EXPERIENCES OF DISABLED, CHRONICALLY ILL AND NEURODIVERGENT STAFF AND PGRS AT NEWCASTLE UNIVERSITY

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Executive summary

Overview

This document concludes a listening exercise conducted with 37 respondents during the academic year 2022-2023 and co-funded by the Newcastle University EDI Fund and HaSS Faculty. The exercise aimed to identify and explore the challenges and obstacles facing disabled, neurodivergent and chronically ill people who do research at the university, including both staff and PGRs. While a lot of research has been done about disability and/in academia since the Equality Challenge Unit's 'Enabling Equality' 2011 report (ECU 2011), this consultation is, to our knowledge, the first to focus on the specific experiences of researchers.

This listening exercise follows up previous research by Mearns and Hopkins (2021) as well as the Research Culture Roadmap (Newcastle University 2021) and subsequent Action Plan (Newcastle University 2022), which emphasised the importance of an 'inclusive, supportive and safe research environment' and of 'diverse contributions to research'. This report:

- Presents and discusses key findings based on respondents' accounts and international literature;
- Provides up-to-date context on language and issues to inform NU policy and practice;
- Makes a series of recommendations so that Newcastle University can embed equality, diversity and inclusion for disabled, chronically ill and neurodivergent staff and PGRs 'into all processes and practices that support and facilitate research' (Newcastle University 2021).

Key findings

When asked about the relationships between their individual impairments and their role as researchers, respondents all expressed a variation on the same theme: *it's not the research, it's the environment*. In other words, the role of researcher and doing research are not the issue; rather, the wider institutional context in which people do research urgently needs to be recognised and remedied.

1. A profound cultural change is needed

Recognising the complex landscape of disability

As a university, Newcastle must urgently recognise the varied and complex landscape of disability. This is important not only for decision-makers and line managers, but for anyone working at the university. This complexity is reflected in the contested language surrounding disability.

While individual impairments and situations vary immensely, all disabled, neurodiverse and chronically ill people have to manage personal impairments in a social context that was not designed for them, does not always accommodate and, sometimes, downright excludes them. This is why disability should be understood not as an individual characteristic, but rather as the product of the interaction between individual impairments and societal barriers, in line with the social model of disability.

A threatened sense of belonging

All findings should be read in the light of an overshadowing sense of threat to respondents' sense of academic identity and belonging to the research community at NU. This general sense of not feeling desirable nor valued as researchers, independent of their impairments, manifested slightly differently among PGRs because of their liminal status (between students and staff).

2. Disabling structures, processes and practices

Understanding disability as a social (rather than individual) phenomenon allows us to identify disabling structures, processes and practices which all contribute to creating disability. This summary identifies three key disabling factors.

The disability workload

Disabled, neurodivergent and/or chronically ill people face a well-documented additional workload, created by the necessity of managing their impairments in a system that doesn't automatically accommodate or welcome them. This may involve medical or administrative tasks, the emotional labour of self-advocacy, or simply a greater need for rest and recuperation. It is essential to recognise this additional workload, as it has a critical impact on their working lives.

Lack of institutional consistency

Too often, the delivery of disability equality is dependent on 'line manager lottery', which has already been documented at NU. Respondents seemed to believe that positive experiences of support were down to luck and to who was offering support. This both reveals their low expectations in terms of support, and reinforces the idea that they are misfits in a system that was not built for them. This lack of institutional consistency also affects how support routes are signposted and what advice respondents received.

Disclosure and adjustment processes

The disclosure and adjustment processes emerged as key disabling practices. Both implicitly treat disability as an individual issue to be compensated for through localised interventions, and place a significant additional burden on disabled, neurodivergent and chronically ill staff. The report identifies structural issues and calls for an institutional overhaul of these processes.

3. A constant race for time

Academic culture of overwork meets disability workload

While the culture of overwork is a frequently noted and sector-wide concern, it raises additional obstacles for disabled, neurodivergent and chronically ill researchers. The issue of how to protect research time, which many academics experience, emerges as an overwhelming source of concern for respondents in this study, who already face the additional burden of the disability workload.

Adjustments are not only physical

Time consistently appears at the top of adjustment needs. Such adjustments may take many forms, such as workloading, time-to-completion pressures, meeting deadlines or needing more rest.

Personal and career lifecourses

The lifecourses of disabled, chronically ill and neurodivergent people cannot be understood through the same normative lens as those of their peers. This is also true of their career progression – or lack thereof, as they often don't meet 'milestones' at the expected time (time to PhD completion, progression between career stages...). This raises multiple questions, including about retention rates, promotion criteria and the disableist notion of academic excellence as it currently stands.

Key recommendations

A detailed version of this list and more recommendations are available at the end of the report.

1. Changing the culture

1.1 Belonging and academic identity

Create a regular forum on disability, neurodivergence and chronic illness for all NU employees, to foster an ongoing dialogue with these colleagues, and ensure that they feel listened to.

Engage in reflection on what type of academics are considered desirable and 'a good fit', under the lead of an academic who identifies as disabled, neurodivergent and/or chronically ill.

1.2 Language

Move beyond the use of *disability* and *disabled* as umbrella terms in NU's communications. Instead, use more inclusive and descriptive language that most relevant people might identify with, e.g. *health and disability*, *health, neurodivergence and disability*, *neurodivergent, disabled and/or chronically ill staff*.

Where needed, also address neurodivergent or chronically ill staff separately, to ensure that they are aware of all policies relevant to them.

1.3 Organisation-wide EDI strategy

Conduct a multi-level assessment of EDI strategies and how they deal with health, disability and neurodivergence.

Conduct an institution-wide audit to compare support routes for disabled students and disabled staff.
- Identify all areas where support for staff lags behind support for students.
- Use this information as the basis for an action plan to improve support for disabled staff.
- Include both trade unions and NUSU in the audit and following action plan.

1.4 Universal design

Create a dedicated employee- and occupational-focussed unit committed to the principles of Universal Design, in order to consistently plan for diversity.

1.5 Workloading

Create a task group, as a matter of urgency, to address the workloading of EDI network participation.

Create an institution-wide action plan for support options regarding the workloads of disabled, chronically ill and neurodivergent staff.

1.6 Accessibility

Draw up standard guidelines for making accessibility of research events the norm, not the exception, with the expectation these are used across NU events, online or in person.

1.7 Training

Make mandatory specific training to all line managers on support routes for disability, neurodivergence and chronic illness.

1.8 Careers

Launch a disability-informed audit of promotion and redeployment opportunities.

Reflect the need for flexibility (which may concern any member of staff, regardless of personal impairments) at every career level.

2. Improving access to support

2.1 Communications and signposting

The SharePoint page of People Services should clearly signpost disability, neurodivergence and chronic illness-related policies. This information should also be signposted from the University EDI webpages.
Monitor the current improvements to the accessibility of available advice/support/guidance about routes for support, with input from colleagues with lived experience.

2.2 Disability advisor and multi-level disability contacts

Recruit a new University level Staff Disability Advisor as a matter of urgency.
Introduce a PS disability contact for each Faculty and each School/Unit.

2.3 Disclosure and adjustments

Reframe institutional understandings of disclosure and adjustments, using research findings from this report. Involve disabled, neurodivergent and chronically ill stakeholders.
Offer disabled, neurodivergent and chronically ill staff the opportunity to devise a personal disclosure plan.
When devising adjustments, provide the member of staff with a wide, varied, up-to-date and easily accessible list of possibilities.
When needs arise that haven't been planned for, they should never be assumed based on visible characteristics, but rather assessed and discussed in a collaborative process with the individual. Don't try to fit the person into pre-planned adjustments.

3. PGRs

Conduct a listening exercise specifically aimed at disabled, chronically ill and neurodivergent PGRs, coupled with an audit of student disability services, to ask 'how are the needs of disabled, chronically ill and neurodivergent PGRs being met at NU?'.
Taking heed of UCU's 'PGR-as-staff' campaign would go a long way towards facilitating the inclusion and participation of disabled, neurodivergent and chronically ill PGRs.
Allow PGRs access to support information stored on SharePoint as a standard practice. Create a separate page for this group.

Contents

Introduction

Background

The listening exercise reported upon here follows up the more general consultation by the Contested Spaces of Diversity project on 'The Experiences of Students and Staff with One or More Disability' (Mearns and Hopkins 2021). It also follows the Research Culture Roadmap (Newcastle University 2021) and subsequent Action Plan (Newcastle University 2022), which emphasised the importance of an 'inclusive, supportive and safe research environment' and of 'diverse contributions to research'.

This report makes recommendations for Newcastle University to embed equality, diversity and inclusion for disabled, chronically ill and neurodivergent staff and PGRs 'into all processes and practices that support and facilitate research' (Newcastle University 2021).

Our research

In 2022-2023, we conducted 10 in-depth, semi-directed interviews and created an online survey, for which we gathered 27 responses. The research took a qualitative approach, aiming to drill down into complex lived experiences of working at NU. It also included an international literature review.

While it is important to acknowledge the relatively small size of our sample, it is also necessary to point out the difficulty of engaging people on EDI issues, and specifically disabled, neurodivergent and chronically ill people. Reasons for this include the additional workload created by managing impairments in a disableist society, and the difficulty of engaging with such a diverse and complex population, which may or may not identify with labels such as 'disability'.

These 37 respondents occupy a variety of roles, all in relation to research, at different career stages.

- 15 are postgraduates;
- 9 have fully academic roles, from postdoc to professor;
- 8 have other research roles;
- 1 is a technician;
- 4 have experience as researchers and currently occupy roles in research administration.

Some of the 15 PGRs were also undertaking part time research assistant roles, creating some cross over in roles and experiences.

In order to preserve anonymity, respondents are only identified by either 'interview' or 'survey [response]' followed by a number, and all are referred to using the neutral *they*/*them*/*their*.

Impairments disclosed were varied, ranging from physical disabilities such as deafness to various forms of neurodivergence and chronic illnesses. Most respondents disclosed to us more than one impairment and described complex, multi-faceted situations.

It should be noted that both authors of this report identify as disabled. The research was conceived and conducted by Daniel Jones and Anne-Charlotte Husson, and Anne-Charlotte Husson led on the write-up. Many thanks to Rachel Pain, HaSS Faculty Director of EDI, for her precious support and contribution throughout the project, including in writing up some of the recommendations.

Changing the narrative around disability

Addressing disability as an equality issue means acknowledging not only that it takes many forms, but also the complex and diverse ways individuals position themselves in relation to this label. Disability

is an integral form of diversity, and there is immense diversity among disabled people. What they all have in common is having to face societal obstacles on their path towards full participation.

Whether talking about disability, neurodivergence or chronic illness at NU, it is important to adopt a complex approach to impairments and how they might interact with the obstacles people encounter while working as researchers. Here are but a few ways in which narratives about disability need to be complexified.

- Disability is not a tragedy, nor is it abnormal. The 2021 Census estimates that close to 10 million people in England alone are disabled (17.7% of the population).
- In the context of the UK's ageing working population, disability is part of the normal horizon of human life.
- Bodies, minds and needs change over time, and some impairments might fluctuate on a daily basis.
- Individuals might present more than one form of impairment, which affect them differently and may not all be felt as worth disclosing.
- Some impairments might not be visible, which makes disclosure even more sensitive and vulnerable, and may affect the dynamics between co-workers.
- One in three disabled people in the UK suffer from a form of energy impairment. Energy-limiting conditions should be considered as one of the main factors of disability.

Terminology and approach

When it comes to health, disability, and neurodivergence, best practice with language is not straightforward and changes over time. Reasons for this include:

- The contested nature of the word *disabled*, within and outside the disabled community;
- The weight of stigmatisation which surrounds this category, and is specific to disability as a social category and a social justice issue: the idea of *being disabled* brings to the fore some narratives that are damaging to disabled people and might make it difficult for some to self-identify as disabled;
- The weight of the medical understanding of disability, which defines it as an individual deficiency caused by impairments. From an EDI point of view, impairments and disability should be understood separately.

Chronic illness	A condition lasting one year or more which requires ongoing medical care, limits daily activities, or both.
Disability	(See box below) Product of the interaction between individual impairments and societal barriers to inclusion and participation.
Disabling	Characteristic of a feature or practice which contributes to creating disability.
Disableism	Oppression, in the form of prejudice, discrimination or violence, which contributes to creating disability and perpetuates the marginalisation of disabled people.
Impairment	Physical, sensory, emotional and/or cognitive characteristic of an individual, which is part of normal human variation and may lead to disability.
Neurodivergence / Neurodiversity	Neurological, normal variation which leads individuals to process information differently. This includes the autism spectrum, learning disorders (dyslexia, dyspraxia...), AD/HD, Tourette Syndrome... Readers may be more familiar with other terms, such as *neurodiversity*, *neurotypical*, etc.

ABOUT THE TERMS *DISABILITY* AND *DISABLED*, AND HOW/WHEN TO USE THEM

The language of this report might occasionally differ from the language we recommend using. This is because our analysis is informed by disability studies, while our recommendations are informed by the data collected from respondents.

Because of the stigma it carries, the category of disability is hotly debated by stakeholders, who may or may not identify with it. As an employer, NU needs to be aware of such debates and of phrases commonly used by stakeholders.

From the beginning of the consultation, we received feedback from stakeholders who contested the use of the word *disabled* to neurodivergent people. There is significant pushback, among the neurodivergent community, against what is seen as a pathologizing label. Meanwhile, self-identifying as disabled is far from obvious for many people who suffer from chronic illnesses or chronic pain, either because they feel the label doesn't belong to them or because they reject its social connotations.

Disability and *disabled* remain essential concepts for disability scholars. In line with the consensus in disability studies, we define *disability* as the product of the interaction between individual impairments and societal barriers. This allows us to move away from the medical understanding of disability as an individual deficiency to be remedied and, if possible, eradicated through therapeutic means (Wilson and Martin 2018). Instead, attention is drawn on those *disabling* practices, structures and processes which create disability (Cameron 2011).

While such language and definitions remain operative in the practical work of equality, diversity and inclusion, they may differ from the way stakeholders think and talk about disability. Our recommendations are meant to help the university navigate this discrepancy when addressing disabled, neurodivergent and chronically ill staff.

Complicating the narrative around disability

The concept of disability, and the stigma it carries, can often conceal the immense diversity and complex realities of the bodyminds concerned.

> In disability studies, the term *bodymind* acknowledges the intricate connections between bodies and minds, which can render them impossible to distinguish. This concept is useful to understand the experiences described by respondents and how they understand their own impairments.

Some conditions, for instance, manifest both in physical and cognitive terms, something that comes up during the interview process, when a respondent struggles to find appropriate terms: '*You know, what's...? I can't think of the word. This is part of the problem*.' They go on to explain that one consequence of their physical condition is that '*cognitively, it's all a bit different than it was, and I'm different than I was*' (interview #4).

This form of **cognitive impairment**, colloquially known as 'brain fog', goes hand in hand with energy impairments in conditions that require careful management. The same respondent explains that since becoming disabled, they have had to learn to say no to a lot of things, something that didn't come easily: they used to '*say yes to anything and everything and probably to my detriment*.' Because of this negative impact on their health, they wonder if they have '*gone the opposite way, which is being overcautious*', building their own '*safety net to avoid... to be able to do something properly*.' Their health has improved as a result, '*because I'm looking out for myself and not doing, you know, trip away, you know, long days of high contact field work*.'

Several other respondents, as well as one of the authors of this report, suffer from **energy impairments** caused by a chronic illness. Such conditions affect the amount, rather than the type, of activity that people can perform. Their manifestations are dynamic (variable day to day), unpredictable and, most importantly, cannot be fully mitigated by adjustments. Recognising this category of impairments would go a long way towards facilitating the inclusion of people who suffer not only from debilitating conditions but also from stigma and a lack of understanding.

> *Energy-limiting conditions*, or *energy-limiting chronic illnesses*, are thought to affect as many as 5 million people and 'one in three disabled people of working age in the UK', who experience 'impairment of stamina, breathing or fatigue' (Hale, Benstead, Hardy and Ingold 2021: 7). With the Covid-19 pandemic and the subsequent epidemic of Long Covid, there has been increasing awareness of energy impairments, which also affect people with cancers, ME/CFS, fibromyalgia, MS, thyroid disease, heart disease...

The interviewee quoted above shares a very significant anecdote, in which they were unable to attend an important meeting added at the end of an already long day of meetings. They later discovered that due to their absence, NU had been excluded from a major bid, and they were held responsible for this apparent failure by senior management. In this instance, they believe, the need to manage their health (which they explained to the other attendees) led to a form of retribution which could be detrimental to their career.

They are not the only respondent disclosing a **dynamic health condition**, i.e. one causing fluctuations of health, pain or energy. One survey respondent explains that the impact of their condition on their performance at work depends on whether they're '*having a flare or episode*' (survey #16). Such conditions can only be managed '*day by day*' and can prevent people from thinking '*in terms of end goal*;' people need to think '*in terms of managing how* [the condition] *is now*' (interview #4). This mindset and variability are not specific to chronic conditions: disability in general needs to be

understood as neither static nor constant. Thus, support for disabled staff should recognise and accommodate the evolving needs of disabled bodyminds.

The forms of impairments mentioned above – cognitive, dynamic, energy-related – may remain **invisible**, in the sense that the person does not carry visible markers of disability. Other impairments, although they may be considered as physical, can also remain invisible. One d/Deaf respondent shares that '*a lot of people probably don't view me as disabled because I don't necessarily look disabled and, like, you happen to see my hearing aids*' (interviewee #8).

Invisible or mostly invisible disabilities can significantly complicate relationships with colleagues and raise the difficult question of disclosure. The same interviewee explains having to systematically disclose their deafness to colleagues, as opposed to other impairments they also have – '*because that's the biggest thing, you know, making sure I hear somebody.*' Disclosing to coworkers is also a way to avoid misunderstandings or causing offence: '*So you know, I'm not being difficult when I'm saying I'm struggling to understand you*' (interviewee #8).

This respondent is not the only one presenting **several impairments**, unrelated to each other. During the interview, they also disclosed mental health issues, another physical impairment and two forms of neurodivergence. While their mental health and neurodivergence both have an impact on their work as a PGR, they didn't mention disclosing them to coworkers, only to SHWS and to Disabled Students Allowance staff. In other words, many factors may affect staff's decisions when it comes to disclosure, including the visibility of their impairments, the way these impairments affect them day-to-day, and how to manage co-worker interactions.

Neurodivergence, too, raises the question of visibility and disclosure. Some neurodivergent respondents describe their neurodivergence as having a limiting impact on their careers:

> '*I think that my autism has been extremely limiting to my career. There are a lot of aspects of the research career pathway that I'm not comfortable with. Particularly networking, fostering collaborations, working with others, presenting and just the general competitive nature of the role is not something I excel in at all.*' (survey #2)

Because such difficulties can be shared by neurotypical researchers and relate to aspects of the role that may not be material or quantifiable, it is all too common for neurodivergent researchers to struggle in silence and sometimes to be unaware of their own neurodivergence, and the impact it has on their work.

It is also important to note that neurodivergence may play a positive role in researchers' careers. One respondent writes: '*I'm pretty sure my PhD was a dopamine seeking adventure (ADHD) and my autism made it a special interest. So, it got me here*' (survey #24). Another shares that autism '*has helped in lots of ways e.g. high attention to detail, seeing patterns or links that others cannot, ability to write in lay language, creativity, honesty, good organisation skills*' (survey #4). They still acknowledge the limitations autism can bring, such as being unable to '*work as many hours as* [their] *colleagues'*, something which they think has held them back in their career. Like the previous respondent, they experience have '*difficulties with social communication*' resulting in '*being overlooked and forgotten about very often'* (survey #4). In the words of another respondent, '*the ability to communicate well with people and organisations is the mainstay to research nowadays but this is the most difficult problem for people with neurodivergent conditions*' (survey #7).

Two autistic respondents note that their autism is **self-diagnosed**. This a common phenomenon among the neurodivergent and chronic illness communities, and it is also relevant to mental health.

(which may not qualify as chronic). It is explained by the difficulty of accessing medical care in the UK and, with some conditions, a frequent and lengthy struggle to obtain the right diagnosis. Self-diagnosed individuals face further obstacles on their route to securing adjustments when processes require medical documentation. It is also important to be aware of the stigma associated with 'invisible, less known or contested conditions', which are often 'dismissed as a fabrication, malingering and an act of a fundamentally lazy or overwhelmed worker seeking validation' (Brown and Leigh 2018: 987).

Health and disability should be considered as but one aspect of a person's lived experience and identity. They may intersect with other characteristics to create complex experiences and possible sites of oppression, and they may also be affected and made worse by these **intersecting experiences** (Kerschbaum, Eisenman and Jones 2018). A survey respondent writes: '*I'm a neurodivergent, non-binary, pansexual, in a middle-aged/peri-menopausal, disabled, female body. I can't switch one of those parts off without significant energy expenditure and that in turn causes flare ups of my ill health*' (survey #20). However, working at NU has brought a respite to these flare-ups: '*I have never felt the need to mask or perform "normal". This is the first workplace where I feel like I can be openly just me*'.

When asked what language they use to talk about their impairments and their **attitudes towards the label disabled**, respondents' answers vary. We initially received some pushback from a group of neurodivergent stakeholders about the name of our project, 'Being Disabled and Doing Research'. This feedback reflects the attitude of part of the neurodivergent community, who refuse to associate neurodivergence with disability. There is a long history of debate over language and identity when it comes to disability and neurodiversity, in line with neurodiversity movements that take a stance against the need for 'cure' present surrounding disability discourse. This rejection of the project's wording stems from a lack of comfort with the disabled category, perceived to be an inadequate description of the neurodiverse experience in the case of this stakeholder group.

The relationships between **mental illness, chronic illness, pain conditions and disability** form another area of contention. If lasting six months or more, these conditions could legally qualify as forms of disability; however, poor medical and social understanding, as well as stakeholders' own relationship with their impairment, make self-identifying as disabled far from obvious. One respondent explains, for instance, living with several '*chronic conditions*' but not identifying '*as disabled*' (survey #24); another draws a distinction between chronic illness, physical disability and their own injury-related '*chronic pain*' (survey #16).

Attitudes towards the label disabled may also vary over time and reflect an evolution towards self-acceptance. Despite their condition, a respondent initially continued working as before, to the detriment of their health, and refused to consider themself as disabled: '*There was a time very early on (…) I was refusing to even acknowledge the word* [disabled] *in relation to me*'. Officially disclosing their impairment felt like '*coming out*' as '*disabled, and less able than I was*', although it eventually allowed them to better manage their condition. However, they still have some ambivalence towards the idea of disability: '*once I kind of, not embraced, embraced being disabled – that's not quite 100% true, but once I've kind of accepted it, I started to think of myself as a survivor rather than a victim. That was a big switch as well*' (interview #4).

KEY FINDING

As a university, Newcastle must urgently understand and acknowledge the complex landscape of disability. This is important not only for decision-makers and line managers, but for anyone working at the university. Disability may be visible or invisible; people may choose to disclose their impairments in some contexts and not others; some conditions may evolve over time, and sometimes day to day; impairments may be physical, psychological, cognitive, or all of the above, and combine to create complex, deeply individual situations. Finally, individuals may or may not self-identify as disabled, even when they are entitled to legal protection under the umbrella category of 'disability' in the Equality Act. What all disabled, neurodiverse and chronically ill respondents share, however, is having to manage personal impairments in a social context that was not designed for them, does not always accommodate and, sometimes, downright excludes them.

A threatened sense of belonging

It is essential to acknowledge that academia and higher education were never meant to include disabled bodyminds. Disabled people were not only historically excluded from such institutions, but also treated as pathological subjects who, according to proponents of eugenics, should be eradicated (Dolmage 2017). The drive to include disabled bodyminds, lead for decades by disability scholars and activists, is a recent and contested endeavour, one that has tended to focus on fee-paying students rather than staff (ECU 2011). This inclusion drive goes against some **deeply anchored beliefs** – about the nature of academic work on the one hand, and on the other hand about the nature of disabled bodyminds.

Academic work is typically conceived as an endeavour of the mind, in which bodies (historically, generically cisgender male and white ones) have little to no place. According to Kumari Campbell, the dominant imaginary of the 'healthy academic's body' is constantly reaffirmed 'in student evaluations, perceptions of what an academic looks like, feedback, ideas of "objectivity" and scores' (2020: 208). Cognitive impairments, meanwhile, 'may carry even more stigma within academia than other work environments, as it is such a cerebral profession' (Finesilver, Leigh and Brown 2020: 153).

Excluded from the dominant, self-perpetuating narrative about what an academic looks like, disabled people also suffer from stigma and low expectations, especially in intellectual terms. They are often 'assumed to be not working, "on benefits" or scroungers' and 'incapable of the intellectual work necessary to hold down a job in academia' (*ibid.*: 149). In the words of one respondent, including disabled people within the research community implies recognising that '*really big, important thoughts and skills are held by a disabled person*' (interview #5). Such recognition is still lacking. Contrary to the ideal image of what academic excellence looks like, disabled bodyminds are complicated and messy; they have needs that cannot be simply ignored.

Most respondents agree that research in itself is not the issue: there is nothing that inherently prevents disabled people from doing research. Rather, the **research culture**, and more generally the environment in which they do research, is what they all point to.

> '*So it's the environment surrounding the research, not the research at all, and it's very spiky and hostile.*' (interview #5)

> '*When I went into redeployment, suddenly all sorts of* [PTSD] *triggers are around me that aren't normally so I've had a real fight with HR because I'm saying, I don't have a disability that affects my day job. I have a disability that affects everything else around the day job. Like if I go into training, if I go into interview situations and if even the fire alarms, the fire escape isn't working […] and so it's those sort of fringe things that you wouldn't necessarily* [think about].' (interview #5)

> '*Nothing is accessible, nothing is inclusive, and although there are a few people doing a lot of work in it, there are more hurdles than there are opportunities and that results in people competing for money to improve various things, which is absurd and things should be made more inclusive and more accessible, because that's a human right.*' (interview #9)

Respondents also express a sense that, as disabled researchers, their competence and ability to perform their role is automatically questioned. One recalls an email from People Services in response to a request for reasonable adjustments, in which staff purportedly used the phrase 'we're concerned that you can't fulfil your contract'. This phrase echoed with their experience of being perceived as less

than able by co-workers and the institution: '*That phrase alone* [suggests that] *I am not competent*', something which is of course deeply offensive to them (interview #5).

Such attitudes perceived or real, towards disabled people often lead to a form of **performance of competence**. While bolstering their sense of academic identity and belonging, this performance can be very detrimental to their health and wellbeing. It also seems specific to academic workers: 'working in academia continues to be romanticised and is still seen as worth striving for,' which leads disabled individuals to focus on 'managing their emotions and bodies in an attempt to compete with non-disabled colleagues' (Brown 2020: 67). Unlike other professionals, academics invest so much of their sense of identity into their work that those 'with disabilities or illnesses work hard to hold onto their academic work and identity whilst compromising other aspects of their life', where, in similar situations, non-academics reported that work was the first thing they dropped to maintain their personal lives and relationships' (Brown and Leigh 2018: 987).

One respondent used to put a lot of effort into '*trying to appear normal*', to pass as '*this strong able-bodied person who was not gonna be beaten by this*' (interview #4). Another remembers that when starting a lectureship as an early-career researcher, the demands of academic work built up to the point that they started to have '*a really big negative impact*' on their mental health, since they were becoming '*more and more aware of* […] *feeling less capable of doing things*' (interview #9).

Another consulted a coach to help with their career progression and was advised to '*shadow someone or [...] do these things voluntarily*' (interview #5). They followed this advice and now think that it '*wrecked* [their] *health altogether*', causing them to be '*forced out of the job*.' They also recall feeling '*really disheartened*' sitting in a training session at NU, where respondents were apparently told:

> '*If you want to get ahead as a researcher, what you're gonna need to do is you're gonna need to do your job and as well as that, you're going to need to invest in your future funding plans and they basically spelled out that you need to be doing it minimum x times full time equivalent, is how. And I just sat in that training session and thought, Never gonna be able to do that.*' (interviewee #5)

This type of messaging about what it takes to do research, and **who belongs in academia**, can be very detrimental to disabled people, who often already struggle to keep up with the academic hustle. The same respondents talks of feeling '*unwanted*' and '*getting messages that I'm not really the person that they want to be employing*' (interview #5). Such institutional messaging, added to the difficulties created by their personal impairments, threatens their sense of belonging in the research community.

When asked about the role played by their impairments in their careers, respondents often list expectations that are part of the unwritten assumptions about academic careers and that they personally struggle with.

> '*I am losing a lot of my research time. I am unable to attend events that are not online which means I am not able to go to most conferences etc. I do not have the capacity to apply for big grants. This is a massive issue.*' (survey #11)

> '*All of the extraneous necessities of the job are really difficult for me* [because of my autism]*. Seeing as you need to demonstrate your ability in these areas in order to get continued funding, I'm not sure I can continue successfully in academia.*' (survey #2)

These 'extraneous necessities', everything that is not research per se but has become an undisputed part of the role, threaten respondents' ability to do research and constantly place them at odds with the bulk of their coworkers, who don't face the same access barriers in travelling to conferences,

finding the time to apply for funding, or networking and socializing with co-workers during and outside of working hours. Instead, disabled academics must learn to protect their time and set firm boundaries.

Such constraints place them in a **precarious position** towards coworkers, who may suspect them of '*making the decision to not bother*' (interview #5), and towards the institution, with its promotion criteria and other, sometimes implicit expectations. While the academic culture of overwork has been well documented and is an almost universal concern in UK universities, disabled staff simply do not have the option to participate in this culture.

Because of such invisible barriers, disabled researchers find themselves in the position of **misfits**. According to Garland-Thomson, 'fitting' requires an encounter between 'a particularly shaped and functioning body and an environment that sustains that body' (2011: 594). Instead of acting as 'sustaining environments', the research culture at NU and academia in general 'create misfits.' This is the result of the encounter between disabled bodyminds and the 'unsustaining environments' of academia, which do little to foster disabled researchers' sense of belonging. The only alternative, then, seems to be between fitting in at all costs (including the cost of one's health and wellbeing) and staying in the margins of the research community.

> ## KEY FINDING
>
> All the barriers faced by respondents have a lot more to do with the research culture than with the role of researcher itself, or respondent's abilities as researchers. Nevertheless, because of harmful stereotypes about academia and disability, they feel pressured to perform 'normalcy' and competence in order to 'fit' within an institution which, by default, does not accommodate them. They express a sense of being misfits, of feeling unwanted and even undesirable, due to pervasive messaging about who belongs and how to succeed in academia.

The disability workload

The *disability workload* results from the combined pressures of managing personal impairments, the administrative workload this generates, and having to self-advocate to access care, support and equal treatment.

Respondents use the **language of exhaustion** to describe the effects of the disability workload, which is well documented in disability studies (Inckle 2018).

> *It keeps and keeps and keeps and keeps coming back to* [...] *having to advocate for yourself. And it's exhausting to have to advocate for yourself and to have to advocate for the others around you and to even know that these resources exist to advocate for.'* (interview #9)

> [Having to constantly explain accessibility requirements] *It's exhausting. You have to constantly explain this.* […] *That's a huge one to learn, the constant thinking ahead of what obstacles might be is really exhausting. It's exhausting.* […] (interview #4)

Interactions with coworkers and the need to repeatedly ask for the necessary adjustments often generate this sense of exhaustion, while also placing the disabled person in a **vulnerable and potentially antagonistic position**.

> *'Other than me walking around with a sign or something, I just... it's so difficult, isn't it? Because sometimes I feel the only way forward is to be kind of very demanding, and the stroppy person that* [...] *goes into a meeting and you know* [asks for the adjustment they need]*.* […] *What do I have to do though? I mean, what more can I do other than constantly be saying I can't read that or...?"* (interview #4)

> *'I'm so tired and embarrassed of having to repeatedly ask, I just either suffer the pain of the bright light, leave early or don't go.'* (survey #14)

> *'In general, it feels like no one cares about others' needs, or don't understand how much it affects them, so make no effort to accommodate people. I'd love to see more education on this and low lighting, quiet spaces, allergy free food, accessible spaces being THE NORMAL, rather than each person having to repeatedly request adjustments.'* (survey #14)

The **disclosure and adjustment** processes were by far the most discussed themes, and the ones raising the most complaints. Survey respondents were asked to rate 'how straightforward' they found the disclosure process on a scale of 0 to 5, where 0 meant 'not straightforward at all' and 5 'completely straightforward'. Among 27 respondents, 6 found the experience 'not straightforward at all', meaning they 'found it very difficult to find relevant information on who to contact and what to do'. 11 rated their experiences 2 or 3, while the last 7 rated it a 4 of 5.

One respondent is used to being *'required to ask for adjustments'* rather than adjustments being offered. In the past, this has lead them to not *'say anything and either just miss out or struggle on* [their] *own'* in order not to *'be seen as awkward or creating problems all the time'*, nor having to face their request being denied (survey #4). Another respondent concurs that *'there felt like a lack of proactivity from the university in terms of offering what possible adjustments were feasible, rather the emphasis was placed on me to suggest things without knowing whether they would be considered'* (survey #8).

Most respondents mention the added **administrative workload** created by the disclosure and adjustments processes, as well as their **emotional toll**. Disclosure was described as *'exposing'* and

'*confusing*' (survey #9 and #25), while the difficulty of '*navigating policies*' means that one respondent has '*often been left to advocate for* [them]*self*' (interview #9). In one particularly difficult case, disclosure is described as an '*ABSOLUTE NIGHTMARE! So stressful, so much extra work was placed on me (...) when I was already struggling, people services treat people disgustingly (I've not met a single HR person that treated me like a human being*' (survey #14). This respondent concludes: '*I was so overwhelmed, humiliated and bullied*'.

The institution, and in particular those involved in supporting disabled staff, need to recognise that the very act of disclosure may create mixed feelings in those it is supposed to help. There are necessarily power relationships at play, which should be given special consideration. Disclosure can be a vulnerable act, which some might feel pressured to perform in order to be able to work, as an exercise in rendering 'one's body legible to the gaze of administrators [and] colleagues' (Sanchez 2018: 212) and in proving 'one's fitness for participation' (Taylor and Shallish 2019: 10).

Contrary to its managerial purpose, disclosure is also not a single event but rather an ongoing process, with no end in sight (Kaul 2018). The need to disclose is dependent on the context, on evolving relationships between coworkers, and on people's evolving needs. In the words of a survey respondent:

> '*It is very difficult to apply some adjustments given I work with different groups of people/teams as a researcher. I don't want to have to continually disclose my health issues and what I 'can't' do all of the time and I'm not sure how to resolve this. I try to generically state that I have disabilities in the hope that people will understand to be inclusive* […] *but this often doesn't work and I end up feeling distressed, not performing as well as I could and suffering from low self confidence as a result.*' (survey #4)

Meanwhile, because adjustments are individualised and enacted reactively rather than anticipated (Martin 2020), they can be understood as 'attempts to provide quick fixes for more systemic problems and concerns around accessibility in academia' (Brown, Leigh and Thompson 2018: 83). In other words, adjustments may appear to disabled staff as a way to restore some normalcy, by compensating for the individual deficiencies of disabled bodyminds. As with disclosure, the adjustment process should be understood not as a one-off event meant to solve a localised issue, but one that needs regular reviewing, allowing for bodies, minds and needs to change over time.

Instead of using adjustments as a reactive, individualized means to correct for a lack of inclusivity, they could be anticipated according to the principles of **inclusive planning and universal design**.

Universal design is a strategy for maximum inclusivity. Its aim is to conceive and implement environments, products, technologies and services usable by as many people as possible, without needing to be adapted before or after use. In higher education, universal design is often discussed in relation to teaching.

There already exists within NU extensive expertise about universal design, which can be tapped into and extended to topics like policies and physical environments.

The individualisation of adjustments and the need to request options that could be offered as standard (such as online access, allergen-free food or a quiet space to recover between sessions, to name but a few) are both signs of an absence of inclusive planning and universal design. They are also compounded by a lack of understanding, and often a **lack of imagination**, regarding what true accessibility and inclusion might look like – on the part of disabled people and of those organising

support. This is especially true of non-physical disabilities (Kerschbaum, O'Shea, Price and Salzer 2018).

Survey respondents were asked whether they had asked for adjustments and, if they answered 'no', were given several options to explain their reply:

- I don't need adjustments.
- I need adjustments but wasn't sure what to ask for.
- I've been discouraged from requesting adjustments.
- I've had a bad experience with the adjustment process in the past.
- Other.

10 answered 'no', two of whom chose the second option, 'I need adjustments but wasn't sure what to ask for'. This goes to show that the individualisation of adjustments, and placing on individual staff the responsibility to imagine and request what they need, are both limiting factors and endanger staff's ability to be fully included.

When asked about adjustments for research events, a survey respondent begins by stating that a request would be useless. They describe struggling with '*long distance travel, long time sitting, and lack of movement*', as well as '*certain beds*', concluding: '*but again, this isn't something I can actually do anything about*' (survey #23). Yet every one of these difficulties could be better managed through inclusive planning (online access, thoughtful scheduling) and/or individual adjustments (type of accommodation and bedding).

While disabled stakeholders often don't know what inclusion might look like and what to request, there is also a **lack of specificity** in the adjustments offered to disabled staff. One respondent describes having to '*jump through pointless hoops*' for a specific model of chair to be prescribed by an Occupational Health physiotherapist, only to then be asked by Estates staff to look at chairs the university already owned and determine which was '*comfortable*': '*the person didn't recognise that the problem came when sitting for longer periods and I wasn't really qualified to judge whether the chair would give the right support over longer periods*' (survey #23).

An interviewee recounts derisively how they were offered a new chair for blindness-related impairments (interview #4). Another takes issue with Occupational Health recommending a specialist chair to supposedly make them '*more comfortable*', a poor choice of words when the adjustment was '*so that I could still sit upright by the end of the day, so I could still walk by the time I get home, so I wasn't in pain when I get up to use the photocopier*' (interview #5). They were then offered a number of chairs the university already owned, none of which took into account the specificity of their requirements. In the end, they had to go through three years of back-and-forth and turn to Access to Work in order to obtain a suitable chair.

Going through these processes requires staff to **feel comfortable enough in their work environment**. One survey respondent explains not pursuing adjustments because they did not '*feel safe*' to do so '*because of the office situation*' (survey #12). In fact, research on disclosure in higher education has found that 'students are more likely to ask for adjustments to cater for their needs than staff' (Brown, Leigh and Thompson 2018: 83). Another respondent also gave up on seeking adjustments, and describes how the situation affects their work:

> '*I need so many more adjustments than I have, but I don't have the time or mental energy to fight for years for each one. My work is very much negatively affected by having to work in a*

bright, noisy, cold office and lab with painful seating, and nowhere to eat lunch that is quiet with low lighting.' (survey #14)

When negative past experiences lead staff to avoid disclosure and adjustment processes, **career progression** may even be at risk:

'[Instead of] *progressing to a level I'm capable of achieving* [I've] *chosen an easy lower paying job which allows the flexibility I need, because the things I need are not standard at higher levels, and I wouldn't have the time to fight for all the adjustments I need if I were busier*.' (survey #14)

In fact, it is important to acknowledge that disability 'disrupts the stages of the life course', both personal and professional, 'in terms of when normative life stages are achieved (if ever) and the time it takes to complete activities' (Ljuslinder, Ellis and Vikström 2020: 36). The lifecourses of disabled, chronically ill and neurodivergent people cannot be understood through the same normative lens as those of their peers. This raises multiple questions, including about retention rates, promotion criteria and the disableist notion of academic excellence as it currently stands.

In terms of work and productivity, the disability workload highlights the fact that **time is not a resource equally available to all**. In a context where 'research excellence' is the stated goal and epitome of desirability, 'one needs the time and opportunity to nurture and display' such excellence (Merchant *et al.* 2020: 275). These commodities, however, tend to be in short supply when 'one's private life one's private life is facilitated by supporters or carers, if a disabled person is also a carer, or if the technology one needs is not available' *(ibid*.). The disability workload takes many forms, which we could only gesture at in the space of this report, so as to highlight the structural disadvantage in which it places disabled staff.

> ## KEY FINDING
>
> NU must urgently recognise and address the breadth and impact of the disability workload, and its ramifications in terms of productivity, career progression and employee wellbeing. The disclosure and adjustment processes, which are meant to support disabled staff, instead emerge as major disabling factors. They both need a major overhaul in consultation with disabled stakeholders, in order to truly serve their needs.

Other disabling practices

While the disclosure and adjustment processes, administrative by nature, have an obvious impact on the disability workload, our research brought to the surface multiple other disabling practices, which all create barriers for researchers at NU and contribute to the disability workload. Such practices 'erode confidence in institutional mechanisms to resolve inequalities' and result in 'accumulated experiences' of disableism (Kumari Campbell 2020: 220). In other words, the number of disabling practices facing disabled staff result in experiences of exclusion and discrimination and a generally disabling environment.

One significant other disabling practice is a **lack of consistency**, at institution level, in the delivery of support and disability equality. One way this was revealed is by respondents' widespread use of the language of luck when describing positive experiences. This both reveals their low expectations in terms of support and reinforces the idea that they are misfits in a system that was not built for them.

> '*I am really lucky with my* [APR] *panel* [because it is understanding of neurodiversity and disability].' (interview #6)

> '*I've received quite a lot of support for* [autism] *from a couple of people in particular over the course of my PhD* […] *I've been quite lucky in some respect for my supervisors.*' (interview #3)

> '*I'm kind of lucky in my office. If I'm around people who are quiet* […] *sometimes I just* [am going to] *be really fidgety and that kind of thing* [and colleagues are fine with it]. *I'm not sure that would necessarily be the same elsewhere.*' (interview #6)

When positive experiences are down to luck, they can always be overturned when different people are in charge of delivering support:

> '*The new boss didn't like the adjustments* [that] *the previous boss had put in place. So it's a roller-coaster of having adjustments that one person doesn't agree with, the adjustments that somebody else agreed*.' (interview #5)

This 'line manager lottery' is troubling and has been identified both in other NU research and sector wide. In 2011, the Equality Challenge Unit already warned that 'how disabled staff are treated, and what reasonable adjustments they are able to secure, often appears to be down to luck about which department a person is in and who their line manager is' (ECU 2011: 13). While this 'lottery' issue isn't specific to NU, there is an opportunity here for the university to spearhead some sector-leading reforms to this widespread problem, as detailed in the recommendations.

Another institution-wide issue with the delivery of support has to do with **signposting and accessibility of information**, which also currently lacks consistency. There is a general sense of frustration over SharePoint, where respondents found it difficult to find the relevant information. The People Services page does not clearly signpost any disability-related policies, nor does the university's EDI page.

Respondents also report difficulties finding out relevant points of contact in their respective School/faculty/department, since they seem to vary from unit to unit. A respondent talks of a '*scattering of different places, different responsibilities*' that often turns out to be '*completely unnavigable*' (interview #5). Knowledge about disability support and policies appears difficult to locate, scattered as it is across campus and among many different roles and services, without necessarily being attached to clearly identifiable roles.

This issue is amplified for PGRs, whose supervisors, School PGR directors, etc., can be more or less *'open to communication with the students and […] approachable'* (interview #1). Occasionally, academic staff may take on the informal role of a *'triage system for pointing people in the right direction'* (interview #1) based on their own ad hoc experiences of support. This self-selection increases the overall lack of consistency. It also contributes to the disability workload of those disabled staff who, because they had to navigate the same systems, take it upon themselves to offer signposting advice to students or coworkers.

Several respondents mention their positive experiences with the former Staff Disability Advisor. Before encountering her, they had struggled to access relevant information, but through her found out about key schemes such as Access to Work: '*I had no idea what access to work was until a year or two ago. None*' (interview #9).

Another disabling factor, this time specific to researchers, is the **lack of accessibility of research events** (such as seminars, conferences, networking events and more). Although they form a key part of academic work and play an important role in sustaining research communities, they are rarely designed to include disabled researchers.

The drive for disability inclusion has long focussed (with very mixed results) on **physical accessibility**, especially for wheelchair users. A previous report found that NU's policy of slowly improving the accessibility of its build environment over time was paying off, and that the campus 'was generally far more accessible than the spaces of the city in which it is situated' (Mearns and Hopkins 2011: 6). Yet 'sizeable parts of the campus were still incredibly difficult to navigate', a situation eloquently summarised by one of our respondents: '*nobody is actively thinking how it feels to move around, as a disabled person*' (interview #5).

Meanwhile, the shift to open-plan working spaces raises issues in terms both of mobility and of sensory challenges. One respondent explains that open-plan offices are challenging because of a vision impairment ('*lighting is too bright and causes significant left eye pain after about 5 minutes of being in the office*'), of autism and associated sensory sensitivities ('*the electrical noise from computers, background noise from other workers, office is so cold I can't concentrate*') and of PTSD ('*can't wear noise cancelling headphones due to overexaggerated startle response*' - survey #20).

In the case of research events, accessibility needs to be thought of in a much broader way. This is illustrated by a respondent who share the struggle of managing their food allergies, getting too small portions that sometimes accommodate one allergy but not another, and missing out on opportunities to network and socialise over meals. This respondent insists that '*having food allergies makes overnight conferences or working away VERY difficult and stressful and miserable*' (survey #14).

Out of 27 survey respondents, 16 thought that their impairments equally affected their ability to give public presentations of their research and to attend research events at NU, elsewhere in the UK, or internationally. One question was about which adjustments they might need in order to participate fully in such events, among a series of options. The most common answer was online access (22% of answers), followed by access to livestreaming, live captioning or live BSL interpretation (15%), support with travel to location (12%), catering for allergies and sensitivities (12%), support with accommodation (8%) and physical accommodations (e.g. mobility aids, disabled toilets – 5%).

When asked about whether they had received any adjustments from NU for research events, most respondents described negative experiences, where they were either refused adjustments or had to organise them for themselves. Here again, the individualisation of adjustments, in lieu of inclusive planning, acts as a barrier and occasional deterrent to participation. While there is an increasing

number of guides for inclusive events, these often lack detailed consideration of practicalities and challenges, and there remains a desperate lack of precedents to be emulated – in other words, once again, a lack of imagination regarding what universal design and true inclusion might look like (Brown, Leigh and Thompson 2018).

Research events are as much about socialising and networking as they are about sharing one's research, since 'so much of academia involves social connections' (Carter, Catania, Schmitt and Swenson 2018: 97). Like in the case of the respondent who had to opt out of a meeting and later discovered they were excluded from a major bid (interview #4), or those neurodivergent respondents who feel they keep being passed over because of communication issues (survey #4, interview #9), those missed opportunities and misunderstandings are impossible to quantify in themselves but lead to very real consequences.

Promotion opportunities are another area where concrete evidence (e.g. the lack of disabled staff in leadership roles [Martin 2020]) stands alongside more complex, subjective factors (e.g. personal reasons for promotion avoidance). Survey respondents were divided on the topic. The question 'Would you say that, as a disabled/chronically ill/neurodivergent person, you have had access to equal promotion opportunities? Please specify whether you're talking about Newcastle University or another institution' received 21 answers almost equally divided between 'Yes' (8), 'No' (7) and 'Unsure' (6). This topic would require more detailed investigation than our research allowed, to determine the role of factors such as type and onset of impairment (before or during academic career), career stage and type of contract.

The question of promotion avoidance and its relationship to disability is especially sensitive.

> '*I avoid promotion as it would put me in situations that don't accommodate my needs (there's no reason these accommodations couldn't be made - I'm perfectly capable of doing a higher-level job, but not willing to fight an entire system set up for neurotypicals and healthy people*.' (survey #14)

Indeed, previous research on disclosure of higher education teaching staff found that 'teachers with a disability were less likely to apply for promotion due to perceptions of disability being perceived as a deficit and, of course, the potential adverse impact on the teacher's self-esteem and overall levels of confidence' (Marshall, Fearon, Highwood and Warden 2020: 1114-15).

The question of disabled staff's ability to work as many hours as non-disabled colleagues surfaces again.

> '*I do find the thought of promotion rather daunting; I feel like i need to work harder to deserve one but I am working really hard already.*' (survey #1)

> '*The bar is already set very high in terms of expectations for promotion but it is unattainable almost when you cannot work as many hours as other colleagues (e.g. late into the evening). I work full time hours already (sometimes over) just to keep on top of workload but I am only paid for a part time role. I have to do this to achieve what is expected of me and don't feel any genuine adjustments in expectations are/would be made for disabled colleagues in terms of promotions.*' (survey #4)

The last disabling practice identified in the research related to **training**, which can play a major role in changing the culture, alleviating the disability workload, and removing some of the barriers faced by disabled staff. With adequate training for all members of NU, the responsibility for access and

inclusion could start to shift from disabled staff, those co-workers able/willing to support them and designated support staff, and instead be shared by everyone across the university.

One interviewee mentioned repeatedly having to remind coworkers of their adjustment needs. When asked if they thought training would be useful, they were ambivalent about the possible added workload for themself:

> '*And I don't know whether does that kind of training exist. I don't know. And again, is it then my responsibility* […] *to make sure that other people go on a training course to accommodate me? That's just* […] *a minefield.*' (interview #4)

This is why such training should be compulsory on an institutional level, and not just restricted to staff knowingly working with disabled colleagues. Instead of singling out those colleagues, and possibly creating resentment for having to accommodate their specific needs, all staff should learn about disability support and be prepared for when, rather than if, they might have to work with disabled coworkers.

In order to mitigate the 'line manager lottery', training on support routes should be mandatory for line managers. Too often, respondents describe turning to their line managers, who then have to figure out how to help them. The scattering of information and the lack of visibility of disability support roles (when they exist) described above also affect line managers, who could benefit from bite-size training as well as being able to turn to a named point of contact in their unit.

Training should also include fundamentals about physical and digital accessibility. According to one respondent, '*the university just hasn't trained its administrative staff, that if they're organising an event, don't just say no to a reasonable adjustment without at least asking someone who understands things*' (interview #5).

Another issue with the training offer has to do with its occasional unsuitability for disabled staff. The same respondent reports that while there are '*huge amounts of training*' available to researchers, '*none of it to my mind has been assessed, whether it's capable of training autistic and non-autistic people,* […] *people with OCD.*' They recall a training session about 'Coping with change' where they asked about how reasonable adjustments fit into the change process:

> '*If it's destructive to my disability, I don't have to suck it up and get with the program.* […] *You know, someone with a disability, a relevant disability, doesn't have to cope with that change if it's going open plan and you can't work open plan.*' (interview #5)

The answer they received was apparently that '*None of this advice will work if you actually have a condition like OCD.*' The respondent then commented:

> '*Well, why not say that before, if it's not going to be suitable for autistic people or people with OCD, which are two categories of people who might want to sign up to coping with change training? Say upfront, this training is only suitable if you are someone who can suck it up and get on with it.*' (interview #5)

Existing training materials should be assessed from a disability-informed perspective, and the need for training specifically aimed at disabled, chronically ill and neurodivergent staff needs to be investigated. Across the sector, there is a lack of access to leadership training and a lack of disabled role models, which contributes to setting barriers to disabled academics' career progression (Martin 2020).

KEY FINDING

This section discussed five practices which, like the disclosure and adjustment processes discussed in the previous section, create structural barriers for disabled researchers:

- Lack of consistency in delivering support,
- Lack of consistency in access to information,
- Lack of/inadequate training,
- Lack of inclusion and accessibility of research events,
- Unequal access to promotion opportunities.

These disabling practices need to be tackled both through a fundamental cultural change and by improving access to support.

Postgraduate researchers

Postgraduate researchers (PGR/PhD) were included in this project as a subcategory of researchers. PGRs occupy a grey, in-between space between staff and students, forcing them to navigate complex power dynamics. While all the issues discussed so far are relevant to this group, they also face specific obstacles when it comes to being included in the research community at NU.

Because of the current landscape of academic funding, or lack thereof, the PGR experience fundamentally **lacks consistency** from the outset. The majority of funding comes from outside NU, through a wide variety of national and international organisations or governmental bodies, thus contributing to huge discrepancies between self-, internally- and externally funded PGRs. This lack of consistency is echoed in the experiences of disabled, chronically ill, and neurodivergent PGR respondents.

Many talk about how their **support and access adjustments are outsourced** to other organisations, and in some instances to other universities also.

'It's outsourced. You basically fill out and complete a form with Newcastle University. You have to have the initial funds to be able to pay for the assessment […] *you're then outsourced to an external agency to do the cycle of testing and everything like that.'* (interview #)

[The Disabled Students Allowance, or DSA] *'can get confusing sometimes because some of the PhD funding streams do it through them rather than student finance.'* (interview #8)

Due to their liminal status between students and staff, PGRs don't have access to Occupational Health. Instead, they can apply to the DSA, which is a governmental scheme available to students experiencing 'a mental health problem, long-term illness or any other disability' (GOV.UK 2023). It is supposed to help with specialist equipment, non-medical helpers (e.g., BSL interpreters) and extra travel costs. Unlike internal support routes, it requires official assessment through DSA assessment centres.

Accessing support through the DSA not only requires PGRs to have the initial funds for assessment, but also creates a significant amount of administrative workload. They need to act as points of contact between the DSA, the university, their unit and their supervisors.

One dyslexic participant describes how, years after being bought a license for some specialist software obtained after an outsourced assessment, they still have not received any training on how to use the software, despite repeated requests for training. For each of those requests, there was some uncertainty on the part of NU staff as to whether support could be organised internally or if the PGR had to go back to the DSA, which would then need to contract out a separate company. This respondent would *'feel more comfortable'* if support were organised *'within the university'*, so that they could *'go and speak to somebody'* (interview #8).

The outsourcing of support can place PGRs in a vulnerable and stressful position, forcing them to go through outsourced assessments and discuss their diagnoses with strangers who might be unfamiliar with the specifics of their conditions or symptoms. Repeatedly having to justify their need for support in order to access specialist software or physical equipment also adds to the emotional toll of the disability workload.

While there are **internal support routes** available to them, our research found, once again, a lack of signposting and consistency across the institution. PGRs currently don't have access to all information stored on SharePoint, nor is there a specific page there dedicated to support routes for this particular group. When they seek support internally to NU, they are often signposted to the Student Support

Plan (SSP) system within the Student Wellbeing Team, which is meant to cover them. However, a respondent recounts being '*shamed*' by disability support staff '*for putting in an SSP at PhD level*' and told that they '*shouldn't need that and they don't usually do this as PhD students are expected to just get on and manage*' (survey #13). In this instance, PGRs' liminal status seems to have been used against this respondent: while students are supposed to be entitled to support, academic staff and PGRs are simply supposed to '*get on and manage*' to prove that they belong.

KEY FINDING

Issues of academic identity and belonging, which have been the focus of this report, affect disabled PGRs in specific ways – because of their intermediary status and of systemic disabling practices. This double bind is even more important to acknowledge when considering the issue of retention of disabled scholars. PGRs find themselves at a crucial point in their academic careers: they have to prove that they belong in academia by demonstrating excellence, a fraught notion if there ever was one, and are faced at every turn with obstacles to their full participation, and reminders of their misfitting. It is essential for NU to demonstrate its commitment to disability inclusion by focussing on this group and engaging meaningfully with UCU's 'PGR-as-staff' campaign.

Recommendations

Based on the analysis of findings from this research, the research team has produced a series of recommendations for Newcastle University. For clarity, these have been divided into the categories of 'changing the culture'; 'improving access to support'; and 'postgraduate researchers'. Although PGRs have a dedicated section, we argue that addressing all of the prior recommendations would also have a positive impact on PGR experience.

The numbers in the right-hand column indicate levels of priority (1 or 2).

1. Changing the culture

1.1 Belonging and academic identity	
Create a regular forum on disability, neurodivergence and chronic illness for all NU employees, to foster an ongoing dialogue with these colleagues, and ensure that they feel listened to. • These forums should occur at least once a year. • Stakeholders such as DIG and other staff networks should be closely involved in organising these events. • Ensure rotating participation of various senior management figures, as well as representation from services involves in support processes (People services, OH, NUIT, Estates…). • Identify a person with ongoing responsibility to organise these events, e.g. the University Disability Adviser. They will be in charge of sustaining the dialogue beyond the forums and to ensure that what is learned from them is embedded into institutional practice. • Make these events fully accessible, thus creating a blueprint for all other institutional events. Accessibility should be the norm, not the exception.	1
Engage in reflection on what type of academics are considered desirable and 'a good fit', under the lead of an academic who identifies as disabled, neurodivergent and/or chronically ill. This reflection should, among others: • Acknowledge the wider academic culture of overwork; • Adopt an intersectional approach, i.e. take into account other protected characteristics such as age, race and gender; • Feed into training for people involved in recruiting academics and PGRs, and conducting career progression/career development reviews.	1
Acknowledge mutual responsibility in recognising and talking about diverse embodiment of academic identity. • Launch a communications campaign to reflect NU's commitment to celebrating disability equality. • For this campaign, recruit (visibly or non-visibly) disabled, neurodivergent and/or chronically ill academics working at NU. Posters could include a photographic portrait paired with a quick summary of their profile and expertise and the slogan 'This is what an academic looks like'.	2
1.2 Language	
Move beyond the use of *disability* and *disabled* as umbrella terms in NU's communications. Instead, use more inclusive and descriptive language that most relevant people might identify	1

with, e.g. *health and disability*, *health, neurodivergence and disability*, *neurodivergent, disabled and/or chronically ill staff*.	
Where needed, also address neurodivergent or chronically ill staff separately, to ensure that they are aware of all policies relevant to them.	1
Make sure to distinguish between *impairment* and *disability*, using a social rather than medical approach to disability. Reflect this in institutional discourse.	2
When communicating around health and disability and writing policies, include the categories *energy-limiting conditions* or *energy-limiting chronic illnesses*.	2
Assess institutional communications for language used and review regularly in consultation with stakeholders.	2

1.3 Organisation-wide EDI strategy

Conduct a multi-level assessment of EDI strategies and how they deal with health, disability and neurodivergence.	1
Conduct an institution-wide audit to compare support routes for disabled students and disabled staff. • Identify all areas where support for staff lags behind support for students. • Use this information as the basis for an action plan to improve support for disabled staff. • Include both trade unions and NUSU in the audit and following action plan. *This recommendation is directly inspired by the 'Enabling Equality' report (ECU 2011).*	1
Create a task group to examine the need for neurodivergence-specific policies, decoupled from disability policies.	2
When designing policies about health and disability, tap into the collective knowledge of stakeholders who share a common interest in change, e.g. the Carers network and DIG.	2

1.4 Universal design

Create a dedicated employee- and occupational-focussed unit committed to the principles of Universal Design, in order to consistently plan for diversity. • The Universal Design approach for Learning and Teaching has been championed at the university for some time. There is expertise there to be shared in order to generalise this approach. • This unit's remit should include, among others, physical environments and policymaking. *This recommendation is inspired by Kumari Campbell (2020).*	1

1.5 Workloading

Create a task group, as a matter of urgency, to address the workloading of EDI network participation.	1
Create an institution-wide action plan for support options regarding the workloads of disabled, chronically ill and neurodivergent staff. This action plan should: • Identify good practice regarding workload adjustments; • Ensure that these adjustments are not dependant on informal arrangements, but rather planned and offered as a matter of policy; • Ensure that support is offered consistently institution-wide.	1
Recognise the burden created by the disability workload, and reflect it for instance when considering promotion criteria.	2
Wherever possible, aim to reduce the disability workload.	2

• Do not ask disabled staff and PGRs to undertake additional, unpaid work to help the university improve its practices. • See recommendations on disclosure and adjusments.	

1.6 Accessibility

Draw up standard guidelines for making accessibility of research events for disabled, neurodivergent and chronically ill researchers the norm, not the exception, with the expectation these are used across NU events, online or in person.	1
Ensure that all blanket decisions about physical environments are made in consultation with stakeholders such as DIG and the University Disability Advisor.	2
Communicate more widely and clearly about the taxi scheme for disabled individuals to navigate the campus.	2
Create, in partnership with disabled stakeholders, an online 360° tour of campus with detailed information on accessibility. This alternative map should include information such as optimum routes, entrances and exits, accessible toilets and ramp access. It could be made available as an app.	2

1.7 Training

Make mandatory specific training to all line managers on support routes for disability, neurodivergence and chronic illness.	1
Evaluate leadership training through the lens of ableism and consider including the expertise and lived experience of disabled staff in such training materials.	2
Organise regular reviews of existing training to ensure it is up to date in terms of language and practices, in an ever-evolving landscape.	2
Offer awareness training regarding communication styles, explaining the key role neurodivergence may play in situations such as collaboration or promotion opportunities.	2
Include energy-limiting conditions in EDI training as well as training materials for line managers and PhD supervisors. Involving people with lived experience of such conditions will help challenge stereotypes surrounding chronic fatigue and chronic illness.	2

1.8 Careers

Launch a disability-informed audit of promotion and redeployment opportunities.	1
Reflect the need for flexibility (which may concern any member of staff, regardless of personal impairments) at every career level.	1

2. Improving access to support

2.1 Communications and signposting

The SharePoint page of People Services should clearly signpost disability, neurodivergence and chronic illness-related policies. This information should also be signposted from the University EDI webpages.	1
Monitor the current improvements to the accessibility of available advice/support/guidance about routes for support, with input from colleagues with lived experience.	1
Monitor how effectively and frequently disability, chronic illness and neurodivergence-related policies available online are accessed in practice. This could include looking at the number of hits and downloads for electronically stored policies and how frequently, and recording enquiries related to policy documents.	2
Ask the future University Disability Advisor to work with library support services and NUIT on a digital, regularly maintained library of disability, neurodivergence and chronic illness equality publications, for use by both staff and students. This library could include links to	2

external routes of support and advocacy, from Citizen's Advice to disability-specific organisations.	

2.2 Disability advisor and multi-level disability contacts

Recruit a new University level Staff Disability Advisor as a matter of urgency. • Consider placing this role within the Central EDI team, to make it more visible and facilitate exchange of expertise. • Communicate widely around this role and what the advisor can do to support staff and PGRs.	1
Introduce a PS disability contact for each Faculty and each School/Unit. This disability contact: • Should be required to attend disability equality training, sit on relevant EDI committees, understand university policies and liaise between various services involved in disability policies. • Would serve as a point of contact for all staff and PGRs. • Should be different from EDI leads. The idea is to diversify possible points of contact at school and faculty levels, to make it easier to negotiate possible interpersonal challenges. The disability contact would provide support and expertise to school and faculty EDI leads. • Would help reduce responsibilities of line managers and instead coordinate more central assistance for disabled staff. • Would liaise with SHWS disability practitioners to better support PGRs.	1

2.3 Disclosure and adjustments

Reframe institutional understandings of disclosure and adjustments, involving disabled, neurodivergent and chronically ill stakeholders.	1
Offer disabled, neurodivergent and chronically ill staff the opportunity to devise a personal disclosure plan. This plan should: • Be co-created with their line manager, at least one disability adviser/contact (see above), and Occupational Health. • Aim to facilitate day-to-day interactions with co-workers. • Be part of a 'Staff Support Plan', analogous to the Student version.	1
When devising adjustments, provide the member of staff with a wide, varied, up-to-date and easily accessible list of possibilities. Don't place the responsibility solely on disabled, neurodivergent and chronically ill staff to imagine what adjustments could look like.	1
When needs arise that haven't been planned for, they should never be assumed based on visible characteristics, but rather assessed and discussed in a collaborative process with the individual. Don't try to fit the person into pre-planned adjustments.	1
Commission a disability-informed assessment of Occupational Health service provision, looking for instance at: • The range and types of adjustments offered; • The weight of the medical (rather than social) understanding of disability, and how this affects support; • How OH staff follow up on the implementation of adjustments in the long term; • Whether OH staff are fully aware of the specificities and demands of academic careers.	2
When hiring someone who had physical adjustments put in place by their previous employer, consider purchasing the relevant material instead of automatically making the new hire go	2

through the disclosure and adjustment processes again. This could lessen the disability workload.	
When moving across campus, special attention should be given to specific furniture purchased as part of the adjustment process.	2
Recognise energy impairments alongside any other type of impairments for which employers have a legal duty to make reasonable adjustments.	2

3. PGRs

Conduct a listening exercise specifically aimed at disabled, chronically ill and neurodivergent PGRs, coupled with an audit of student disability services, to ask 'how are the needs of disabled, chronically ill and neurodivergent PGRs being met at NU?'.	1
Taking heed of UCU's 'PGR-as-staff' campaign would go a long way towards facilitating the inclusion and participation of disabled, neurodivergent and chronically ill PGRs.	1
The PGR population does not have access to the same opportunities for EDI training as staff. Allow access to such training in order to help improve the work culture.	2
Allow PGRs access to support information stored on SharePoint as a standard practice. Create a separate page for this group.	1
Removing the outsourcing of support for PGRs would ensure better communication and overall levels of support.	2
As long as PGRs are considered as students, clarify and generalise the practice of allowing PGRs access to Student Support Plans.	2

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