is not the reality.

43:24
JJ: Illness or disability can affect anybody at any time in their lifetime and we saw this during the COVID pandemic.

43:35
JJ: When we say disability in this forum, we include people with chronic illnesses or and people who neurodivergent.

43:45
JJ: So I'm saying this is a catch all term because basically disability is defined as something that affects your ability to function in this world.

43:57
JJ: As Hamied already referred to, this world is built for people who are a certain way.

44:02
JJ: It's not a very inclusive world.

44:08
JJ: And so an accessible world is one that allows everyone to function no matter how they are.

44:19
JJ: So, we're referring to the social model of disability.

44:25
JJ: Disabled people are our colleagues, our friends, our loved ones, our neighbours.

44:33
JJ: And with disability on the rise, we absolutely cannot afford to exclude disabled people from the workplace.

44:44
JJ: We can't afford to lose their skills, their knowledge, and their valuable insights that they bring into the workplace and that their lived experience specifically brings.

44:58
JJ: As a healthcare worker, it doesn't feel right to me to support people and then just send them back out into a society that is then going to put them down.

45:11
JJ: I feel like I'm only doing half the job if I'm also not then going to advocate for a more inclusive society.

45:20
JJ: Science often attracts neurodivergent people who have another way of thinking, and this is a huge asset for problem solving.

45:31
JJ: But the social structures we have built around career progression make it impossible for many neurodivergent people to then navigate these structures.

45:43
JJ: So, this presents us with a really difficult dichotomy, and I have seen this when presenting on EDI panels when people have been described as difficult when asking for their needs.

46:00
JJ: Support needs to be met. By reducing support for disabled people.

46:08
JJ: It's a false economy because the taxes we pay and the skills we bring to the table more than cover the cost of the support that we require, especially when you consider that with getting adequate support to do a higher level job that I'm more than capable of doing.

46:37
JJ: I pay higher taxes.

46:39
JJ: But that's not what is going to end up happening if many of these policies are going to go down the way that they seem to be going.

46:51
JJ: Students get lots of support, but aren't we just setting them up to fail if they're then not going to carry on getting that support when they become staff members?

47:05
JJ: So, what's the point?

47:09
JJ: I have 3 degrees, over 20 years of experience, a successful track record and just last week I got my 90th peer reviewed publication accepted.

47:26
JJ: Lots of skills and knowledge and you get to keep me in the workplace for the low low cost of a support worker.

47:37
JJ: But that's now being threatened by these Access to Work changes that are possibly going to be taking that away from me.

47:55
JJ: And so I might not be able to continue working and setting the healthcare of tomorrow for my patients.

48:09
JJ: And that's because disabled people are easy targets for every single government and the media.

48:25
JJ: I also face constant discrimination which undermines my own sense of self.

48:35
JJ: I would also like to add here the importance of intersectionality.

48:40
JJ: As you can see, I am not just neurodivergent and have health problems.

48:47
JJ: There's a lot more to my identity.

48:50
JJ: I'm also brown.

48:51
JJ: I'm also a woman, the only box I don't tick on the minority list is LGBT.

49:01
JJ: Sadly, both aspects also make it harder for me to navigate life on this continent.

49:14
JJ: Yet the law doesn't recognise how difficult it is for me when you put all those things together and actually neither do institutions.

49:29
JJ: And because of that I've actually had to leave the university setting because of the discrimination I faced from all those three things.

49:41
JJ: Now I've actually been very fortunate because I've continued to be successful.

49:46
JJ: For now outside of the university setting, and I hope that continues, but it's come at a massive emotional and physical cost.

49:58
JJ: But how many other talented people have we lost to the system due to systematic barriers that have been put in their way?

50:11
JJ: How much more do we have to bleed before we actually take action and stop?

50:21
JJ: And how much more talent do we have to lose?

50:25
JJ: How many more skills do we have to lose?

50:30
JJ: And how many more of us are going to keep struggling on before we go?

50:33
JJ: I can't do this anymore.

50:41
JJ: But there is more to my identity than that.

50:45
JJ: I'm also a clinician, I'm a scientist, I'm a traveller, I'm a nature lover and I'm a lover of jigsaw puzzles.

50:54
JJ: Often feels like we're being asked to play oppression Olympics between each of the groups with protected characteristics.

51:02
JJ: We're put in competition with each of our own causes.

51:07
JJ: And to me it feels reminiscent of the British Empire, actually, all the empires where they got all their colonies to fight against each other so that we wouldn't upset the status quo.

51:21
JJ: Because if we're all bickering, then we can't fight against the true powers.

51:27
JJ: And that's what it feels like is happening within the EDI space.

51:32
JJ: But instead, we should be working together, supporting each other and, and that's where our power lies.

51:44
JJ: Disability is often the one aspect that is left out of the conversation in the EDI space or is a passing thought as it is so poorly understood and so highly judged.

52:03
JJ: But when you have disability and something else, it's actually magnified in a way that is greater than the sum of its parts.

52:18
JJ: No person is a single identity.

52:20
JJ: We're all a prism of multiple facets.

52:26
JJ: I could name any number of famous scientists and many of them you probably wouldn't even realise that they had disabilities that they were dealing with.

52:36
JJ: But I'm not going to do that because

52:40
JJ: We're not here to be your inspirations.

52:42
JJ: We shouldn't have to be exceptional to be allowed to function.

52:50
JJ: We just want to do a job like anyone of you.

52:56
JJ: We just want to be allowed to get on with our lives like everyone else.

53:04
JJ: In this white paper, we cover all of these issues.

53:09
JJ: Based on the evidence, we propose action points which are achievable in the short, medium and long term.

53:17
JJ: There are too many people doing endless surveys and we're tired of it.

53:22
JJ: We need action and we need it now.

53:27
JJ: We needed it yesterday actually, but we'll settle for now. In order to make workplaces inclusive.

53:36
JJ: There is so much evidence to show that this will not only help disabled employees but support the wider workforce, as we saw during the COVID pandemic.

53:50
JJ: There's also evidence to show that this makes research better.

53:56
JJ: If this country really wants to be at the forefront of STEM, this is the only way to go.

54:07
JJ: So, in the White paper we have action points for employers, for funders and for policy makers.

54:16
JJ: So, I do encourage all of you to identify the relevant action points, take them to the change makers in your organisations, hold them to account to get them to implement them.

54:34
JJ: Make noise to the government and hold your policy makers to account as you never know when you might be affected, when your loved ones might be affected.

54:46
JJ: There is so much evidence to show that your research will be improved by having a more diverse workforce.

54:56
JJ: And how can we say that our research is representing all populations or the populations we say that we're serving, if our research teams don't even represent those populations?

55:14
JJ: And I mean research teams.

55:16
JJ: I don't just mean patient participant involvement panels, because that's tokenism.

55:26
JJ: But this event isn't about just complaining or being disheartened in the view of all the recent bad news that has come out.

55:36
JJ: It's about celebrating positive action and not being despondent.

55:40
JJ: It's about showing that we can be proactive.

55:44
JJ: This white paper is about knowing that we can do something.

55:49

JJ: And so today we are celebrating the strengths that diversity brings and recognising that equity is about not giving an advantage, but instead levelling the playing field.

56:03
JJ: And that's what support is.

56:07
JJ: So I encourage you all to visit the website that we have built to dedicated to the STEMM Action Group that Hamied mentioned.

56:19
JJ: And it is going to be evolving.

56:22
JJ: So visit it frequently because as we develop this campaign, there's we're going to be uploading not only the white papers already up there, but we're going to be setting actions that you can all do, which will be updated frequently.

56:37
JJ: There'll be events, more papers coming out.

56:42
JJ: So please do keep going back and having a look at it.

56:46
JJ: Please do tweet.

56:50
JJ: It's not tweet anymore, but whatever it's called or on Blue Sky, LinkedIn, whatever social media platform of choice you have, spread the word to your networks by however means you can.

57:05
JJ: We need to get the word out.

57:07
JJ: We're going to be doing a write to your MP campaign at some point.

57:12
JJ: And yeah, take as much action, action as you can without making a noise.

57:17
JJ: We can't get change to actually happen.

57:21
JJ: And with that, I'm going to open up a panel discussion to my amazing co-authors.

57:29
JJ: And also I think we need to thank Jen for putting on this event.

57:33
JJ: She puts herself down far too much.

57:37
JJ: And we'll take all your questions and we need to get the discussion going.

57:43
JJ: So I'd love to hear from the audience both online and in the room about your thoughts as well.

57:49
JJ: Thank you.

58:04
JR: Straight to questions, straight to questions.

58:09
JR: Please say who you are and then say what your questions.

58:13
J: Hello, I am Julie, I am from the University of Glasgow and I have worked with some of your panellists today and in the past.

58:25
J: My question is something that I didn't know since the National Association is now an entity and do you also organise and deliver training for people or maybe workshops or maybe seminars for I?

58:43
J: I think we've had this discussion.

58:45
J: I do want to promote the social model of disability versus the medical one, but I do think especially higher education needs to hear that a little louder.

58:57
J: So that might not be something that you will you are doing or you will do in the future.

59:12
HH: Hello.

59:13
HH: Yeah, nice one.

59:14
HH: So thank you for the question, Julie.

59:17
HH: So, yeah, we, we are an entity now.

59:19
HH: So we could do things like that.

59:21
HH: But actually there are already brilliant organisations out there, our sister organisations, who would be able to deliver sessions around the social model of disability versus the medical model of disability.

59:34
HH: And we would be very happy to partner with those organisations in delivering something more catered for the higher education sector.

59:43
HH: Definitely.

59:44
HH: Thank you for the question.

59:45
JR: Any other questions from the audience?

59:50
JR: Yes, thank you.

59:56
E: Hi, my name is Emma Sewens.

59:57
E: I'm a trustee with the Scottish Union for Supported Employment.

1:00:02
E: I was just interested in what you said and that very personal and very impassioned talk.

1:00:08
E: So thank you for that, about more inclusive workplaces not just being beneficial for disabled people, but benefiting the whole workforce.

1:00:16
E: I wondered about is there something about

1:00:20
E: Wider society and some of the perceptions around this, that if something is worth doing because it benefits disabled people, that in some way that's not good enough for everybody and that you have to prove how it benefits everyone else in order for it to have weight.

1:00:37
E: And.

1:00:38
E: And if that is the case, how, how do you feel about that?

1:00:42
JJ: Yeah, I think that very much is the impression.

1:00:48
JJ: I know many of the changes, many of the changes that were implemented in in during COVID were requested by disabled people for many, many years beforehand and were never implemented, even though they clearly were easy to implement until they benefited the wider population.

1:01:16
JJ: So yes, unfortunately there is the perception that just benefiting disabled people isn't worth it.

1:01:24
JJ: And then on the other hand, you've got the rhetoric that disabled people don't work, they're lazy.

1:01:29
JJ: Well, how can they work when they don't get supported?

1:01:34
JJ: And now you've got all the cuts that the government have announced.

1:01:37
JJ: So disabled people are in this catch 22 situation.

1:01:41
JJ: They desperately want to work but they can't without the right accommodations.

1:01:47
JJ: And then they meant they're made to feel bad about the accommodations.

1:01:55
Panellist: If I could just add in, I think there's also a fundamental misconception about accommodations.

1:02:02

Panellist: It is often, or they are often perceived as a leg up or an unfair advantage where we are simply asking to be on the level playing field.

1:02:13
Panellist: We are asking, for example, that our funding applications do not disadvantage us because we are incorporating basic needs into them.

1:02:23
Panellist: And I think it's really important to try to get that message across.

1:02:28
Panellist: And certainly one of the issues the disabled scientists encounter is a perception that, well, you're a doctor, you're a professor, you can't be disabled because you have reached a particular level in your profession, which simply isn't the case.

1:02:46
Panellist: So I think there's there needs to be a broader conversation about why are these accommodations a necessity?

1:02:55
Panellist: What do they actually do in terms of allowing somebody to reach their potential?

1:03:01
Panellist: And why do we not or why should we not talk about just getting disabled people into work?

1:03:08
Panellist: Why should we be talking about helping people or supporting them to get into the professions that they are trained to go into?

1:03:17
JR: Have you got any other questions?

1:03:23
JR: Oh yeah, Sally.

1:03:28
SC: Thanks Jen.

1:03:29
SC: Hello there.

1:03:30
SC: I'm Sally Conde.

1:03:30
SC: I work for Glasgow Council for the Voluntary Sector, so the voluntary sector organisation, not

academia, but been working with Jen and other universities on all sorts of opportunities really and have a real interest.

1:03:42
SC: We've got a project called the three projects, third sector human rights and equalities first approach projects.

1:03:48
SC: So lots of interest.

1:03:49
SC: And I guess I was really struck by Jen's first comment about we tend to talk to each other and it and I'm hearing yes, tweet it and yet or whatever the new version is and those sorts of things.

1:04:00
SC: But I'm just a bit worried that we're still going to do that.

1:04:03
SC: This looks like an absolutely brilliant paper, but how do we stop talking to each other and how do we know when we're want to make those messages really happen?

1:04:14
JJ: We need, we need to get, we need to get policy people on board.

1:04:22
JJ: So whether it's policy people at the university, policy people in government, policy people at the funding bodies, they are the people we need to get on board.

1:04:35
JJ: So our next event that we're doing in London is with the Welcome Trust and that event is going to be focusing on the policy makers.

1:04:54
FD: It really is a case of an absolute paradigm shift is needed in relation to how disabled people, including neurodivergent people, are perceived.

1:05:03
FD: And it's time for an absolute end to this vilification of how we are seen the way that we are infantilized and treated as subhuman and lazy and work shy when we're not.

1:05:19
FD: It's horrific what's going on, especially with the way that even the Prime Minister is saying that

1:05:27
FD: The budget has gone up, the welfare budget has gone up since COVID is because of people's mental health.

1:05:35
FD: There's too many of autistic people being diagnosed without even acknowledging why there's an increased post COVID lockdowns such as oh more adults becoming aware that they might be neurodivergent or the fact that there's been backlogs because of people not being able to get assessments in place and the COVID pandemic in itself has affected people's mental health.

1:06:01
FD: It's absolutely horrific the way that we are being seen as being a burden on society and blaming that.

1:06:10
FD: And honestly the PIP reforms are absolutely horrific when they are already brutal enough as it is, traumatic enough.

1:06:23
FD: They are degrading and full of lies in the assessments and it's no wonder really that so many get overturned at tribunal and yet they're wanting to take money even more away more, make it even harder.

1:06:39
FD: It's going to end up pushing even more people out of work in the end rather than trying to get more people in place in the workforce, especially when Access to Work is also being eroded.

1:06:51
FD: And yet they're saying, oh, we need to make it harder, make diagnosis harder to fit their narrative.

1:06:57
FD: And that's just because, oh, we need to save money from one end.

1:07:01
FD: So we're going to take it from disabled people because they're easy to target.

1:07:04
Panellist: I think there's a thing we, you know, people are saying that like mental health issues are over diagnosed, but we don't say that broken arms are over diagnosed.

1:07:14
Panellist: So we need to move the narrative.

1:07:15
Panellist: This isn't a choice necessarily.

1:07:18
Panellist: And there's been a conflation.

1:07:20

Panellist: And I think the current policy suggestions, I'm going to call them suggestions because hopefully they won't come back, are associating PIP assessments with work, PIP assessments with work.

1:07:33
Panellist: Sorry, but PIP is not actually supposed to be anything to do with work.

1:07:38
Panellist: It's supposed to help offset the extra and additional costs that come with being disabled.

1:07:44
Panellist: And conflating the two doesn't help.

1:07:46
Panellist: So we need to be really careful about making sure that there are separate conversations around PIP, around Access to Work, around reasonable adjustments.

1:07:55
Panellist: Melanie has put a thing we need to think about what's reasonable, who decides what's reasonable?

1:08:00
Panellist: It's not like we're asking for white kittens, although I personally quite like some kittens that don't have to be white.

1:08:07
Panellist: But we need to make sure that these things are separate, but also that they're research evidence.

1:08:12
Panellist: If you look through the white paper, you'll see that there are vignettes which are a way to try and engage people with the emotional impact because yes, we're passionate.

1:08:23
Panellist: Yes, we many of us have personally experienced these things, but this isn't our story.

1:08:26
Panellist: This is many people's stories about their experiences in science and around science.

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Panellist: So we wanted to try and highlight the emotional impact, but also make sure that that is backed up with robust evidence and data.

1:08:42
JJ: I also think the media has a really big part to play in this.

1:08:48

JJ: We invited so much media to this launch and unfortunately, they haven't been very good at engaging with us.

1:08:56
JJ: Though the IOP did did put out a story.

1:09:02
JJ: as Editor’s choice today, which is fantastic, but the mainstream media has not engaged very well, which has saddens me because this is very topical based on what's going on in the news at the moment.

1:09:20
JJ: But unless they're vilifying disabled people, they're not interested.

1:09:28
JJ: And I think I unfortunately, I think that's, that's just the way it is.

1:09:32
JJ: It's very, very sad.

1:09:34
JJ: And when you're faced with that, plus all the discrimination you're facing, plus the suffering from your diseases, is there any wonder that many people with chronic illnesses, disabilities, neurodivergence have mental health issues?

1:09:55
JJ: If you didn't, you'd be superhuman.

1:09:58
JJ: I don't think that's true depression.

1:10:00
JJ: That's a normal response to the challenges you're facing.

1:10:05
JJ: And so I study, one of my topics is the psychological impact to visual impairment.

1:10:13
JJ: And I, I think conflating depression and the response to all of this stuff that's going on is, is wrong because if you didn't have a mental health response to all of that, you wouldn't, you literally wouldn't be human.

1:10:34
JJ: I mean, just think back to COVID.

1:10:35
JJ: People who were shielding were not allowed out of the house.

1:10:38
JJ: We were not allowed to have a mental health with being cooped up.

1:10:46
JJ: Everyone else was, but not those of us who were shielding.

1:10:54
JJ: Where's the justification?

1:10:58
JJ: We were expected to be superhuman.

1:11:03
FD: And it's also worth bearing in mind that this is still carrying on for people who have increased vulnerability to COVID, such as those of us who are immunocompromised.

1:11:14
FD: It's still going on.

1:11:16
FD: It is still a fear.

1:11:17
FD: There are still people out there needing to shield in effect as and when they can, even though all the barriers now are being removed.

1:11:26
FD: And it is absolutely petrifying to the list because people just are now acting like, oh, COVID is over, it's gone.

1:11:35
FD: No, it's still carrying on.

1:11:36
FD: And just in relation to some of the fears that are happening around these cuts, it makes you think, when are they going to stop?

1:11:46
FD: Are they going to make it even stricter in the future?

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FD: How disabled is disabled enough in order to get support?

1:11:53
FD: And it's straying very scarily into eugenics territories territory.

1:11:58
FD: And it's been going on for a long time.

1:12:00
FD: And it is a very, very slippery slope.

1:12:03
FD: And we can see what's going on.

1:12:06
FD: That needs to stop and it needs to change.

1:12:09
FD: That's why we need such a crucial paradigm shift, really.

1:12:12
JJ: And yet, despite all of this, you've got people who are desperately trying to have a career.

1:12:19
JJ: I mean, if you want anyone to work for you, you want someone like that because you know they are going to succeed no matter what.

1:12:32
GB: I just wanted to add that, you know, we all grew up at a time when we didn't exist in terms of, you know, seeing other people who were successful, fulfilled, you know, making a valuable contribution to society.

1:12:50
GB: Those role models didn't exist.

1:12:53
GB: And we still exist at a time where it is assumed perhaps that undergraduate students might be disabled, perhaps maybe a master's, and then less so and less so and less so.

1:13:10
GB: We are not seen to exist and we are not catered for and it is absolutely imperative that people recognise that disabled scientists exist, that they make a really valuable contribution to the sector, often having insights that others might not have, you know, whether that's from personal lived experience, whether that's from a creative way of thinking.

1:13:37
GB: And we have started, for example, to recognise that rather than perhaps doing research on disabled people, we should do research with them and involve, you know, patients and people in the design process and that the conduct process of research.

1:13:57

GB: But it's time for research led by disabled people, so people who have both the lived experience and the expertise, through their education and their skill development, to lead on those sorts of projects.

1:14:13
GB: And we see these kinds of experiences as something valuable, as something important, and not something to ignore.

1:14:22
GB: You know, it has been far too long for people to be waiting to be recognised and we're not asking to be, you know, put on a pedestal or recognise as some form of inspiration porn.

1:14:36
GB: We're just asking to be able to do our jobs in a way that recognises that there are some things that should be put in place to make sure that we're not disadvantaged.

1:14:49
GB: Because if that doesn't happen, we won't be in the workforce.

1:14:53
GB: And all that experience, all that knowledge, the skills that we have developed will be lost from science.

1:15:01
GB: And that is an incredible shame if you have talented people who really want to do their own disciplinary work and are also doing often a lot of advocacy work as well.

1:15:14
GB: But we'll be lost from that sector.

1:15:20
MMS: Just to continue that point that Gayle made, we absolutely do need role models, more role models for, you know, disabled scientists.

1:15:30
MMS: And we've seen it, you know, being extended across, you know, other walks of life.

1:15:36
MMS: You know, the disabled people can excel.

1:15:38
MMS: I mean, who would have thought that a deaf person could win Strictly Come Dancing?

1:15:42
MMS: You know, these are examples where people can excel.

1:15:47

MMS: I mean, I'm an example of a person that became disabled after having reached the peak of my career.

1:15:54
MMS: I became deaf and partially sighted in my 40s and just to the point where I was being invited to give seminars at prestigious conferences.

1:16:05
MMS: And I remember one example where I went to a conference.

1:16:09
MMS: So this was a peak of my career.

1:16:11
MMS: And apparently I gave a very good talk when it came to questions.

1:16:15
MMS: I floundered it.

1:16:17
MMS: I just, I couldn't hear.

1:16:18
MMS: I realised that in the room I couldn't hear the questions.

1:16:22
MMS: I've not been asked to give many talk since then.

1:16:25
MMS: Whether that meant I didn't do a good job with the questions, I'm not sure, but that's just an example.

1:16:31
MMS: And then everything starts to slide and it slid and I was, my job was threatened.

1:16:39
MMS: You know, I'm a researcher and a teacher, more on the research side of things before the pandemic.

1:16:44
MMS: And my job was threatened because my research productivity went down.

1:16:48
MMS: And it was said, if you can't get your lab going, Martin, we're going to have to change your your career pathway.

1:16:55
MMS: And then suddenly overnight, the pandemic hit and everybody was at home expected to only teach.

1:17:03
MMS: And then suddenly captions came in.

1:17:06
MMS: It kind of natural for people to communicate with through remote working captions were there and I could now engage with society.

1:17:17
MMS: I could now engage with my colleagues and Access To Work bought me two massive monitors so I could see the captions and I could now fully engage and see more clearly what I was involved in with the research.

1:17:33
MMS: So that's a a personal story.

1:17:35
MMS: I hope you didn't mind me sharing that is the solutions are there and I hope that story has demonstrated very quite simple changes, captions and larger monitors and inverting contrast.

1:17:52
MMS: These are all examples of simple things that instantly meant that I could go back doing my original job that I was expected to do.

1:18:01
MMS: Thank you.

1:18:01
JR: Thank you.

1:18:03
JR: We've got Melanie on the screen who's had her hand up for quite a while.

1:18:06
JR: Melanie, do you want to unmute and ask your question?

1:18:10
M: Yeah.

1:18:11
M: Hi folks.

1:18:12
M: Lovely to see quite a lot of my tribe here today.

1:18:17
M: Sorry I couldn't be there.

1:18:18
M: It's tad far away from London.

1:18:21
M: I just obviously I concur on pretty much everything that's been said.

1:18:27
M: So I'm not going to say all of that because we'll be here for three weeks.

1:18:31
M: One, I'll put the stuff about reasonable adjustments.

1:18:37
M: It irks me no end and I find it highly offensive.

1:18:42
M: I think another one of the media rhetorics, which I'm sure quite a few people are going to be nodding, is not everybody is on the spectrum.

1:18:53
M: I'm a neurotypical person.

1:18:56
M: My gobby students referred to me as neuronormative if they feel like it, or neurovanilla.

1:19:03
M: But I do know quite a bit about it.

1:19:05
M: And I do know that a lot of the students and staff that I work with are neurodivergent.

1:19:13
M: Struggle navigating.

1:19:15
M: I work in the university.

1:19:16
M: So it's, it's, it's, it's like a, it's not a real life environment anyway.

1:19:21
M: It's a very strange place.

1:19:23
M: But saying oh, everybody's on the spectrum negates the difficulties that my students and my colleagues deal with on a day-to-day basis.

1:19:35
M: I did want to add something.

1:19:38
M: I'm a little bit joyful.

1:19:42
M: I'm an outreach.

1:19:43
M: I'm a disability outreach officer and part of my job is I actually employ some of our self selected self identifying disabled students.

1:19:53
M: And I currently have two neurodivergent students of mine on fully funded PhDs, both in science fields.

1:20:04
M: So there is looking for good practice is like really really hard.

1:20:11
M: But my 2, they get DSA, they get support, within their cohorts, they are not marginalised.

1:20:28
M: At all my concern about this is that when they do leave our environment, they are going to come up against all the stuff that my colleagues here have been experiencing.

1:20:46
M: But you know, to get fully funded PhD scholarships is quite an awesome event and with added neurodivergence on top of that, I think it's absolutely amazing.

1:20:58
M: So I just wanted to share something lovely.

1:21:00
M: I'll shut up now.

1:21:02
JR: Always good to have good news.

1:21:04
JR: Yeah, absolutely.

1:21:05
JR: Everyone's giving you the wave.

1:21:06
JR: If you can't see us because your camera's facing front, we're giving you a big wave.

1:21:10
JR: And so we'll go more questions, but also feel free to comment to each other like you can make this a discussion.

1:21:17
JR: And it would be great if we also continue to crowdsource expertise on Sally's questions.

1:21:22
JR: How do we stop talking to each other and start talking to the people that we're struggling with?

1:21:27
JR: I know Jane and Jodie, you've had your hands up for a little while, so I'll come to Jane and then Jodie.

1:21:36
JE: Hi Jane, Essex University of Strathclyde.

1:21:40
JE: We've talked about sort of the need for research informed evidence and I absolutely agree.

1:21:50
JE: But one of the problems, and not everybody here may be aware of it, is there's quite a bias against people who want to research disability in anything other than the context of a poor wain type.

1:22:07
JE: And I'm particularly interested I'm so I'm going to be a bit naughty, but Wellcome and now engaging.

1:22:13
JE: That is excellent because they have systematically declined to fund work involving young people with additional support needs/ SEND for a long time.

1:22:27
JE: And I think this is, I don't know where the panel agrees, but if you haven't encountered this, would it be fair to say that one of the policy changes we need is that study researching that relates to people with disabilities should not start from the assumption that there is no value in such a study, which is often the response when I apply for funding.

1:22:52
JE: Why would you want to waste time on that?

1:22:54
JE: I've had it said to me.

1:22:56
JE: So perhaps policy needs to look at these, the ways in which we are silenced in the evidence body by extreme bias in funding bodies.

1:23:10
GB: Others might want to chip in here, but I absolutely agree.

1:23:14
GB: I think there is very little EDI focus funding.

1:23:20
GB: It's certainly a challenge that we've had and the people who are typically doing this work are those who are themselves marginalised or facing additional challenges, which makes it even more difficult for them to do both their disciplinary work and the EDI work.

1:23:40
GB: We do have a number of suggestions in the White Paper aimed at the funders and how this can be addressed.

1:23:49
GB: But I think that the work needs to be recognised and valued, not just from a human point of view, but from an economic, from a scientific type of approach.

1:24:01
GB: Because often it isn't funded and it isn't necessarily taken into account, let's say in promotion criteria etcetera.

1:24:10
GB: So there's a sector wide issue as well as an issue which effects people's professional development.

1:24:19
GB: Yeah, I'm very happy to take this one.

1:24:23
Panellist: In terms of education, Nuffield might be a good shout because I specialise in my own case, my children.

1:24:30
Audience Member: I love working with my heart, but because my working with children with complex ASM, they're very individual when we do science and spend with them and I can't do, I don't think it's

honest to do statistical work because work like that just turns to extremes into a meaningless out of the job.

1:25:02
Audience Member: And what I think we need to engage with something that it wasn't like research is different, but of equal value and equal value and potential and therefore nothing.

1:25:14
Audience Member: No, they're not interested.

1:25:19
Panellist: Yeah, well, I mean, I'm a qualitative researcher, I think, and a lot of my work is around academic culture and research culture, which is not seen as fundamental discovery research.

1:25:30
Panellist: It's not seen as fundamental to do science, which I shout at Wellcome and lots of people about.

1:25:37
Panellist: Yeah, look at the interface.

1:25:38
Panellist: I shouldn't normally with lots of swear words.

1:25:42
Panellist: But I think one of the things, I think there are several points definitely as Gayle said that we have said that we need to have EDIA work.

1:25:51
Panellist: So including the accessibility to equality or equity and diversity and inclusion, we need to have that recognised, we need to have it valued, we need to have it funded.

1:26:01
Panellist: Because even people and funders like the Royal Society of Chemistry who have done so much good work and do a lot of good work, when they have a funding call that time you're not allowed to include time, you're not allowed to include buy outs.

1:26:15
Panellist: And so what that means is that the grant, even if you win a grant, it's seen as less worthy, less valuable, less important than other kinds of funding which bring in FEC estates costs.

1:26:26
Panellist: And it means that you also have to do that work above and beyond and over, over and above even your day-to-day job.

1:26:32
Panellist: So even though you brought in money, you're just giving yourself more work.

1:26:36
Panellist: And in terms of promotion is what you said, a lot of the advocacy work that I've done, marginalisation, which has been published in top journals, I have colleagues who are co-authors who've had to remove that from promotion applications because it would detract from them being seen as a proper scientist.

1:26:53
Panellist: So it's really, really difficult.

1:26:55
Panellist: And we do need like a culture change around this.

1:26:58
And that's going to be incredibly hard, particularly with everything that's going on in the United States, where I think we know unless we're careful, anything to do with inclusion is just going to be something that funders don't want to touch because they're scared.

1:27:14
Panellist: And I don't know what to do apart from saying we probably need to shout the fact that we have got Wellcome on boards.

1:27:20
Panellist: They are funding the London event, which is aimed at policy makers.

1:27:25
Panellist: And they have said that they're, they're currently having like a huge restructure and this kind of work is going to be more valued.

1:27:31
Panellist: Whether that will translate into them giving us giving me millions of pounds just to do the work that we know needs doing, I don't know yet.

1:27:38
Panellist: Exactly.

1:27:39
Panellist: I'll cross my fingers all the time.

1:27:40
Panellist: I think every time I see Shamari, I'm like, can you give me some money?

1:27:43
Panellist: He says no.

1:27:44
Panellist: Is it all right if I keep asking?

1:27:45
Panellist: He says yes.

1:27:46
Panellist: So I keep asking.

1:27:48
But it is really, really hard.

1:27:50
Panellist: And it's quite scary, I think at the moment.

1:27:54
HH: Jane, we need you to come to the to the event in London.

1:27:57
HH: Since it's being hosted by Wellcome, We'll have the.

1:28:06
HH: We're hoping you know, on this discussion actually around disability and how we get more people into the room on disability.

1:28:14
HH: So what we're trying to do now with the Wellcome event particularly is to get the CEO of welcome those kind of top level people into the room to talk about these issues.

1:28:24
HH: Because usually ends up just being the EDI leads or the, the, whoever the, you know, the senior people are doing the EDI.

1:28:33
HH: They get invited into the room or sent by their CEOs while they kind of just ignore the conversation really.

1:28:42
HH: So it's about bringing them in somehow into that room to talk to them and make them involved and get them to commit to understand firstly and to commit to actually make some action happen.

1:28:57
JJ: That's why you've got to keep checking the website because before that event we need to build momentum to make sure that there's a lot of pressure on the policy makers before they even get there.

1:29:12
JJ: So we are going to be having a lot of proactive campaigns before that event and creating a lot of

noise and forcing people to take notice of us, including the media, including the policy makers, and we have some big ideas.

1:29:34
FD: I think that's one of the things that I often encounter, at the very least as an excuse as to why not to do this.

1:29:42
FD: It's too hard work, it's too expensive and it's the same old, same old all the time about disability inclusion.

1:29:50
FD: It's too difficult to do, it's too costly, it's too expensive.

1:29:55
FD: Why bother?

1:29:56
FD: And that seems, it seems even more critical now more than ever, that we have to change that view, that perspective, that it is valuable to make this inclusive and to change this narrative, change this perspective that people have, that it is not too hard work, that it is not too expensive.

1:30:22
HH Nancy, you had your hand up before.

1:30:25
NH: Yes, I did.

1:30:26
NH: I didn't know whether I should say anything.

1:30:28
NH: Oh, my name is Nancy Hansen.

1:30:30
NH: I'm from the University of Manitoba in Canada.

1:30:35
NH: And the same thing is happening over here.

1:30:38
NH: There's, there's so an initiative in, in, in a quotation marks where they're trying to make, they're trying to make research more inclusive, but it's rather like putting lipstick on a pig.

1:31:00
NH: They're tinkering around with language, but the actual process itself hasn't changed.

1:31:06
NH: So what's happening is that we're still being excluded by institutions that never wanted us there in the 1st place.

1:31:14
NH: So I think this is an incredibly important initiative.

1:31:18
NH: I think that the most dangerous question we can pose to funders continuously is why are you doing this?

1:31:26
NH: And hold them to account and, and don't be subtle because they don't get subtle.

1:31:31
NH: I think we have to really get in there and, and be up at ecrypts, if you will.

1:31:38
NH: So congratulations on this fine initiative.

1:31:40
NH: I think it it's a very important step in something that really needs to be taken care of.

1:31:46
NH: And we've been waiting for far too long for the rest of the world to catch up to what we know we can do.

1:31:51
NH: Thank you very much.

1:31:53
HH: Thank you, Nancy.

1:31:54
I'm just going to pass the mic over to Jodie.

1:31:59
J: Hi.

1:31:59
J: I'm Jodie from the story gentled earlier about me rounding up a group of grown men to get them to listen.

1:32:08
J: Yeah.

1:32:10
J: Yeah, I thank you for this paper.

1:32:13
J: I think it's a really, really exciting paper as someone who is neurodiverse and in academia and as of the start of this month is now in an EDI role nationwide in Scotland.

1:32:26
J: I'm very excited about a lot of what's mentioned here.

1:32:28
J: And actually, I'm doing a lot of what's mentioned in here, but I'm quite conscious that a lot of the stuff in the sort of medium to longer term requires getting the attention off organisations who don't like to pay attention.

1:32:41
J: And I say this as someone who specialises in LGBTQIA + inclusion and has spent six years trying to convince people to change a little flag that they use for a fun run, which is rainbow to a little flag that they use for the Queer community.

1:32:56
J: I did it, but it took six years.

1:32:58
J: The point of all of this is for me to question, I guess, what we can do to like as people external who can like maintain momentum. Because I'm conscious with my pessimistic day-to-day academic head on that when you go towards a white paper, there's a lot of excitement and a lot of momentum.

1:33:18
J: And that's great and completely valid.

1:33:20
J: And you mentioned things like REF 2029.

1:33:23
J: But how do we make sure that the momentum continues?

1:33:26
J: And particularly when we're in such a intense and alarming news cycle, how do we make sure that it doesn't get lost and keep going?

1:33:33
J: Because it's something that I think is critically important, but it doesn't happen.

1:33:37
J: Sorry, that was a lot of rambling, but hopefully you got my question.

1:33:43
JJ: I think one of the unfortunately money talks loudest.

1:33:50
JJ: So one of the strongest cases you can make is financial.

1:33:55
JJ: As I said in my talk, it's a false economy to cut back on the support for disabled people.

1:34:02
JJ: The amount of support I get from Access To Work is less than the way, way, way less than the amount of tax I pay.

1:34:14
JJ: But right now, that support is a is threatened by the Access To Work changes being proposed.

1:34:23
JJ: Take that support away.

1:34:24
JJ: Take my support worker away.

1:34:26
JJ: I've actually cannot work.

1:34:31
JJ: So it's a false economy.

1:34:34
JJ: It's a completely false economy for this government, for any government.

1:34:40
JJ: So you make the economic argument, you're more likely to get people to pay attention.

1:34:50
JJ: I think we were talking about it earlier.

1:34:52
JJ: And Gayle, you made you made the good point that, you know, with my qualifications, it's pointless me doing low level things like putting numbers in a spreadsheet.

1:35:09
JJ: You want to pay me to do the actual research of directing it, of thinking about the ideas of figuring out where to go.

1:35:18
JJ: That's what I need to engage my brain and energy on, not the little admin tasks that the support worker helps me with.

1:35:30
JJ: So yeah, unfortunately that that's the best language I can think of right now.

1:35:40
JJ: With the language that I hear other people talking about, the moral arguments don't seem to hold any ground.

1:35:48
GB: I would also add in that, you know, we need everybody to keep it on the agenda.

1:35:56
GB: And that can be as simple as when you initiatives are announced, being that ally who puts their hand up and says, but how does this affect disabled colleagues?

1:36:09
GB: Because we often don't talk about the emotional toll that it takes as well as, you know, being quite confronting sometimes always being that person in a meeting who is perhaps putting their head above the parapet and saying we need to take a step back and think about our disabled colleagues, etcetera.

1:36:29
GB: So I think making sure that it is on the agenda because disability is often the last thing on an EDIA list because it's not associated with a charter in the same way.

1:36:45
GB: So things like that, but also pointing out some of the advantages as Jasleen said, of, of addressing these things.

1:36:54
GB: So we've talked a reasonable amount today about, you know, some of the funding that's required in the investment, but lots of these things don't need funding or investment and actually a lot of things can be really financially advantageous.

1:37:08
GB: For anybody in the room who has been an external examiner at a university, you will be familiar with the experience pre pandemic of spending the whole day on a train to go to a one or two hour meeting and sit and look through some spreadsheets and then go home.

1:37:29
GB: I don't know how much that used to cost all the universities in terms of buffets and train costs and so on.

1:37:38
GB: But I can certainly say from the human side of it how exhausting it used to be to spend the entire day doing that and then getting home late at night.

1:37:47
GB: Whereas now it's kind of normal to go to an external examiner meeting just by logging on.

1:37:55
GB: I've got the whole rest of the day to do my work and it's saving them money by not requesting my physical attendance.

1:38:04
GB: So I think there are lots of other things that we can be doing to, to kind of implement practice, albeit often on a lower, if you like, level of the scale, but to influence our immediate environments and immediate sectors.

1:38:19
Panellist: I just, I would just like to add that you've got six years experience or more of doing this.

1:38:24
Panellist: Tell us, talk to us, give us some ideas, help please.

1:38:30
JR: OK, we're running.

1:38:31
JR: We're running out of time for the panel.

1:38:34
JR: Stuart, you had your hand up earlier, did you, did you want to say something just because you've had your hand up for a while?

1:38:44
S: So thanks to everyone for all that helpful speech season sessions and I have added to the paper.

1:38:50
S: One thing which came up from some of my colleagues was about how we could increase the uptake and let the qualifications offered, then the skills, and they were seen a bit doing more about the careers side, about what's an offer out there and how these could be made more accessible.

1:39:07
S: What plans does this programme of work have to help with that and how could individuals get involved in helping support that?

1:39:17
HH: Yeah, about careers in schools and colleges and how we get into that.

1:39:27
Panellist: About normalising direction, so partly it's about learning how to use a microphone, but so increasing the awareness, not inspiration porn which is not the same as disability porn.

1:39:44
Panellist: That's something completely different.

1:39:46
HH: Thank you, thank you for clearing that.

1:39:49
Panellist: Just so you know, so things like the Research Her book, which was on Hamied's side, which kind of is showing lots of different pathways for women in academia.

1:39:59
Panellist: I think the Royal Society and the Royal Society of Chemistry have done that kind of life history case studies.

1:40:06
Panellist: Look, look at these people and where they've gone, which I do think are valuable because it's showcasing people and having role models.

1:40:13
Panellist: The flip side of that is.

1:40:15
Panellist: Not everyone wants to be a role model or has to be a disabled academic.

1:40:19
Panellist: They might just want to be a scientist and not always known as a disabled scientist.

1:40:24
Panellist: But I think it is about showing that it is possible.

1:40:26
Panellist: And if we don't have the role models, then it's about showing young people that there is a willingness for them to be in that space, which we can't do if it's not accessible.

1:40:35
Panellist: I would also say that there's work to be done around challenging the disability narratives.

1:40:43
Panellist: So a lot of the time a description of a condition is can't do X, difficult to do Y.

1:40:53
Panellist: We need to be thinking about the strengths associated with different conditions and the

skills and the adaptability and all of these sorts of things which are advantageous to somebody who's going into the workplace.

1:41:08
Panellist: So I think addressing some of the deficits associated language around disability is also important and of course, educating the employers as well as the students.

1:41:22
HH: One of my sorry, go on Martin, you go 1st and then me.

1:41:26
MMS: OK, I'm, I'm struggling to keep, keep up with all of the conversation here because I rely on lip reading.

1:41:32
MMS: I should learn BSL.

1:41:34
MMS: Actually, I, I just want to add in an extra thought here about, you know, many of the comments have been made and you might be sitting there thinking, well, you know, it's an uphill struggle.

1:41:46
MMS: How are we going to change things in our institute in our, in our area of employment?

1:41:53
MMS: You know, I think we collectively have had a lot of experience in changing practises within our own institutes and changing policies, procedures, ordinances within universities to try and make them less, reduce the level of ableism that's there.

1:42:13
MMS: And I hope that we can offer, you know, advice.

1:42:17
MMS: You come to us to, you know, to gain advice, you know, if you're struggling with those in Leicester.

1:42:23
MMS: We have just got to the level of the Leader level, the highest level of the disability confidence scheme.

1:42:31
MMS: And, and we've gained that by changing many, many of the, the practices and policies and application forms there.

1:42:39
MMS: And I'm sure my colleagues and say they've also done similar through their networks.

1:42:45
MMS: So that was just a thought.

1:42:48
HH: I mean, so growing up my role model, I guess in a way was one of the probably one of the most famous disabled scientists of the time, which was Professor Stephen Hawkin in his famous wheelchair and had his computer speaking for him.

1:43:07
HH: He was a huge kind of role model for me that somebody who's who is visibly disabled could be such an amazing scientist.

1:43:18
HH: But the contributions he made to the field were, you know, extraordinary as that disabled person.

1:43:25
HH: But one of my favourite sci-fi programmes was Star Trek.

1:43:29
HH: Anybody remember Star Trek?

1:43:31
HH: So in the Next Generation, like there's this this episode where Stephen Hawking's kind of appears and he sits at this billiards table playing cards with Isaac Newton and Einstein all sat at the same table.

1:43:46
HH: And that image and where Stephen Hawking is assisted by Commander Data, but that image of those scientists sitting together, one disabled, the others not disabled, not visibly anyway.

1:43:59
HH: Sitting together, playing cards together was a huge kind of image for me and a huge support to me that can be done.

1:44:07
HH: That disabled people can contribute science on an equal level to non-disabled people if they have the support they need in place.

1:44:17
HH: And that equity that we require that we need to do that Stephen Hawkins and and Einstein and Isaac, old white men.

1:44:26
HH: And of course we have much more diversity amongst ourselves, our scientists in the field and intersecting with race, ethnicity, gender, all sorts for their identities.

1:44:37
HH: But just an example that is possible if we make it happen.

1:44:42
HH: So that's, I mean that they were very privileged people, privileges we don't have.

1:44:48
HH: But if we had the support we need, we could also contribute to the field in that same way.

1:44:55
JR: That feels like the perfect note to end on.

1:44:57
JR: So we've run a bit over time, but I think that was to be expected.

1:45:02
JR: Please spend the last five minutes talking to each other, talking to us, sharing contact details, if you have ideas to share or ideas you want to crowdsource from this group.

1:45:13
JR: We definitely need to go back to Sally's question and how do we stop?

1:45:16
JR: And I remember talking you through as it was happening.

1:45:19
JR: I was like this, this group said, no, there's been no response from this Faculty of science.

1:45:24
JR: There's been no response from the Faculty of engineering at this uni, this uni, this uni.

1:45:29
JR: And then we would get emails saying we've forwarded this to our EDI representative.

1:45:33
JR: And I'd be like, I don't want it to go to your EDI representative because they probably get it.

1:45:38
JR: I want to talk to the research lead, who has the budget, who's organising the meetings, who's doing procurement.

1:45:44
JR: And at one point I am going to manage to convince everyone to go on dirty protest about it.

1:45:48
JR: But until then, we're going to have to follow the standard approach to improving inclusivity.

1:45:53
JR: But you're part of it.

1:45:54
JR: You're here.

1:45:55
JR: Thank you so much for coming.

1:45:56
JR: Yeah, use this last time to eat as many crisps as you can, pocket a bottle of whatever you like, and hopefully we'll see you soon at another event.

1:46:07
JR: Thank you very much for coming.

1:46:08
Thank you so much.