

NADSN



National Association of Disabled Staff Networks

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Greetings!

We are the **National Association of Disabled Staff Networks (NADSN)**, a super-network connecting and representing disabled staff networks. We are a Community Interest Company (CIC) made up of and led by impassioned disabled people; we are non-governmental, independent, and self-determining. We act as a collective platform to share expertise, experience, and good practice. We focus on the tertiary education (i.e. further and higher education) and public sectors and are open to any individual and organisation interested in intersectional equity and the inclusion of disabled staff. We endorse the Social Model of Disability, especially within the social justice and human rights contexts.

The **NADSN STEMM Action Group** is an active steering group within NADSN comprised of people with experience of disability, chronic illness, and/or neurodivergence, who work in and around the STEMM (science, technology, engineering, mathematics and medicine) disciplines. Since its inception in 2020, members have worked to develop recommendations for funders, institutions, and disciplines to address barriers faced by those who are marginalised due to disability.

NADSN and its STEMM Action Group are proud to present:

**Towards a fully inclusive environment for disabled people in STEMM:
A NADSN White Paper.**

We commend this position paper to all concerned.

Kindest regards,

Dr Hamied Haroon, Mrs Jacqueline Nicholson and Mr Stuart Moore
Directors, NADSN CIC

Towards a fully inclusive environment for disabled people in STEMM[‡]: A NADSN White Paper.

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Executive Summary

This White Paper aims to:

- Raise awareness of the inequity and discrimination experienced by disabled people in STEM;
- Highlight the benefits of an inclusive STEM environment that values disabled people and supports their career development;
- Provide short, medium, and long-term recommendations to address systemic ableism in STEM; and
- Promote understanding and transformative change to improve the experiences of disabled people in STEM including the sharing of good practice.

Our recommendations are that funders, learned societies, and higher education and research institutions work together to:

In the short-term:

1. Recognise the specific challenges and barriers for disabled researchers to enter, remain, and progress in STEM.
2. Improve work-based training for managers and allies around disability, neurodivergence, chronic illness and intersectionality.
3. Build inclusivity into operational systems and structures, and provide clear, timely routes for requesting and receiving adjustments/accommodations.
4. Ring-fence and publicise specific funds for disability support.
5. Budget for and improve physical environments for disabled researchers.
6. Provide support for accessing research funding from pre-application to post-award.

In the medium-term:

7. Endorse an intersectional framework for disability and inclusion in higher education and research.
8. Require organisations to be held accountable to their working practice policies; with regular reviews to ensure they are accessible, inclusive, embed meaningful consultation, co-design, Equality Impact Assessments, and Equality/Equity, Diversity, Inclusion and Accessibility (EDIA).
9. Establish Access to Work pathways for disabled researchers.
10. Reconceptualise the indicators for 'good' research, researchers, and environments.
11. Stop promoting and funding toxic research cultures.
12. Allow disabled academics to work part-time with no detriment to their pension or opportunities for progression.

In the long-term:

13. Create inclusive research cultures and ecosystems.
14. Recognise and reward work in research cultures and ecosystems.
15. Change equality law to recognise the impact of intersectional discrimination.

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The National Association of Disabled Staff Networks

The National Association of Disabled Staff Networks (NADSN) is a super-network connecting and representing disabled staff networks. We are a Community Interest Company made up of impassioned people; we are non-governmental, independent, and self-determining. We act as a collective platform to share expertise, experience, and good practice. We focus on the tertiary education sector (i.e. Further and Higher Education) and are open to any individual and organisation interested in intersectional equity and the inclusion of disabled staff. NADSN has been involved in the identification of People, Culture, Environment indicators for the 2029 Research Excellence Framework with Vitae and CRAC, and has contributed to the Good Practice in Research network.

The **NADSN STEM Action Group** is an active steering group comprised of people with experience of disability, chronic illness, and/or neurodivergence, who are working in and around the STEM disciplines. Since its inception in 2020, members have worked to develop recommendations for funders, institutions, and disciplines to address barriers faced by those who are marginalised due to disability.

NADSN STEM Action Group outputs

- NADSN Response to the Women and Equalities Committee Inquiry to scrutinise the implementation and further development of the National Disability Strategy. Evidence accepted and published by the Women and Equalities Committee March 2023 (Ref: NDS0011).
- NADSN response to the Diversity and Inclusion in STEM Inquiry. Written evidence accepted and published by the Science and Technology Committee January 2022 (Ref: DIV0017). Oral evidence presented by NADSN members April 2022 (HC903). Report published March 2023.
- NADSN Response to the Public Accounts Committee Inquiry on Revising Health Assessments for Disability Benefits. Evidence submitted June 2023 (Ref: OKC494623).

Guiding principles

We recognise that ableism is endemic in society and that the barriers faced by disabled people in STEMM are extensive and systemic.

We aspire to attitudinal and structural transformation, the end to exclusion and discrimination of disabled people, and genuine inclusion and celebration of diversity in all forms.

We are mindful that while we are focusing on disability, discrimination is intersectional, and there is great heterogeneity in the experiences of disabled people.

To achieve genuine disability inclusion, urgent transformation is needed, and equity, diversity, inclusivity, and accessibility (EDIA) principles must be embedded at the heart of all work.

There is an urgent need for funding bodies, Higher Education Institutions (HEIs) and Learned Societies to acknowledge and address the systemic, attitudinal, and physical barriers which exclude and discriminate against disabled people in STEMM. Even within EDIA specific forums, disability is an under-discussed and under-represented issue.

While we have focused on recommendations for disabled people, building in inclusivity and accessibility will improve working conditions for everyone. Addressing unrealistic expectations of researchers and normalising adjustments such as working from home, will protect careers for anyone experiencing a temporary change in their circumstances; due to caring responsibilities, an accident, short-term illness, or a consequence of ageing.

Terminology and language

The language used to describe disability varies across different disabled communities and the world. In this document, we use 'identity-first' language consistent with the UK Disability Justice movement. We recognise different language preferences (e.g., identity first or person first language) across individuals and communities and will continue to reflect on and adapt our use of terminology as appropriate.

We use 'equity' instead of and together with 'equality'. Equality describes a state in which all people are treated in the same way. Equality does not consider whether some people face greater barriers than others, or do not start from the same place. Equity allows provision of additional support to overcome additional barriers so everyone can arrive in the same place. Equality alone will not remove systemic barriers.

Why address disability inclusion in STEMM?

The proportion of disabled people in the population is increasing; from 16% of the working population in the UK in 2018 to 22% in 2021. In 2024, the proportion of the working age population thought to have a condition that would be recognised as a disability under the 2010 Equality Act is estimated at 30%.¹ Yet the proportion of academics known to have a disability according to the UK Higher Education Statistics Authority is just 6.4% (an increase from 3.9% in 2014).² Statistics generally underestimate disabled populations. They cannot include people who do not have or who are waiting for a diagnosis, people who meet the legal definition of disability but choose not to disclose due to fear of stigma or discrimination, or people who do not identify as disabled.³

Many groups are underrepresented in STEMM^{4,5} including disabled people.⁶ There are systemic problems of harassment and bullying within scientific research cultures⁷ which are magnified for disabled scientists; 62% experience bullying or harassment compared to 'only' 43% across all scientists.⁷ Unsurprisingly, the numbers of people sharing their disability are lower in STEMM than other disciplines, with declaration rates lowest where there is a pronounced gender imbalance.⁸ Disabled scientists face barriers due to ableism, discrimination, a lack of accessibility, and a lack of awareness, which combine to create a hostile and unsupportive working environment that makes it harder for them to progress.⁹⁻¹² They are underrepresented in the membership and committees of Learned Societies. Less than 1% of applications for UKRI[†] research funding are from researchers disclosing a disability,^{5,13-16} and when they do apply, disabled researchers are awarded less than half the amount compared to non-disabled researchers.¹⁷

Disabled people are less likely to become leaders in science,¹⁸ and as a result, disabled people have little visible influence over research. These factors are intersectional,^{19‡} which means they compound for those who are further marginalised for example due to their race or ethnicity, gender, or sexuality,²⁰⁻²⁵ and contribute to the lack of diversity within the scientific community. Diversity is crucial to ensure the best people, culture, and environments for scientific research.^{7,26} Diversity helps build public trust in science²⁷ and health research.²⁸ When there is diversity throughout every level of the scientific community, a scientific career becomes more accessible.²⁹ Diversity helps prevent the epistemic injustice that excludes disadvantaged communities from contributing to research and research agendas.³⁰

Disabled people are often positioned as participants in or subjects of research and innovation; excluded from meaningful participation or seen as an underutilised epistemic resource for scientists.³¹ In contrast, this White Paper sets out the conditions needed to promote inclusive and accessible environments that will support disabled scientists to achieve success and mean their unique perspectives, expertise, and innovative approaches contribute to scientific progress.

[†] United Kingdom Research and Innovation

[‡] Intersectionality is a term developed by Kimberlé Crenshaw to describe the compounding barriers Black women faced due to sexism and racism. It is used here to describe the compounding barriers an individual may face if they are disabled and also identify with one (or more) other protected characteristic(s) such as race, ethnicity, religion, sexuality, or gender.

Disability in society

The Equality Act (2010)³² considers a person to be disabled if they have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on their ability to perform normal daily activities. Disability has traditionally been framed as a consequence of physical disease or injury that must be repaired to restore 'normal' function. This 'medical model' of disability is focused at the level of the individual and disability is seen as an impairment.³³ By implication, the medical model positions disabled people as 'less than' their non-disabled peers. The medical model amplifies misconceptions about disabled people's capabilities, performance, and ability to contribute to society and the economy. It feeds into the idea that disabled people are outsiders, that they suffer or are victims of their disability and require 'fixing' by expert medical professionals. This ableism, or pejorative view of disabled people contributes to the stigma around being disabled as well as the discrimination, barriers, and microaggressions so many disabled people face every day.^{34,35}

In contrast, the social model of disability, as developed by Michael Oliver,³⁶ makes a clear distinction between the physical, mental, or sensory experience associated with a condition and the disabling impact of the social, physical, and cultural environment. The social model places the emphasis on society and societal change in order to 'fix' the issues of disability. It moves responsibility for access and engagement from individual disabled people and makes it collective. It recognises that excluding disabled people is a social choice. The social model is inclusive by design, recognising everyone who is disabled by exclusion and inaccessibility, whether they identify as disabled or not. This means that proponents of the model acknowledge that anyone can become disabled in any sphere of their life, including work, at any time. The social model differentiates between how people can be disabled by their environment and society and the impairment experiences caused by their condition. It frames disabled people rather than medical professionals as the experts of their experience. Other models such as the Capability Model³⁷ and Affirmation Model³⁸ place a greater emphasis on contextual factors and positive social identity, though both reject the idea that disability is an individual deficit.

Most disabilities are not visible, and not all disabilities are physical.³⁹ Disability encompasses mental health conditions, neurodivergences (including Autism, Attention Deficit Hyperactivity Disorder (ADHD), Dyslexia, and Epilepsy), long term physical health conditions, mobility impairments, brain injuries, and symptoms without diagnosis. Disability may exist throughout a person's life or be acquired at any age through illness or accident. The symptoms and impact of a condition on daily life may fluctuate. Many effects of disability are not apparent externally such as chronic pain, mental health conditions, and autoimmune conditions. Disabilities can be subject to a 'hierarchy'⁴⁰ that deems some more or less socially acceptable or subject to stigma and discrimination than others. Some chronic illnesses are seen as being more worthy of support or understanding (for example cancer vs fibromyalgia).³⁹ Many disabilities, chronic illnesses or neurodivergences are not visible to others, yet they still impact day-to-day life.³⁹ Disability is intersectional.¹⁹ Systemic health inequalities⁴¹ compounded by poorer health outcomes for disabled people⁴² impact diagnosis,^{43,44}

healthcare,⁴⁵ and the prevalence and severity of disability. The incidence of disability varies with ethnicity. The 2021 UK Census recorded the highest proportions[§] of disabled people within the "White: Gypsy or Traveller" (33.2% in England; 39.1% in Wales) and "Mixed or Multiple ethnic groups: White and Black Caribbean" (22.4% in England; 26.7% in Wales) categories.⁴⁶

In line with the World Health Organisation,⁴² and the United Nations Convention on the Rights of Persons with Disabilities⁴⁷ NADSN endorses and supports the social model of disability in all of its work. We stand by the ideology "nothing about us without us".

[§] age-standardised rates of disability

Disability in work

Employers have a legal responsibility to make reasonable adjustments for disabled employees.⁴⁸ In addition, the government complements employer adjustments or accommodations and provides additional support for disabled people to get into or stay in work and overcome workplace barriers through the Access to Work scheme.⁴⁹ The Department for Work and Pensions highlighted that investing in and supporting disabled people to gain and retain employment “makes economic sense” in 2011.⁵⁰ Adaptations developed specifically for disabled people can be of substantial benefit to the wider population, as seen with the technological solutions for remote working for disabled employees prior to the COVID-19 pandemic which became a standard working solution during lockdowns.⁵¹ Money spent through Access to Work was estimated to yield a 1.5 greater return for the Exchequer, with the social benefit even higher.⁵⁰ However, the Office for National Statistics reported 2023 employment rates for disabled people⁵² of only 53.0% compared to an employment rate of 81.6% for non-disabled people.

There is a significant disability pay gap. The median rate of pay for disabled people was just £13.69 per hour compared to £15.69 per hour for non-disabled people.⁵³ Occupation was one of the factors contributing to the overall disability pay gap of 12.7%. However, the two highest occupation categories had high levels of uncertainty as fewer people were employed at these levels. Senior leaders/managers/directors had a pay gap of 11.1% (confidence interval 4.5 - 17.3 percentage points) and professionals had a pay gap of 8.4% (confidence interval 4.8 – 11.9 percentage points).

The disability pay gap is affected by gender (narrower for men), full-time/part-time status (narrower for part-time), severity of disability (narrower for those less impacted in their day-to-day life), and type of disability. Autistic people experience the highest disability pay gap at 27.9%.⁵³ In comparison, the pay gap for Epileptics is 26.9%, and for people with severe or specific learning difficulties is 20.3%.⁵³ When the data are controlled for occupation by adjusting pay levels to those working in professional occupations such as scientists, the pay gap for Autistic employees narrowed to 15.3 percentage points.⁵³ Where there is a greater share of employees in a professional occupation this would tend to equate to a higher level of pay, so the narrowing of the gap implies there is a smaller proportion of Autistic people working at this occupational level. The 2024 Buckland review highlighted only 36% of autistic graduates were likely to be employed 15 months after graduation. It reported: “*Autistic graduates are most likely to be overqualified for the job they have, most likely to be on zero-hours contracts, and least likely to be in a permanent role.*”⁵⁴ Neurodivergences such as ADHD and Autism are often trivialised as being ‘overdiagnosed’,⁵⁵ with ‘sufferers’ seen as broken.^{56,57} Neurodivergent people with physical health conditions can find their concerns and needs dismissed due to a lack of awareness and understanding of comorbidity.^{58,59} It is likely the stigma and discrimination faced by Autistic people contribute to their low employment rates and the large pay gap.

Disability in Higher Education

Disabled people are less likely to attain the level of qualification necessary for a career in STEM. In 2021 only 24.9% of disabled people aged 21-64 had a degree as their highest qualification compared to 42.7% of non-disabled people.⁶⁰ The proportion of undergraduates declaring a disability increased in the period 2014 - 2023; from 11.6 to 18.9% overall and in STEM subjects from 11.1% to 19.4%.^{61(p44)} For postgraduate research students (MRes/PhD) over the same period the overall proportion of disabled students grew from 7.0% to 16.0% and in STEM from 6.2% to 14.6%.^{61(p44)} The proportion of disabled students accessing funded adjustments is low; only 24% of doctoral students with a declared disability are in receipt of Disabled Students Allowance.⁶²

Despite the prevalence of disability increasing with age which might lead us to expect an increase in numbers of disabled staff compared to students,⁴⁶ the number of academics known to have a disability according to the UK Higher Education Statistics Authority is just 6.4% (an increase from 3.9% in 2014).² The Higher Education Statistics Authority do not break down disability according to disciplines. Drawing on data from Learned Societies, we can see the proportions of disabled people in STEM are lower than those in the wider population. The Royal Society of Chemistry surveys its members regularly and reported 4% as disabled in 2022, though up to 10% potentially met the 2010 Equality Act definition of disability as they described experiencing barriers or limitations in their day-to-day activities.⁶³ According to analysis by the Lighthouse Foundation, the proportion of disabled physicists has fallen from 14% to 7.7% in recent years.⁶⁴ The proportion of disabled staff in Higher Education falls with seniority; from 6.7% at the most junior level of academic contract, to 5.8% at a senior level and only 4.5% at professorial level, demonstrating the endemic ableism or discrimination against disabled people in academia.⁶⁵⁻⁶⁷ When line managers are ableist they act as career blockers, preventing their progression and scapegoating their success.⁶⁸ Diversity data for science demonstrate that the STEM workforce has fewer women and other minoritised genders, LGBTQIA+** people, Black, and other marginalised race and ethnic groups, and that the proportions and numbers of marginalised individuals decreases with seniority.^{5,16,20,23,24} As such, any actions taken to address ableism in STEM must also consider the broader lack of diversity.²⁷

EDIA in Higher Education and academia is largely leveraged through sector initiatives such as Advance-HE's Athena SWAN^{69,70} and Race Equality Charter Mark^{71,72} which have at times been linked to research funding incentives. Such schemes are thought to have contributed to improved research culture⁷³ though are not without criticism of being too policy focused to bring about real change.^{74,75} In comparison, there is often less emphasis placed on disability within institutional strategies⁷⁶ and very little evidence that voluntary initiatives aimed at employers such as Disability Confident or Two Ticks have had any impact for disabled people.^{77,78} Without a legal or financial incentive it can be challenging to address institutional ableism.

** Lesbian, Gay, Bisexual, Trans, Queer, Questioning, Intersex, Asexual, with the + holding space for other identities including Two-Spirit and Pansexual.

Equality/Equity, Diversity, Inclusion, and Accessibility (EDIA) in STEMM

The NADSN STEMM Action Group conducted a collaborative autoethnography^{79–81} over four years to capture lived experiences of disabled scientists. This did not need ethical approval, as all those involved in data gathering were also involved in the analysis and dissemination of findings and chose to be named as an author (or not). As a collective we analysed our data thematically identifying areas in need of reform to create an initial problem statement. In this we identified three overlapping themes of areas in need of reform to fully include disabled scientists (see Figure 1 and Appendix 1):

- **Enabling inclusive cultures and practices;**
- **Enhancing accessible physical and digital environments; and**
- **Accessible and proactive funding.**

We then consulted with a wider network of scientists and EDIA specialists. The responses illustrate how disabled scientists experienced the burdens of pressure, lack of job security, disclosure, and the impact on mental health. After further analysis of the collaborative autoethnographic data and consultation responses, we identified common burdens, suggested solutions, and formulated short, medium, and long-term evidence-based recommendations for funders, Learned Societies, and institutions. These are presented below, organised into two core themes; ‘Burdens’ and ‘Solutions’, which are illustrated with quotes from respondents to the problem statement. Burdens incorporates the sub-themes ‘Reasonable’ adjustments’ and ‘Pressure’. Solutions incorporates the sub themes ‘Environmental’, ‘Recognition’, and ‘Inclusion’.

We synthesised research-based, creative, non-fictional vignettes⁸² to illustrate disabled scientists’ experiences; sharing “*true* but not *real*”⁸³ stories. This strategy was successfully used to highlight the embodied and emotive experiences of women and other marginalised groups in STEMM by the award-winning International Women in Supramolecular Chemistry Network.²⁵ Audiences respond differently to creative research outputs.⁸⁴ They are a means to humanise stories so they resonate with people who have similar experiences, reassuring them their voices are being heard, and allow emotional connection so those who have not are able to relate and understand the impact.

There is limited literature on the human impact of the specific barriers faced by disabled staff in STEMM.^{9,10,18,35} This White Paper and our recommendations add to that. They are intentionally intersectional and incorporate the awareness that lived experiences of disability are diverse and intersect with other minorities and marginalised identities. They are made in the context of the Social Model of Disability,³⁶ the UN Convention on the Rights of Persons with Disabilities,⁴⁷ the ideology *Nothing About Us Without Us*⁸⁵, and incorporating the recommendations made in *Ableism in Academia*⁶⁶ and *Disability in Higher Education*.⁶⁷

Recommendations

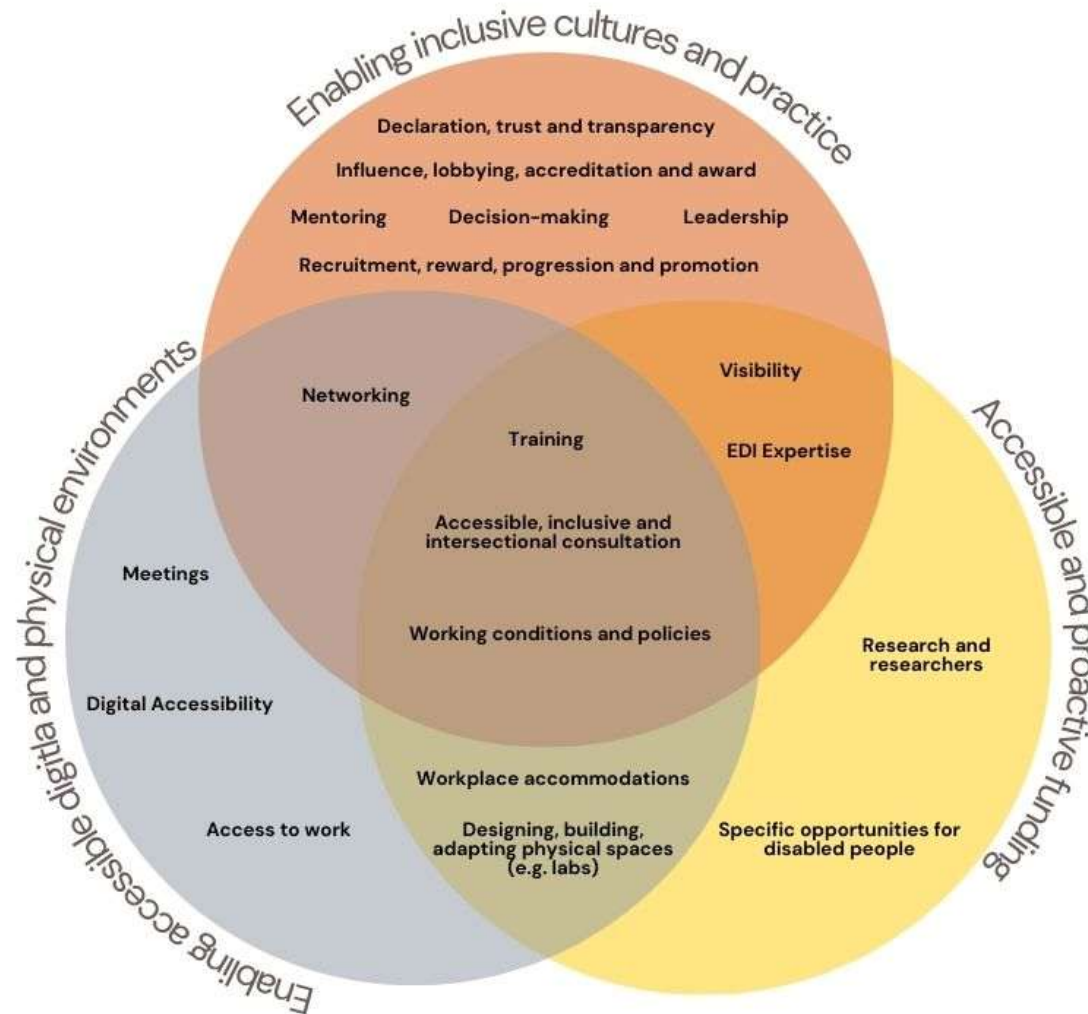


Figure 1: Venn Diagram showing recommendations and overlapping themes of Enabling accessible digital and physical environments, Enabling inclusive cultures and practices, and Accessible and proactive funding.

Burdens

Just because I am disabled, it does not mean I am not capable. No, it is not true that my **[visual impairment / hearing impairment / physical disability / neurodivergence / mental health / chronic pain*]** means that I do not belong in science. Yes, I can still do my job. No, I cannot work the 70+ hours a week that seems to be necessary in academia right now, but that is because it is **inhumane**. Not because I am disabled.

***please delete as applicable**

A consistent theme identified in the problem statement and responses was the positioning of the disabled researcher as 'the problem'. This resonates with the medical model of disability, which sees the disabled person as an 'impaired' person, and situates the problem in them rather than recognising the systemic barriers in the policies, practices, and physical environment around them.

'Reasonable' adjustments

Looking at me you might think that I've made it. I'm here. I've even got the *Nature* papers and the funding. I'm doing things that will help make the world a better place. I just wish it all came with an instruction manual. But the moment I disclose my disability it is weaponised against me. I have to "disclose" like it's something to be ashamed of. Like my gender. My ethnicity. Sexuality. Then I'm accused of playing the diversity card as though that's the only reason I am here. Disability is not the 'sexy' face of EDI. Everyone is playing Oppression Olympics. I could go to any number of networks for marginalised women, or any number of acronyms: LGBT, BME, BAME, BIPOC whatever you want to call it. But there's not even an 'A' for Accessibility. Disability rarely gets a look in or when it does it's only students who are allowed to be disabled. Succeeding in education means you must be 'normal'. I am that definition of a driven, ambitious, and hyper-productive academic. But what is the cost? The worst leaders I have known have been like that. They expect everyone to work long and punishing hours. To follow the same path. I don't want to be like that. I'm lucky because I thrive on pressure. All I want to do is science. This is my happy place. What I never realised is that the skills I need to be a researcher, to be a scientist, are not the same as the ones I need to deal with this toxic culture. I can do the science no problem, but that doesn't mean that I know how to manage people or the never-ending politics and people-pleasing I never knew I would have to do just to get access to facilities, let alone help.

Resources and policies invariably designed to provide a route to accessibility and inclusion were described as being weaponised and used as barriers to exclude disabled people, for example health and safety initiatives in laboratories.⁸⁶ Although employers have a legal duty to provide reasonable adjustments, the definition of what is 'reasonable' or not can be disputed.⁸⁷ Reasonable adjustments could include provision of specialist or adaptive equipment such as large screens, ergonomic chairs, or speech-to-text software. It might also include installing visible alarms, wider walkways, or powered doors. Although retro-fitting a laboratory for accessibility might be prohibitively expensive compared to designing in inclusivity to a new-build, there are many small and inexpensive adaptations that improve accessibility in laboratory environments.⁸⁶ One of the most effective in terms of cost and impact is to fund highly qualified laboratory technicians and managers. Lab technicians and managers would be able to support disabled researchers with physical tasks such as placing samples in a nuclear magnetic resonance (NMR) machine, pipetting, carrying large flasks of solvent, preparing experiments, running experiments where the primary researcher is offsite, and maintaining equipment which would help reduce noise within the lab. In doing so, *all* researchers would be supported, not just disabled ones. Disabled researchers would have support so their ideas and research design were the primary drivers of their work, rather than having to 'make do' with what was accessible to them. Disabled researchers should not be put in a situation where a physical limitation, a need to work remotely to protect their health, or any disability-related reason shapes or stops their science.

There are significant costs associated with disability; such as specialist equipment and assistance. While universities have structures in place to support disabled students, there are typically less well developed or less well funded equivalents for academic, professional services, and technical staff:

"The university funds services for students but not for staff and that means we have hosts of staff who are struggling to get the correct support"

"It is important to recognise [that] the need for such support applies to postgraduate students who are employed to support teaching and learning."

This lack of support can be particularly challenging for scientific researchers, who are often employed on successions of short-term contracts lasting around three months to three years when they are early-career.⁸⁸ Expectations that researchers are able to move to a new location regularly are challenging for people with complex medical or care needs who are not easily able to leave the support they have in place. Access to Work is not designed for this work environment as support is specific to a job rather than an individual and does not automatically move with them to a new position even if the role is similar. Numbers asking for help from Access to Work have increased in line with the numbers of disabled people in employment;⁵² yet they still support less than 1.5% of employed disabled people.⁸⁹ Backlogs mean that although Access to Work states it fast-tracks new employees within six weeks, wait-times in December 2024 were around nine months. Disabled researchers on short term contracts find themselves without support or unable to work for the majority or entirety of their contract. In addition, changes to the staff guidance in May 2024 impaired the service Access to Work is offering to customers. New practices and policies appear

ableist and assume disabled people are incapable of working at senior levels or understanding the nature of the tasks they do. Advisors and case managers appear to be focused on saving costs rather than supporting individual needs above and beyond employers' reasonable adjustments or facilitating economic growth. Disabled scientists are finding their support cut, and being allocated administrative rather than scientific support, putting their work and livelihoods at risk. Rather than breaking down barriers for disabled people in work, Access to Work is now introducing additional obstructions through confusing categories and limitations of both hours and wages for support workers and job aides. The scheme no longer appears to be able to adequately support disabled people with professional or highly skilled careers earning significantly above the £13.69 median wage for disabled people.

Reasonable adjustments are not just for physical environments. Accommodations can be used to ensure that documents and agendas are shared ahead of meetings, or to account for the additional time it takes disabled people to carry out specific tasks. For example, lectures are commonly allocated 50 minutes for content delivery with 10 minutes to move between rooms or sites. If it takes a person with a mobility impairment 20 minutes to walk to the allotted lecture theatre and back, the one-hour slot will in reality take up 1 hour 30 minutes of their time. Similarly, if there is an expectation that academics mark four assignments per hour and because of a disability they can only mark two and a half in that time, marking a cohort of 20 would take eight hours instead of five. Reasonable adjustments in workload allocation models could be applied to account for such discrepancies so that disabled people are not further disadvantaged in comparison to their peers.

Reasonable adjustments can also provide flexibility around activities that contribute towards cases for promotion and allow for differences in communication styles. For example, an Autistic person might find the 'political' aspects of academia more challenging because they are misread or struggle to read others easily. An accommodation might be for written communication rather than in-person meetings without an agenda.

Barriers to reasonable adjustments are often due to opaque systems coupled with those with budgetary responsibility and decision-making power having a lack of training and knowledge about disability in STEMM. Increased awareness and designated contacts would help:

"Better understanding of STEMM specific access solutions including assistive technology specific to tasks and systems required for a particular field."

"Having a specific resource and a contact to advise individuals and their employers on what is available seems to be very much needed."

Disability without adequate support extracts emotional and health tolls. Disabled researchers shared feeling increased stress, depression, and low self-esteem over and above the low mental health experienced by the majority of academics from the start of their career.^{90,91} Disclosure⁹² was particularly challenging due to fears around discrimination, being seen as less valuable, productive, or less value for money by funders and employers because of additional disability-related costs. Disabled researchers fear being seen as uncompetitive due to lower productivity than their non-disabled peers:

“Acknowledge the impact of productivity-limiting disabilities in academia, such as not having the energy to work extra hours to write up papers, attend optional lectures, or engaging in CV-boosting volunteer work.”

“It would be nice if these limitations were explicitly acknowledged, so that candidates were judged more fairly compared to their non-disabled peers.”

Disabled academics often experience cumulative fatigue which cannot be overcome through standard annual leave, and find it necessary to shift to part-time contracts or take extended periods of unpaid leave.⁹³ Disability is not a “sickness” and disability-related leave should be separated from standard sickness leave. Many disabled people require planned treatments and recovery time to manage the effects of their disability. Extended periods of leave can impact career progression. Institutional policies and practices need to be flexible, recognise the additional challenges faced by disabled staff, that disabilities can change over time, and that disability is not a monolith:

“With regards [to] disability, it is pervasive, but also a catch-all, so experienced in very different ways.”

There is an expectation that researchers travel and disseminate their research. However, travelling as a disabled person might necessitate additional nights before and after an event to prevent pain or injury, incurring extra costs for subsistence and a longer time away from home and the laboratory or workplace, decreasing the amount of time available for research. Such additional expenses are not routinely recognised or approved leaving disabled researchers having to choose to self-fund or being excluded and isolated. Without access to support, it is harder for a disabled researcher to demonstrate their standing within the scientific community and further their career as expected. As a result, securing promotion can be a struggle and careers can plateau. This contributes to the lack of visibly disabled researchers at the most senior levels.¹⁸ We heard from disabled people being forcibly ‘encouraged’ onto less prestigious career paths, working part-time to manage their condition, or exiting the workforce prematurely because there were no real alternatives:

“Need to make sure diverse career paths can be recognized through promotion processes, with emphasis on quality rather than quantity.”

“Expansion of job roles and career prospects to include a broader range of permanent positions with exclusively research or teaching focus (or a hybrid with greater flexibility than the current options) is essential if universities hope to retain or attract staff that simply cannot remain in academia under the current conditions.”

Decisions like these have short and long-term financial consequences. Many pension schemes will offer incapacity or ill-health benefits, but there is no legal requirement to accommodate the financial implications of working part-time due to disability. A consideration of the effects of disability on long-term employment should be embedded within any proposed overhaul of pension systems.

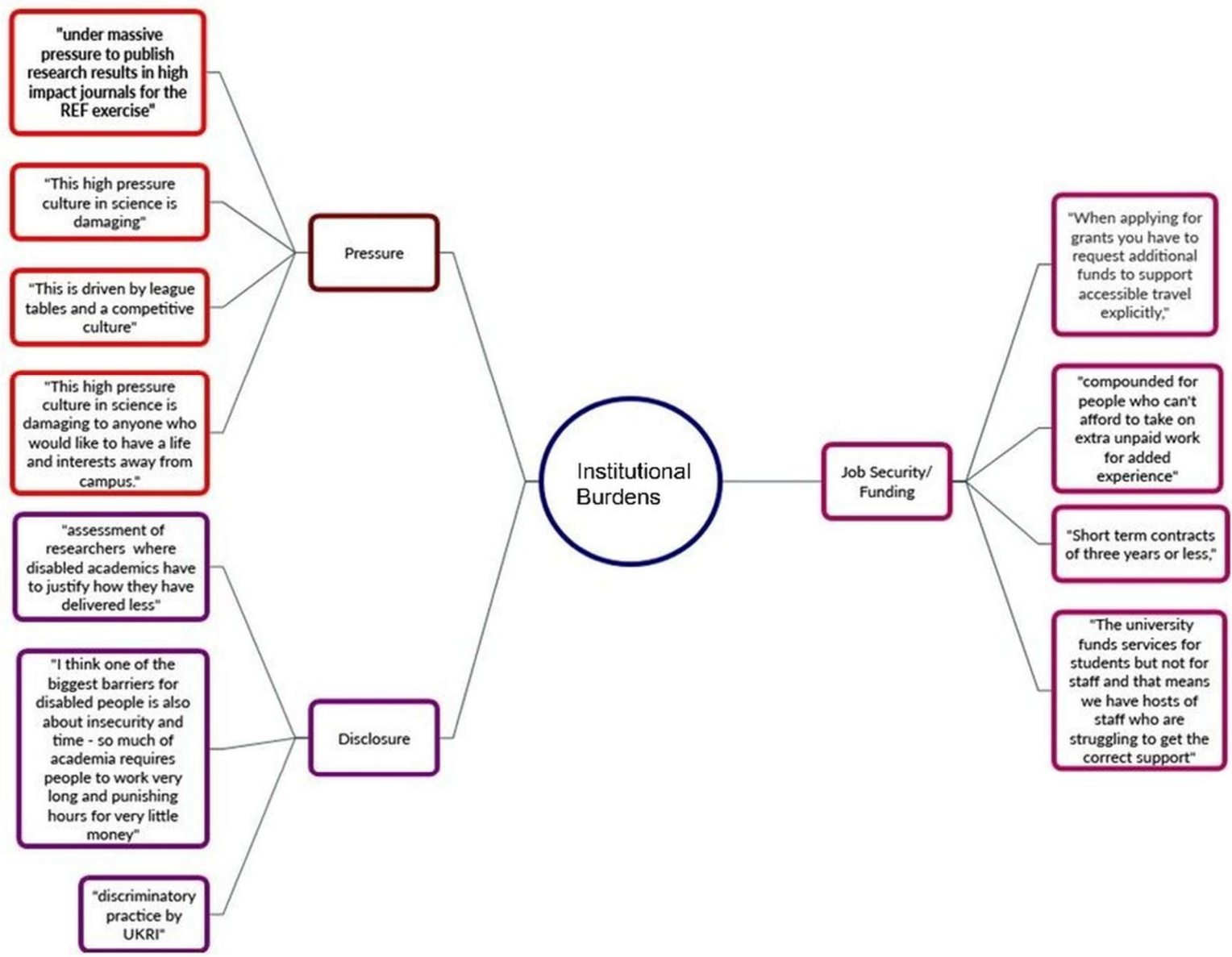


Figure 2: Word tree from responses to the Problem Statement illustrating the burdens of pressure, job security, and disclosure.

Pressure

How can I compete with you? I will never provide as good 'value for money' because I have to cost in every single extra line-by-line in each funding application to make sure that my lab, that my travel, that everything I do, is accessible to me. Every time I go to a conference I am away longer from the lab because I can't travel and talk on the same day. I haven't got a research record as impressive as yours. I haven't brought in as much money, published as much, or worked abroad. My parents didn't have the knowledge and networks yours did that gave you opportunities and internships before I even started to think about research. They could tell you about how the system works. I bet you weren't dismissed by your research manager as not being capable though. You didn't have to consider how being in a different country from the only specialist who actually understands your condition would impact your health before you moved away. You haven't had to spend months working from a hospital bed every year of your life. Even when I am not in hospital my life is impacted though. Every time I push myself too hard my body literally breaks down. That cough you had when you came into the office? I was bed-ridden for three weeks. I scratched my leg in the garden. Ended up with sepsis. Because I rarely ask to be signed off and just keep working as much as I can around the pain and the drips and the trolleys and the pain and the every-four-hour OBS it doesn't count as the clock stopping for funding applications. So you are my direct competition. And it just looks like I haven't done as much. As though I haven't put in as much effort. I'm not as good. Is it too much to ask that these limitations be explicitly acknowledged so I am judged more fairly? Of course it is. God forbid I should want a life outside of science and dealing with the every-day ableism as well. I should probably get back in my box and remember that disabled people are supposed to be the **subject** of research; not the researcher.

The Higher Education sector and context for research has been negatively affected by the pandemic.^{94,95} COVID-19 had an adverse impact on the mental health of the scientific community.^{96,97} The sudden closure of laboratories and pressures of caring responsibilities impacted many scientists.⁹⁸ Women academics responsible for children were particularly affected.⁹⁹⁻¹⁰¹ The higher risk of serious illness and death for disabled people¹⁰² meant that some who had previously not disclosed their health conditions at work had to do so in order to ensure they were adequately protected.¹⁰³ Difficulty and delays accessing health services impacted some disabled people's health.¹⁰⁴ The longer-term career implications of breaks or slow-downs in productivity due to COVID are yet to be fully accounted.¹⁰⁵ While all members of a department may have been denied access to laboratory facilities during lockdown period, an immunocompromised

disabled person would have had to isolate away from face-to-face meetings, conferences, and restrict their activities for much longer. The shift to remote working demonstrated that remote working could be put into place relatively quickly and easily and would benefit many people, demonstrating the power of inclusive design.⁵¹ However, many workplaces quickly reverted back to cultures of presenteeism under the guise of returning to “normality”.

Financial pressures across the higher education sector have led to cost-cutting initiatives such as a move towards large open-plan workspaces.¹⁰⁶ Open plan offices prevent individual ability to control the environment around them and adjust lighting, sound, and the like, creating barriers for disabled and neurodivergent people. When finances are stretched, individual needs and accommodations can easily be overlooked or dismissed, particularly if they are requested by people otherwise presenting as highly functional or do not always identify as disabled:

“A trend towards vast open-space working areas. This may be believed to boost productivity in general, but for a sizeable minority of neurodivergent people (for example with ASD or with general anxiety) it can become a serious challenge.”

Increasing competition between and financial pressures on institutions have led to a tsunami of restructuring and redundancies across the sector.^{107,108} Consequently, the pressures on academics and researchers to be hyperproductive and superhuman^{109,110} just to maintain job security have increased. Admitting vulnerability due to a disability¹¹¹ becomes harder when disability is equated with a lack of competence. Overt discussions of the value of a disabled life in COVID¹¹² heightened longstanding hostilities and negative perceptions of disabled people as less important, less employable, and less able to contribute to society than their non-disabled peers.³⁴ These ableist discourses also result in disabled scientists being considered too ‘high functioning’ or ‘not disabled enough’ to actually deserve support. When directed internally, this becomes internalised ableism.⁹² Many respondents to the original Problem Statement shared systematic issues that prevented an equitable playing field and made it harder to compete against their peers:

“I think one of the biggest barriers for disabled people is also about insecurity and time - so much of academia requires people to work very long and punishing hours for very little money which keeps not only disabled people out but others as well.”

Differences in productivity are perceived as a lack of effort instead of being due to physical difficulties:

“[Disabled researchers] do not have the energy to work extra hours to write up papers, attend optional lectures, or engage in CV-boosting volunteer work. [They need to] accept meeting pre-agreed objectives without additional work.”

People also shared issues around holding institutions accountable despite laws and protections. Currently the law does not recognise the impact of caring responsibilities or coming from a lower socioeconomic background, nor intersectionality and the compounding of barriers due to multiple protected characteristics. A Black, queer, woman disclosing a disability would face the combined and compounded barriers of prejudice due to racism, sexism, and ableism compared to a white, able-bodied man.¹¹³

“I have lost count of the number of times that I have attended an equality and diversity meeting that is primarily or exclusively around women and, to a lesser extent, early career researchers and sexuality without mention of disability.”

Where research is externally funded, funders have a duty to use their power and influence to ensure that host institutions have policies in place that support EDIA. Application processes are one way to support inclusion:

“There is a move to narrative CVs so that the badge collecting by hyper-productivity is removed from the proposal and focus is on science questions and skills of the team.”

Funders have a responsibility to check grant holders and their teams are benefiting in practice, with reasonable adjustments in place in a timely manner, and enforcing this through sanctions where necessary. Best practice has to embed reasonable adjustments throughout the research ecosystem, from pre-award support, to ring-fenced pots designed to ensure that accommodations can be put in place for the grant holder or one of their team at no detriment to the grant holder. Learned Societies can actively support this work through advocating for underrepresented groups and demonstrating best practice with inclusive events and representative committees.

At present EDIA work is underfunded and undervalued. The bulk of EDIA work in STEMM happens because of impassioned researchers who devote time and labour over and above their paid work to advocating for and supporting others at detriment to their own careers:

“Need to recognise and make time and reward for this extra labour in doing this.”

There needs to be recognition of, and value attached to, time dedicated to EDIA initiatives so that no-one is left in the position where they are lauded for their EDIA work yet remain without secure employment or opportunities for progression.

Dedicated money for research on EDIA in research culture is scarce and rarely includes full economic costing or buyout for staff time. It is not recognised as fundamental research. When EDIA work is included within a funding application it is often positioned as an add-on to a scientific programme. This confirms its low status, with the assumption that the only qualification a researcher needs is proficiency in their own disciplinary area. This contributes to a wider research environment where small scale unsuccessful initiatives propagate due to a lack of expertise and knowledge. Without the accolade of external funding, EDIA work is often overlooked in assessments for promotion or progression. We know several researchers who were advised to remove EDIA publications from their portfolio, as including them would lead to them not being taken seriously as scientific researchers. EDIA work in scientific journals is challenging, because it is not always recognised as ‘proper science’.

Solutions

What amazed me is how little it took. It started with just one question: 'How can I help?' There were other little things just there as a matter-of-course – I didn't have to ask for accessible versions of forms – they just were. Paperwork was sent round before meetings, meetings were scheduled in core hours (10-2) and there was always a hybrid option. They don't use heavy air fresheners or cleaning chemicals. The lifts work, and there is automatic door access everywhere. I had a mentor who knew about disability, and what they didn't know they went away and found out. They made sure that I wasn't left out of the 'politicking' in the department and at a disadvantage. They checked I had recognition for the extra labour I put in mentoring others and chairing the disability staff network. I was consulted before equipment and software were ordered to check accessibility. Everyone has access to a quiet space if they don't want to work in the hot-desk area. Everyone can work from home. You might need to take care of yourself or someone else. You don't have to say why or justify it and you're never asked to justify a disability. For the first time I wasn't scared to disclose or ask for reasonable adjustments. It's as though they trust us! And you know what? It means that we work harder. Everyone is more productive. We care more, because it feels like they care about us too.

Environmental

Respondents to the Problem Statement proposed small, relatively inexpensive solutions applicable for researchers in all disciplines that could be implemented quickly and easily to improve the work experience for people with sensory sensitivities or health needs affected by their environment (see Appendix 2):

"I strongly recommend when planning new developments, that for each large open-space area, there should also be a couple of old-fashioned small offices, without large glass panels everywhere."

"I think having 'well-being rooms' in offices would be helpful for people who need to take breaks from their desks/working spaces (due to pain/fatigue etc). Ensure these are sensory safe, so free from heavy air fresheners and perfumes, (also a problem for allergies), and that fabrics on chairs / places to lie down are not in itchy, scratchy fabrics. Sadly, fire retardant coatings on fabrics can also smell. Hypoallergenic cleaning products should be used."

"Perhaps provide a few spare pairs of noise-cancelling headphones just in case they are needed but someone doesn't have any."

“Kitchenette / hot drinks making facilities nearby to hand so that (hot) drinks and water can be easily sorted out and easily transported into the room.”

“Ensure the room has good sound insulation.”

Policies should protect the most vulnerable, for example a policy to use a face mask when ill with a mild cough or cold would help protect staff and students with immune system disorders from any respiratory infections and generally reduce sickness across a workplace at little cost.¹¹⁴ These would be in addition to more specific solutions to increase inclusivity and accessibility within laboratories (see Appendix 3).⁸⁶

Respondents to the Problem Statement also suggested more general solutions for higher education institutions, funders and Learned Societies (see Appendix 4). These fell into two broad categories of recognising the specific challenges of being disabled in science and promoting inclusivity.

Inclusion

In order to effect change, inclusion must be meaningful and intersectional rather than performative.⁷⁵ This is achieved by embedding inclusivity, ensuring representative consultation, and encouraging a culture of collaboration rather than competition; embodying the principle of ‘nothing about us without us’:

“Collaboration and support are the ways forward.”

“Move away from individualism and ensure that this is a community/not individual effort.”

“Go beyond including disabled people in consultation, and make sure they are involved from the start on teams and committees driving change.”

Inclusion and meaningful consultation is essential to create and implement policies that protect and support disabled researchers through specific initiatives or wider changes:

“Emphasise the need for change in working conditions and policies.”

“A funding pot only for disabled academics”

Respondents to the Problem Statement spoke more broadly about inclusivity and considerations of how research could be judged to include its impact on participants and society:

“Funding applications might be restructured to take into account whether a particular proposal carries potential positive or negative outcomes for particular groups. For example, is it disability liberation for more disabled people to be employed within/researching for the benefit of corporations which contribute to the global disablement of millions?”

“Requiring the relative ‘value’ of research to be determined, in some way and to some degree, by its ethics as relates to disabled people and other marginalised groups.”

These suggestions speak to a more decolonised view of higher education and research¹¹⁵ that incorporates and embeds axiology¹¹⁶ as well as ethics.

Recommendations

All funding bodies, learned societies, and organisations working in and around higher education and research must work together to implement the following recommendations. We have grouped them into short, medium, and long term to signify which are the ‘low hanging fruit’ and acknowledge some will require sustained effort and resources. However, all the recommendations are linked and necessary to achieve a fully inclusive environment for disabled people in STEMM.

Short-term

1. Recognise the specific challenges and barriers for disabled researchers to enter, remain, and progress in STEMM

Addressing the underrepresentation of disabled people in STEMM requires full recognition of the impact of intersectional obstacles in education, in wider society, and of the systemic ableism endemic in academic and research cultures. This can be achieved through Recommendation 2.

2. Improve work-based training for managers and allies around disability, neurodivergence, chronic illness and intersectionality

Funders and institutions must mandate training for all staff and ensure that it is high-quality, informed, and fit for purpose. Training should be created and delivered by experts who have knowledge of STEMM and lived experience of disability, neurodivergence, and/or chronic illness. Improving the quality of training will help raise awareness of intersectional and specific challenges and barriers due to disability. This will help create a culture in which disability is not stigmatised or seen as a liability, and negative discourses, assumptions, and stereotypes about disability are not allowed to propagate. Training will also help the implementation of policies, systems, and structures that build in inclusivity.

3. Build inclusivity into operational systems and structures, and provide clear, timely pathways for requesting and receiving adjustments/accommodations

All systems and structures within an organisation should build in inclusivity and protect the most vulnerable. Designing systems and structures to be inclusive removes the burden of declaration or disclosure from disabled people and supports people who acquire disability later in life. Systems and structures that are inclusive by design embody the ethos of the social model of disability by removing barriers and obstacles as a matter of course. Non-disabled people will benefit from clearer, fairer, more equitable systems and structures. Inclusive design committees and teams should include disabled people from the start of a project and not fit it in as a tickbox exercise at the end. Disability Representatives or Officers should be present in all departmental / senior management planning meetings. The time and extra labour for this should be recognised.

Where individuals require further support, the pathway for provision of reasonable adjustments and accommodations in the workplace must be clear, timely, and easy to navigate. Workplace

policies should also be inclusive and designed with in conjunction with disabled people in order to provide a safe and inclusive workplace.

Recruitment and application processes should be accessible as a matter of course, with clear questions provided in advance to all candidates and transparency about availability of support.

4. Ring-fence and publicise specific funds for disability support

Employing a disabled member of staff should be income neutral or preferably have a positive incentive. Organisations should ring-fence funds specifically for disability support in research and publicise them effectively. Where funds are held should be clear, and they should be supported centrally so individual departments are not penalised for employing a higher proportion of disabled workers. Disability support could include specialist technology, software, extra equipment, support workers, job aides, or conference attendance for example. When funds are held by funders it is vital that disabled researchers and research developers are aware of them at application so disability-related costs are not included within a proposal making an application less competitive in value-for-money terms. Ring-fenced funds would encourage host institutions and departments to support disabled people's research bids without fear of incurring unbudgeted costs for necessary accommodations. Ring-fencing money would also encourage Principal Investigators to employ disabled team members at no detriment to their research budget.

Staff should not be asked to justify their disability in order to benefit from ring-fenced funds. Eligibility could be confirmed through provision of a letter from a medical or health professional, a representative or advocate, confirmation of an Access to Work award, Personal Independence Payment, or prior award of Disabled Students Allowance.

5. Improve physical environments for disabled researchers

Improving physical environments for disabled researchers includes improving the general office space and work environment and removing potential sensory triggers. This can be achieved by using unperfumed cleaning products and discouraging strong perfumes, avoiding rough fabrics and surfaces, using sound insulation and providing noise cancelling headphones, and individual control of light and heat levels in working spaces. Large open plan offices should be avoided where possible,¹⁰⁶ and if unavoidable people should be encouraged to choose a comfort zone based on noise or light levels rather than being allocated a space. Individual offices should be available as a reasonable adjustment. There should be designated quiet areas for people who need to take a break from their desk or working space. Staff should have access to a facility to make hot and cold drinks. A culture of presenteeism should be avoided, with hybrid and flexible working options available and staff encouraged to alter their working hours and work from home if they need to accommodate their health, caring, or disability needs. Reasonable adjustments should be offered proactively, with named contacts able to advise on options.

All laboratory and experimental spaces should be designed with inclusivity and accessibility in mind or adapted to increase accessibility for common impairments using best practices and discipline

specific recommendations (please see Appendix 4 and further resources). Departments / Schools / Areas of work should establish a set of best practices, with regular checks from those responsible for overall Health and Safety to ensure they are implemented. This will enable prospective disabled researchers to know they are welcome in the laboratory environment, and it is ready for them to work there even before there are visible role models.

6. Provide support for accessing research funding from pre-application to post-award

Pre-application support should be specific and appropriate to an individual's needs. If a disabled researcher is putting together a multi-million pound bid they will require support from providers with experience working at this level; it is not comparable to the services offered to undergraduate or post-graduate students. For example, neurodivergent researchers may need support from people experienced at writing or reviewing successful funding applications to translate three-dimensional ideas into the format expected in a two-dimensional application form. This might include understanding what is meant by the questions, or what is relevant in a narrative CV.

Funds that allow time to develop a proposal would support disabled researchers with heavy workloads and/or caring responsibilities. Low application rates from disabled researchers^{14,17} indicate their lack of capacity to develop research proposals whilst managing their disability, workload, and other responsibilities. Until workloads are routinely adjusted to accommodate disabled researchers and ensure they are not having to work additional hours (or go part-time), funding to cover a replacement for teaching or other duties would be equitable. Care is difficult to arrange on an *ad hoc* or one-off basis, so should be available to supplement or extend existing arrangements rather than for specific events.

Post-award, establishing a research team and project can be daunting for any new Principal Investigator. Mentors are particularly valuable for people who are underrepresented within the scientific community.^{117,118} A dedicated mentor would help navigate challenges such as hiring team members, ensuring host institutions fulfil their obligations, and development through the grant. Leadership development programmes support new Principal Investigators to transition into the role of a manager and leader; however, they are rarely aimed at disabled, neurodivergent, or marginalised leaders. Establishing oneself as a leader where very few others look like you or have your experiences demands specific coaching and support throughout the life of a grant. Funders need to be proactive and ensure disabled and marginalised grant holders do not have to deal with additional barriers and obstacles and can focus on their research.

Medium term

7. Endorse an intersectional framework for disability and inclusion in higher education and research

A meaningful framework that includes incentives and sanctions, is grounded in actions rather than performativity or data collection and is a condition for research funding would encourage institutions to improve provision and practices around disability and inclusion. Similar schemes such as Athena Swan and the Race Equality Charter are helping to improve research environments.^{72,73} A meaningful framework for higher education and researcher should be developed from a robust model such as the Disability Employment Charter¹¹⁹ with disabled people, advocates, and activists, and improve on existing schemes.⁷⁷ A dedicated framework endorsed by funders and linked to eligibility for funding would help place disability on a more equal footing with other protected characteristics such as gender and race.

8. Require organisations to be held accountable to their working practice policies; with regular reviews to ensure they are accessible, inclusive, embed meaningful consultation, co-design, Equality Impact Assessments, and Equality/Equity, Diversity, Inclusion and Accessibility (EDIA)

All funders and research institutions should be held accountable to the legal requirement to provide reasonable adjustments for disabled people. They should be required to review *all* working practice policies and have robust practices and monitoring processes in place to embed EDIA throughout.

A system of peer reviews and checks, potentially linked to the dedicated disability framework, would ensure that from the outset of any policy review or design underrepresented groups have contributed to meaningful consultations, are represented on teams and committees driving change, that the practices laid out within policies are upheld on a day-to-day basis, that equality impact assessments are consultative and thorough, and that protected characteristics data for employees, funding applicants, and funding successes are reported publicly.

Policy frameworks should include accountability for disability discrimination. Promotion and progression policies must include mitigation for the impact of limitations on working hours, mitigation for the lack of freedom to move for work, and mitigation for lower productivity due to disability. Where possible, individuals should be able to discuss their disability, opportunities for development, seek approvals and the like from more than the one person responsible for allocating work to them to avoid personal bias or personality clashes acting as career blockers.⁶⁸ There should be clear pathways for individuals to seek redress if they feel they have been subject to ableism, particularly in situations where there is a power imbalance. Policy and practice should acknowledge the impact of productivity-limiting disabilities in academia for progression and promotion.

9. Establish Access to Work pathways for disabled researchers

Access to Work (ATW) aims to remove the barriers, obstacles, and additional costs disabled people face when in work. In addition to the general reforms required to ensure ATW functions to achieve this,¹²⁰ disabled researchers require a dedicated pathway that recognises and accommodates the prevalence and challenges of short-term contracts and is compatible with research funding. This should also reflect the unique relationship with the employer of grant employees compared to other jobs, or those with split contracts between multiple organisations (such as a hospital and university). Respondents to the problem statement recommended reframing ATW support from 'getting disabled people into work' to 'addressing the inequalities experienced by disabled people and the 'disability tax''. Assessors would need training to understand health and safety assessments and reasonable adjustments within a laboratory environment and provide options for the specialised environments/equipment/types of support needed to remove additional barriers. The pathway would need to have realistic fast-tracking and include options for awards to remain with an individual as they move role and/or employer. Assessors and case managers would also need implicit bias training to remove the misconception that educated people cannot be disabled which is a frequent attitude encountered by our respondents.

10. Reconceptualise the indicators for 'good' research, researchers, and research environments

As People, Culture, and Environment Indicators are piloted and developed as part of the 2029 Research Excellence Framework,¹²¹ the sector has the opportunity to formally change what is measured as a metric of good research, and what constitutes a good researcher and supportive research environment. Funders and institutions should capitalise on this and establish systems that reward collaboration rather than competition and move away from individualism. Making STEM inclusive for all is a community endeavour not an individual effort.

Reviewers and panels for funding decisions should be encouraged to consider the values-based and ethical approach of a proposal, and how marginalised groups might be impacted by a project's success. Funding application processes should acknowledge and recognise academic-related staff who have contributed to a bid's development as a way to gain context for the amount of institutional support an applicant has had. This would avoid penalising applicants from host institutions with little experience or research support and avoid concentrating funds in the same researchers and institutions which are known to lack diversity.⁷ Within applications there should be capacity to include staff in academic-related roles and encouragement for costing in technicians, laboratory managers, and administrative support as a means of building in inclusivity and diversity. Additional consideration should be given to interdisciplinary research and the value it can offer to a discipline, field, or community. If an element of EDIA or research culture is a requirement for an application, then reviewers and panels should assess how an applicant has planned to gain skills or collaborate with an expert to avoid tick-box activities and replication of unsuccessful initiatives. In health research, patient and public involvement and engagement should be meaningful and address the lack of diversity and representation endemic in the sector.¹²² Similarly, public

engagement should be inclusive and accessible, incorporating academic-related experts and consultation with marginalised groups.¹²³ Public engagement can change people's perspectives on who can engage with and pursue careers in STEMM.

Panel members and reviewers of funding and promotion applications should undertake enhanced training so they understand the limitations and barriers for disabled researchers and other underrepresented groups, and to help eliminate negative perceptions and bias. The expectation that a successful academic has to have worked across different institutions and countries should be discarded, as should ideals of hyperproductivity and unrealistic expectations of output. Interdisciplinary researchers should not be penalised for falling between disciplinary silos. Markers of success should be extended to recognise outputs other than publications and funding. All decisions judging the quality of a researcher should take into account the context in which they are or have been working e.g. percentage of time allocated for research and teaching, access to research development support, and previous opportunities to apply for funding or be recognised as Principal Investigator. Promotions processes should allow for diverse career paths and hybrid academic/academic-related roles to offset the challenges of precarity which are more often experienced by underrepresented researchers.

11. Stop promoting and funding toxic research cultures

Our Problem Statement and respondents did not mention issues of bullying and harassment directly. However, they are prevalent within toxic research cultures. Institutions, as the employers, are responsible for investigating claims of bullying or harassment and sanctioning perpetrators, the majority of whom are in positions of power responsible for managing, supporting, or blocking the careers of others.⁷ When a perpetrator is a 'superstar' researcher bringing in large amounts of funding, often institutional ranks close in to provide protection from sanctions even if a complaint is upheld. Too often the guilty party receives a slap on the wrist while victims and their supporters are asked to leave.¹²⁴ It is hardly surprising that people experiencing abuse are reluctant to formally complain for fear of damaging their career.²⁵ Those who do can be subject to Non-Disclosure Agreements or privacy clauses that prevent them from speaking out. Funders are more likely to keep records of and blacklist institutions for submitting too many applications, or applications deemed to be of low quality, than for failing to deal appropriately with cases where there has been proven bullying and harassment. Without reprisal for bad behaviour and apathetic responses, nothing will change.

Funders should make a contractual condition for host institutions that allows them as funders to conduct investigations or appoint an independent proxy to do so on their behalf if they are contacted with serious issues of complaints or cases of misconduct.

Funders should instigate sanctions for individuals and institutions found guilty of misconduct.

Where serious complaints of harassment have been made about an individual, investigated by an independent body (the funder or their proxy) and upheld, funders should sanction them appropriately so as to discourage others from such behaviour.

Where an institution has failed to sanction an employee found guilty of harassment or misconduct, funders should step in and sanction them for a time limited period. If the institution repeats the behaviour, the time should be lengthened.

Funders should sanction individuals and institutions that do not have or adhere to inclusive policies that embed EDIA.

Funders should hold institutions accountable to their promises, letters of support, and requirements of a grant. If an individual they fund or one of their team is being discriminated against or subject to un-inclusive policies, they should act as mediators to try and find a way forward, and if unsuccessful should support them and their team to move to a different host. They should then blacklist the original host institution for a time limited period, and if the situation is repeated the period should be lengthened.

12. Allow disabled academics to work part-time with no detriment to their pension or opportunities for progression

Disabled academics are more likely to be employed on successive short-term contracts and remain at more junior levels. Precarity and employment at lower grades impact finances negatively, contributing to the 'disability tax'. If a disabled academic has to reduce their hours and work part-time to manage their health, they will also negatively impact their long-term financial security due to reduced productivity compared to full-time colleagues, and a drop in pensions contributions. Disabled people are more likely to work part-time and leave the work force than non-disabled people.⁵²

Funders and institutions should ensure that before reducing hours, a disabled academic has adjustments in place and their workload accommodates their needs and is reasonable. Without these adjustments, a disabled academic's health might be impacted because rather than working a 'normal' week they are having to overwork just in order to keep up. If, once these adjustments are in place, they still need to reduce hours because of their disability, they should not be penalised when there are opportunities for promotion, and they should have no detriment when it comes to their pension.

Long-term

13. Create inclusive research cultures and ecosystems

The research ecosystem currently privileges certain groups over others.¹¹³ According to the Wellcome Trust “disabled researchers and other members of underrepresented groups feel the effects of bad research cultures disproportionately.”⁷

Changing culture requires buy-in from early adopters, visible leads in senior positions to leverage support from others. Funders will need to utilise their power to encourage and reward positive changes. Institutions will need to implement processes that recognise researchers more holistically, and move away from previous models of success. Sanctions should discourage and disincentivise unhealthy or toxic behaviours.

14. Recognise, value, and reward EDIA work in research cultures and ecosystems

Funders and institutions should recognise, make time for, and reward the labour that underrepresented researchers devote to EDIA activities, often over and above their paid work and at detriment to their own careers and health.

Funders should consider including full economic costings for research, and mandating their expectations for how ‘buyout’ is implemented. The current funding climate in higher education has placed most institutions in deficit. Restructures and redundancies have increased workloads and decreased available support and time for research. Funders should consider reviewing full economic costings for research so that it is not seen as a loss-making activity or luxury only open to ‘some’ researchers and ‘some’ institutions. When funding includes the time for researchers to carry out the research in the form of buyout, there are already discrepancies over how it works in practice. It is already common to hear of buyout being awarded while workloads remain the same. Some institutions allocate externally funded buyout of time on top of any internal allocation of time for research. Others use external funding to ‘pay for’ the internal allocation of research time, meaning that bringing in funds can increase workload yet offer no relief. The tasks included in internal allocations for research time vary, as do applications of FTE (full time equivalent) in allocating externally funded time.** Research funding is already highly competitive and disabled researchers and other marginalised groups are at a huge disadvantage when it comes to applying for and winning awards. Increasing expectations and competition while reducing the gains in the form of time to do a project will further disadvantage disabled and underrepresented researchers.

** If a researcher has costed in 0.2 FTE for an externally funded research project and 1.0 FTE = 37.5 hours/week, the expectation might be that they spend 0.2 FTE or 7.5 hours/week of their time on that project with their workload adjusted to accommodate this. However, some institutions would calculate the same externally funded buyout as 0.2 of time *allocated for teaching* rather than the full working week. If a researcher has a contract specifying 60% teaching, 20% research, 20% service and the institutional allocation is 0.2 of 22.5 hours/week. Their workload would only be adjusted to allow for 4.5 hours/week to be spent on the project. If the institution treated external funds as ‘paying for’ any allocated research time, a researcher on the same contract would not be given an adjustment of workload at all.

There should be funding available for all institutions to dedicate to research culture, research environment, and EDIA activities. Concentrating it within institutions that are already successful at securing large funding awards will ultimately damage the sector and decrease diversity in STEMM.

15. Change equality law to recognise the impact of intersectional discrimination

Changing equality law is a large undertaking, and the specifics of this will be the subject of a separate NADSN White Paper. With regard to establishing inclusive environments for disabled people in STEMM, we recommend funders, learned societies, higher education and research institutions **work together** across political parties and support changes to equality law so it is inclusive **and intersectional**, and recognise that intersectional discrimination is greater than the sum of its parts.

DRAFT

Threats

This creative non-fictional vignette, as indicated by the citations included throughout, is derived from wider experiences of disabled people as well as our collaborative autoethnography. It illustrates a new threat to establishing fully inclusive environments for disabled people in STEMM.

Threats to progress and inclusion can arise quickly and unexpectedly. They result from malicious intent or as the unintended consequences of seemingly unrelated decisions; underlying the need for embedded Equality Impact Assessments, accountability, and a holistic strategic approach to policies and practices.

You would think that given who I am and what I have been through that I would define the greatest threat to my existence the **Do Not Resuscitate** order given to me without my knowledge when I had COVID-19.¹²⁵ Like so many other people who were disabled, or who had an 'underlying' or 'pre-existing' medical condition, I was suddenly smacked in the face by just how little our so-called society valued my life.⁵¹ Literally, if they could give that ventilator to someone else they would and hang it being discrimination.^{126,127} I know anti-disability rhetoric is not new.¹²⁸ Disabled people are seen as 'undeserving' or out to 'cheat the system'.¹²⁹ You only have to look at assessments for benefits like PIP [Personal Independence Payments]^{130,131}: "severely re-traumatising" just about covers it.^{132(p997)} If we are in wheelchairs they infantilise us.¹³³ If we are not then we're not really disabled. People literally hate us and make sure we know it.¹³⁴⁻¹³⁷ We are seen as sub-human or monstrous; and anyone who does not try to mask their differences for other people's comfort is a pariah.¹³⁸ Either that or we are held up for your titillation as 'inspiration' which is equally dehumanising.¹³⁹

It's more acceptable to 'other' us than include us.¹⁴⁰

There were 5.5 Million disabled people in the UK in 2024⁵² and the government is failing us badly.¹⁴¹ More than 200,000 people (by their count) are on disability benefits and want to work.¹⁴² If governments really want to reduce economic inactivity¹⁴³ and support disabled people to get and keep employment¹⁴⁴ they need to make the systems add up.

It's not rocket science.

Except when rocket science is actually your job... Why aren't disabled scientists being funded?¹¹ Why are there so few disabled medical doctors¹⁴⁵ and academics?⁶⁵ Why is there an assumption that disabled people can't have professional careers? Why do we face career blocking,⁶⁸ bullying,⁷ and fail to progress?¹⁸ People are scared of saying they are disabled.¹⁴⁶ Coming out as a neurodivergent scholar⁵⁶ becomes infinitely more risky when autism is seen as a danger to society.^{147,148}

Disabled people are less likely to be recruited.¹⁴⁹ The job market was already tough in science.¹⁵⁰⁻¹⁵² Now there are so many academic careers at risk from restructuring and redundancies in the UK it will only get worse.¹⁵³ There has been little positive impact from schemes like 'Disability Confident' or 'Two Ticks.'^{77,78} When it comes to getting or keeping any job, putting reasonable adjustments in place is key¹⁵⁴ and initiatives like Access to Work can be a lifeline.¹²⁰

Except when they are not.

Right now, the biggest threat I face is from Access to Work.⁴⁹ The support I have had from them up to now has been incredible. From the moment I put in my application, just as I started a new job, it was great. I got a response well within the six weeks they promise for new starts. I had a positive chat with my case manager who kept in touch with me via email answering any questions I had. They set me up with holistic assessments of my work environment and my home office. In addition to the equipment my employer provided over the years, at renewals or if I asked, the assessor was able to suggest new software and new tech that I hadn't even heard of before that made a real difference. They can help with training, coaching, even travel costs.

I told everyone I knew about Access to Work. No-one seemed to know about this provision at all. If you were a disabled student you could get Disabled

Students' Allowance, but support seemed to disappear when you entered the workforce. I know that the numbers of people being approved by Access to Work has grown in line with the increase in number of disabled people in work - 67,720 were approved by Access to Work in 2024.⁸⁹ That is still only 1% of the 5.5 million employed disabled people in the UK.⁵²

The aspect of Access to Work that was absolutely transformational for me was gaining a specialist support worker.

When people think about support workers they think about care work. If they translate support workers into employment they generally imagine someone helping you stack boxes in a supermarket because your physical disability would make it much harder for you than for other people. You can do it, but it takes you longer and will hurt you in a way that it doesn't hurt them.

Academia and research is not like stacking boxes.^{110,155} Disabled academics are disadvantaged and blocked at every turn, particularly if they are women or part of another marginalised group.¹⁰⁹ Colleagues who are neurodivergent might need support with logistics, understanding sub-texts in conversations, or opaque university systems to book diaries and handle travel. Just like the supermarket box stacker, it's not that they can't do it just that their disability means they spend a disproportionate amount of time and energy doing so, and they pay a cost others don't.

Now, I have nothing against anyone working in a supermarket, but I am a scientist. I am a disabled scientist.¹⁰ My support worker had to be able to handle scientific equipment that my disability prevents me from handling as quickly or as easily. My support worker isn't doing my job for me – it is very clearly MY work. MY research. They are enabling me to do MY job. Or they were.

Access to Work's aim is to encourage employers to recruit, employ, and retain disabled workers. Now thanks to them, I am at risk of joining the

'economically inactive'. They have removed the support that was working without explanation.

My recent Access to Work award renewal was downright abusive. I was shaking afterwards. Far from a discussion about my needs it was an attack. An ableist attack.

The guy I spoke to asked me to rewrite the table of tasks I provided – the tasks and duties that MAKE UP MY JOB. The fact that I am not stacking boxes in a supermarket was not acceptable to him. Academic work is *complex* at the best of times.^{156,157} I am a scientist *and* an academic. But he seemed to know better than I do what my job entails, and according to him I just need admin support from an unqualified non-specialist. He didn't like the fact I worked so many hours. Neither do I all the time, but I work a lot less with a specialist support worker than I did when I was struggling on my own. He didn't want to hear that the support I have had in place for years is working, that it is enabling me to thrive and to pay taxes; contributing both to my own health¹⁵⁸ AND enabling me to contribute to the solving of global challenges.³⁰

This guy wanted to talk to my line manager and discuss my disability without me there. What happened to 'Nothing About Us Without Us?'⁸⁵ This guy, without any explanation, justification, or assessment of needs, decided to reduce my support. First, he suggested to me that my employer should provide an employee to support me as part of their reasonable adjustments. The Access to Work budget for the whole institution is £2000. Now they are in financial crisis and need to lose £15 million from the pay budget, workloads are increasing daily and you think they will be able to just allocate someone to support me and my work? Are you having a laugh? My employers have always supported me through reasonable adjustments. Access to Work says they support above and beyond.

Well, now Access to Work is going above and beyond to highlight and increase my vulnerability.

Their customer factsheet says “If you know what support you need, you do not need to have an assessment. An Access to Work case manager will discuss the award with you and develop a tailored package of support.” This guy just ignored what I know about the support I need; support that is working. Support that has worked. Without discussion with me or my employer he slashed my hours. Worse, he slashed the rate of pay. I need scientific knowledge and skills – offering minimum wage will not and *should not* secure that.

Then, he said that rather than select and contract someone of my choosing as a support worker, it should go through my institution. He did his best to put pressure on my line manager to hire in-house rather than work with the agency I have always used. The thing about using the agency is that I have autonomy over who I hire to support ME. All my line manager needs to do is approve. She doesn't need to know detailed information on exactly which aspects of my disability I need my support worker for. My support should be based on the recommendation of my assessors who have access to all that information and spent a long time with me to find out how and where I could be supported.

But oh no, *this* guy wanted to send on everything he had asked me to give him about my disability and how it affects me at work. Sharing information with an independent assessor is very different from exposing my vulnerabilities to my line manager. Forcing me to disclose sensitive and personal details is not okay. I'm fairly sure it would count as disability discrimination. If this guy had had his way, he would have forced me to expose myself to my line manager, to the recruitment team in HR, and to any of my colleagues who looked at the job advert. If I soft-soaped things I could risk ending up with a support worker unable to do what I need or even having approval rescinded.

There is enough stigma around disability. I could do without being laid bare.

Access to Work are supposed to operate according to the social model of disability – this *should not* include disclosing a list of impairments to the world at their whim.

This guy was bad. Worse still though, is that he is no longer my case manager. I do not have a case manager now. No-one whose name I know. Of course, even in the good old days it was only emails or phone calls that were allowed. We weren't permitted to see each others' faces on a video link. Now, if I have a question – any question – I am not allowed to email. I have to call up the helpline and wait. Generally, I'm on hold for an hour. Then I ask my question and it gets sent to a pool of case managers. One of them *should* get back to me. Hopefully with the right information in six weeks time. Good job disabled people never have to know anything in a hurry. Being given the right information isn't guaranteed though. I know of far too many people who have been given incorrect advice or told lies about their own case. New applications might wait a year to be assessed even if they are 'fast-tracked'. If you are self-employed apparently you go into a 'different pile' and you can find your business plan subject to more stringent assessment criteria than any bank would employ.

Case managers are making arbitrary decisions in direct contradiction to their own staff guidance. And of course there is no right to appeal. You can ask for a 'reconsideration' but that can take eight months, and there is no more transparency or explanation for decisions. There isn't a way to complain to the Access to Work team. The only complaints process is to the Parliamentary Ombudsman who *should* care. But.

This is an award not a benefit I was told. Disabled people have no right to support I was told. Any award is discretionary I was told. Case managers have been "briefed to save money" and "support workers are the most expensive part of any award" I was told. Access to Work isn't about providing

the support I need anymore, supporting economic growth, or 'Getting Britain Working'.¹⁵⁹ There has been a malicious undermining of its once noble intent.

Dealing with this has taken time and energy that would have been better spent on doing my actual job. Except now my job is in jeopardy. The arbitrary and unexplained reduction in support impacted my ability to perform and be productive. The stress of dealing with it all has taken a toll on my physical and mental health. I have been spoken to and treated as though I am deliberately lying and gaming a system. The whole process has changed from one that set out to support disabled people into and to remain in work to be one designed to rob people of their professional credibility and human integrity. Why? Because we are disabled. That is the *one thing* they know about people who call their helpline or who apply for their support.

Access to Work have damaged me, compounding the damage I already live with because I am disabled. Impaired. I am now on medical leave and subject to performance management processes. Given the university needs to cut staff costs I have no confidence at all that I will be able to retain my employment however many papers I publish or awards I win for my teaching and research. Just last year I was named by the Shaw Trust as one of the 100 most influential disabled people in the UK. Now it looks like I'm going to be just another disability statistic.

It seems to be down to Access to Work to decide what work disabled people can do. I think they are happier with them stacking boxes than doing science.

Conclusion

Without addressing threats and implementing strategies to retain a diverse STEMM workforce, the UK will lose talent and economic viability. It is more critical than ever to ensure all staff are welcomed and all talents are encouraged. Inclusion is an action that will help secure future economic growth. As such, it should not have to be justified. Although this White Paper focusses on research and the higher education sector, the recommendations we have formulated apply equally to the private sector, the healthcare sector such as the National Health Service, and the civil service.

Further resources

- <https://disc.hw.ac.uk/>
- <https://www.scope.org.uk/campaigns/disability-perception-gap/>
- <https://www.nao.org.uk/report/supporting-disabled-people-to-work/>
- <https://royalsociety.org/topics-policy/diversity-in-science/disability-reports/>
- <https://www.uclpress.co.uk/products/123203>
- <https://www.nadsn-uk.org/immune-system-disorders-in-the-workplace/>

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Appendices

Appendix 1: Recommendations from the Problem Statement organised thematically

Enabling inclusive cultures and practices	Enhancing accessible physical and digital environments	Accessible and proactive funding
Consultation – Listen to disabled scientists and ensure intersectional narratives are heard which include multiple minoritised voices.	Consultation – accessible procedures for consultation as well as representative consultation	Consultation with disabled people as researchers not just participants
Working Conditions and Policies – including health and safety, flexible and/or part-time working options and assurances, and designing, building, and adapting accessible physical spaces	Working Conditions and Policies	Funding policies and resources that improve working conditions
Meaningful and effective training for all staff	Training e.g. for managers, Human Resources staff	Training e.g. for panels and reviewers
Encourage and provide opportunities for inclusive mentoring and networking	Networking	Specific opportunities for disabled people
Visibility	Meetings	Visibility
EDIA expertise	Clear and transparent processes e.g. around procurement, estates management, parking, internal and external applications for funding	EDIA expertise recognised as a speciality, not expected as an add-on
Leadership	Workplace accommodations	Workplace accommodations
Cultural Change; challenging ableist attitudes and enabling inclusive cultures and practices	Digital Accessibility (including websites, applications, collaborative tools)	Research and researchers
Influence, lobbying, accreditation, and award	Access to Work	
Recruitment, reward, progression, and promotion		
Declaration, trust, and transparency		
Decision-making		

Table 1: Recommendations organised thematically.

Appendix 2: Environmental solutions suggested by respondents to the Problem Statement.

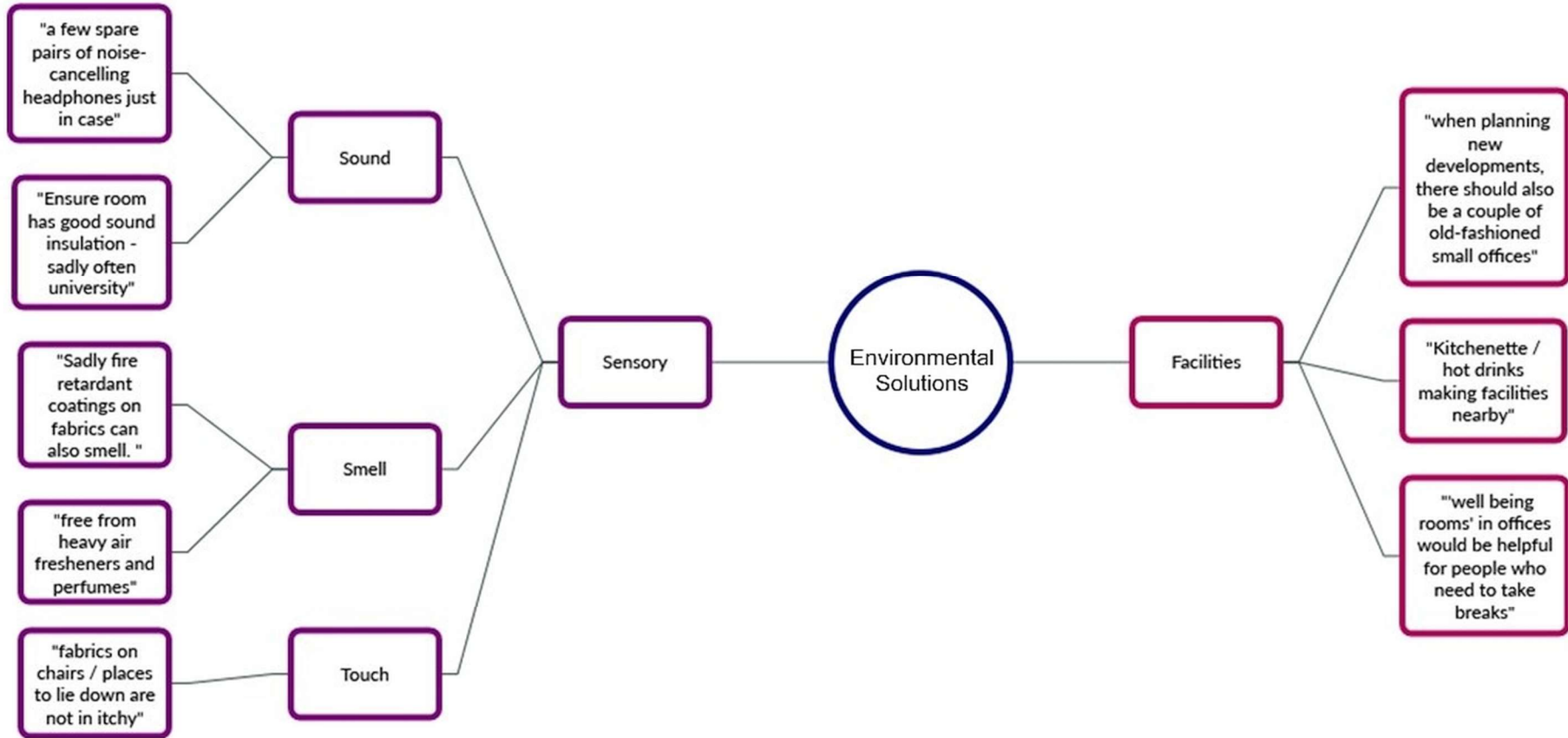


Figure 3: Environmental solutions suggested by respondents to the Problem Statement.

Appendix 3: Table to show suggestions of improvements to increase laboratory accessibility adapted from Egambaram et al (2022).

Laboratory Improvement	Who Is It a Problem for?	Inaccessible Lab Feature
Install automatic lighting inside cupboards	Visually Impaired	Dark cupboards
Ensure provision of portable and desk lamps		Dark workspaces
Use matte white bench covers to aid visibility		Old wooden benchtops
Ensure clear access routes	Visually + Mobility Impaired	Cluttered walkways and trailing leads
Install ramps at all entrances and into rooms with a step/sill (ramps must have 1 in 12 gradients)	Mobility Impaired	Steps and changes in level
Ensure that access routes are free of clutter; these need to be at least 81 cm wide		Narrow walkways and doors
Install automatic door openers to every door (not just main entrances to buildings)		Push/Pull doors
Fit convex mirrors in ceiling corners, and cover sharp corners		Sharp corners/high shelves reducing visibility
Use hanging plug sockets which can be moved as needed		Electrical switches difficult to reach
Install lever action taps rather than twist action taps		Taps difficult to reach or turn
Install handles on doors (not knobs or finger indents)		Fridges or cupboards difficult to open
Providing simple equipment to ease bottle/tube opening and stabilize pouring		Challenges opening and pouring or pipetting
Ensure at least 81 cm gaps are left in key places such as under sinks, under benches, and under fume hoods		No space under the bench for a wheelchair user to pull in close, or a stool user to sit comfortably

Laboratory Improvement	Who Is It a Problem for?	Inaccessible Lab Feature
Store principal chemicals at between 100 and 150 cm height in bottles that are not excessively large		Chemicals stored on high shelves or in very low cupboards
Install visual alarms such as flashing or red lights (that are LED-based and do not flicker) throughout the building	deaf/Deaf/Hard of hearing (d/D/HH) ^{††}	Solely audio alarms and signals
Move loud machinery to support rooms or laboratories, or seek to minimize its use.	d/D/HH + Neurodivergence	Excessive machinery noise from sonicators and vacuum pumps
Regularly maintain equipment to prevent excessive noise.		
Minimize unnecessary noise where possible and allow the use of noise-cancelling headphones (allowing for impact on buddy-safety)		Loud radios and music
Upgrade from fluorescent lighting to LEDs to prevent flickering	Neurodivergence	Flickering lights
Provide zoned or separate work spaces, delineating these by colour/texture on the floor		Fully open plan layout
Clear bench tops and have marked out areas for different activities		Cluttered work areas
Ensure that there are neutral and restful colours throughout		Excessively colourful wall decor

Table 2: Table to show adaptations and improvements to increase accessibility in laboratory spaces by impairment type. Adapted from Egambaram et al (2022).

^{††} deaf” refers to anyone with a severe hearing problem; “Deaf” refers to people who have been deaf from before they could talk.

Appendix 4: General solutions for inclusivity suggested by respondents to the Problem Statement.

General solutions

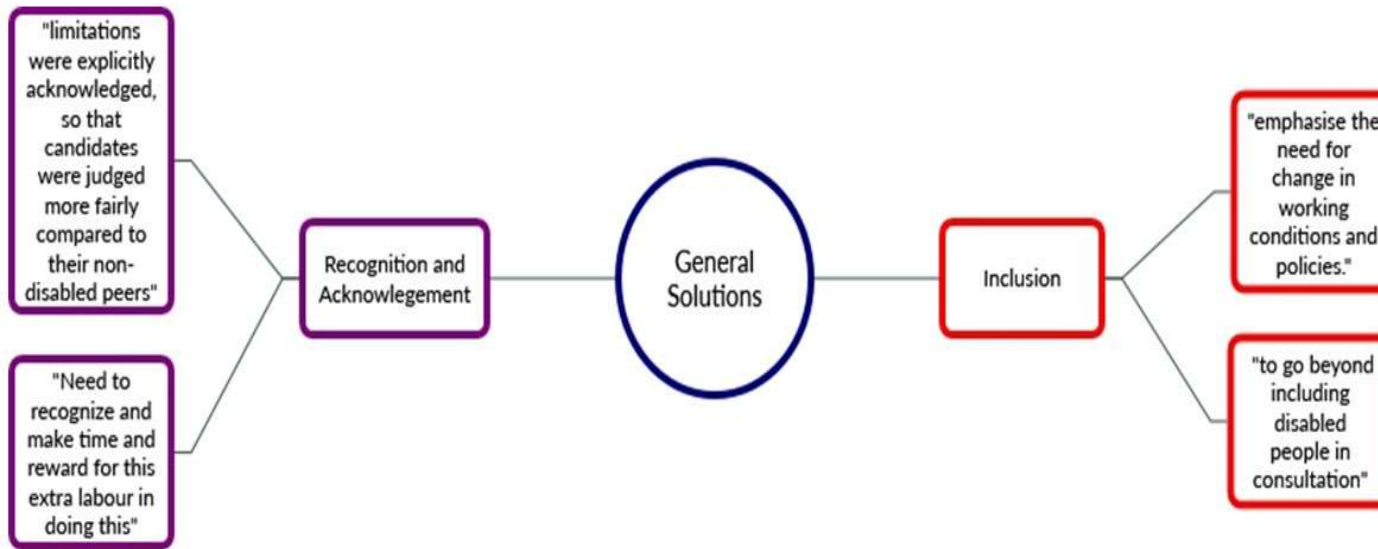


Figure 4: General solutions for inclusivity suggested by respondents to the Problem Statement.