
Qualitative research on barriers to progression of disabled scientists

**Report for the Royal Society
by the Careers Research
& Advisory Centre (CRAC)**

October 2020

**Published by the Careers Research & Advisory Centre (CRAC),
with support from the Clear Company and Nicole Brown.**

© Careers Research & Advisory Centre (CRAC) Ltd 2020

**Careers Research & Advisory Centre (CRAC) Ltd
22 Signet Court
Cambridge
CB5 8LA**

www.vitae.ac.uk

Contact:

**Rachel Handforth, Research and Evaluation Project Manager
rachel.handforth@crac.org.uk**

**Robin Mellors-Bourne, Director of Research & Intelligence
robin.mellors-bourne@crac.org.uk**

About us

The Careers Research and Advisory Centre (CRAC), provides research, intelligence and innovation services for all those who support the career development of people of all ages and in all sectors. CRAC works in partnership with government agencies, education organisations and providers and employers and professional bodies. CRAC is a registered charity No 313164 established in 1964.

CRAC's research and consultancy work focuses on career-related learning, employability development and career transitions, including STEM and researcher careers.

Vitae is a non-profit programme, part of CRAC, with over 50 years' experience of enhancing the skills of researchers. Vitae strengthens members' institutional provision for the professional development of researchers through research and innovation, training and resources, events, consultancy and membership.

Contents

1. Executive summary.....	1
2. Aims, scope and methodology	5
2.1. Context.....	5
2.2. Project aims, research questions and scope.....	6
2.3. Methodology and sample.....	7
3. Evidence Review	11
3.1. Disability and UK employment.....	11
3.2. Disability within HE	12
3.3. Disability disclosure	14
3.4. Disability and academic careers in STEM.....	16
3.5. Supporting disabled scientists	17
4. New analysis of statistical data on disability disclosure in HE	20
4.1. Overview	20
4.2. High-level results and trends	20
4.3. Intersections with age and gender	23
4.4. Further insights into disability and STEM progression	25
4.5. Types of employment contract.....	26
4.6. Disciplinary differences within STEM	29
4.7. Summary	31
5. Experiences of disabled scientists	33
5.1. STEM academic/research culture.....	33
5.2. Institutional support and accessing adjustments	37
5.3. Access to funding	43
5.4. Impact on career progression and trajectories	48
5.5. Summary	53
6. Disclosing disabilities	55
6.1. Experiences of disclosure.....	55
6.2. Factors affecting disclosure	59
6.3. Barriers to disclosure.....	62
6.4. Factors which facilitated disclosure	66
6.5. Summary	68
7. Overall findings, issues and recommendations	69
7.1. Summary of findings.....	69
7.2. Emerging issues.....	71
7.3. Recommendations for the sector, institutions and funders.....	74

1. Executive summary

As part of wider work to address barriers to participation and success in STEM, the Royal Society commissioned the Careers Research & Advisory Centre (CRAC) to undertake a qualitative research project to explore the barriers to progression faced by disabled scientists.

Specifically, the aims of the project were to: identify barriers which affect whether scientists disclose a disability and how these relate to progression, including any variations by career stages and other characteristics/circumstances; understand differences in the attitudes of disabled scientists to disclosing their disability in different contexts and broad disciplines; and identify and propose potential interventions that the Royal Society could make to address barriers to disclosure of disability in a range of different personal and career contexts.

The methodological approach undertaken in this research was first to collate relevant existing knowledge within the HE sector and beyond, presented in the evidence review in chapter 3, together with a small number (7) of scoping interviews with experts who had specialist knowledge and experience. Undertaking the evidence review and these 'expert interviews' informed our approach to the qualitative research with disabled scientists, deepening our understanding of potential issues pertaining to disability disclosure within the current UK HE research environment and helping to refine our areas of inquiry. As a parallel strand of evidence-gathering, we gained access to HESA staff record data which enabled selective analysis to be conducted to verify previously observed trends, assess current statistics, and attempt more detailed and specific analyses. This is reported in chapter 4.

For the main strand of primary research, 25 disabled scientists were interviewed in February and March 2020. Interview participants were those who either currently or had recently worked at a UK higher education (or related) institution. Individuals completed a short, pre-interview online screening questionnaire, which asked for details such as individuals' career stage, current role, subject area and contract type. A purposive approach to sampling was undertaken in order to obtain a reasonably representative sample of interview participants from the details given in the pre-screening questionnaire. A range of personal characteristics were reflected in the sample (see Table 2.1), including different career stages, contract types, modes of employment, disciplinary areas, and who self-identified with a range of disabilities, conditions and specific learning differences (SpLDs).

In aiming to understand wider patterns of disability disclosure in HE, our analysis of HESA data produced a range of new insights. It indicates that disclosure is generally lower in STEM disciplines than outside STEM, and is particularly low in certain subjects, such as engineering, medicine and some physical sciences. Further, rates of disclosure vary considerably with career stage. Disclosure is lower amongst academic staff than doctoral students and much lower than first-degree students, and lower amongst senior academic staff than at early-career stages. In the key early-career stage for staff, disclosure is particularly low amongst those on research-only contracts. Rates of disability disclosure are also generally increasing with time, other than at the most senior levels where little is changing. The increase with time is dominantly due to more common reporting of mental health conditions, especially, and to some extent cognitive/learning differences, whereas there is little or no increase in other types of conditions. In addition, rates of disclosure are higher amongst women than men, higher with

greater age, and higher amongst those working part-time than full-time, in line with the general population, but also somewhat higher in Russell Group institutions than others.

Findings from our qualitative research with disabled scientists generated a range of insights into particular challenges posed within the STEM academic research culture and their impact on individuals' career trajectories. Disabled scientists reported finding the competitive environment of academic STEM difficult in terms of the underlying assumptions about academics' working practices, based on expectations of consistent high levels of research productivity, successful accrual of external research funding, the expectation of full-time working patterns and regular presence at conferences and networking events. Whilst some participants had successfully managed to secure the adjustments that they needed in their workplaces, for the majority negotiating access to institutional support was not straightforward and often there was little faith in the benefit of formal reporting processes.

It was felt that institutions and funders could be more proactive in developing measures which would better support disabled scientists. These included the need for better awareness and understanding of reasonable adjustments amongst line managers and heads of department, as well as the desire for a more proactive approach to providing support and examples of adjustments that could be made, and more support for staff disability networks and for those who were applying for external funding. In terms of funders, a range of adjustments, such as flexibility in the way grants could be undertaken, improvements to the accessibility of the platforms used to submit applications, as well as the possibility of allowing additional funds to be made available for applicants who required reasonable adjustments, were suggested in order to make the process of grant applications more inclusive for disabled scientists. Funders currently do not present an overtly inclusive face, putting the onus on disabled applicants to enquire what support might be possible.

Individuals' experiences of disclosure were variable, with some having positive experiences of securing the adjustments they needed in order to succeed in the workplace. For the majority, though, experiences of disclosure were more challenging. Participants reported a lack of clarity in the process of requesting and securing reasonable adjustments, and a lack of awareness and understanding when they sought support, particularly from formal sources such as HR. Generally, disclosure was only undertaken when considered unavoidable, and was more likely to take place with a line manager rather than through more formal institutional reporting processes. Most did not disclose until after they had secured their job and the majority of participants, particularly mid-career and senior scientists, would not recommend other disabled scientists to disclose their disability. A significant factor which affected disclosure was the visibility of senior disabled scientists, who could act as role models for early career scientists and yet very few senior scientists currently disclose conditions such as mental ill-health.

Perceived barriers to disclosing a disability included persistent stigma and the fear of discrimination, particularly for those with mental health conditions. This was compounded for early career researchers (ECRs) attempting to secure a permanent academic role in a competitive environment. Interestingly, participants felt that disclosure would become easier once a more senior career stage had been reached, yet this does not correspond with patterns evident in HESA data, which show decreased rates of disclosure at senior career stages. Other barriers to disclosure included the lack of clarity as to who would have access to this information and how it would be used, along with the additional time and labour involved in

disclosure. However, a number of factors facilitated disclosure. These included institutions and funders providing clear and comprehensive definitions of disability as well as outlining the types of adjustments which could be made available. In addition, trust in those being disclosed to - which could be facilitated by increased awareness and training of those making selection decisions - was important, along with previous positive experiences of disclosure, which gave individuals confidence that their needs would be sufficiently met.

Recommendations for the sector:

1. To encourage disclosure, the sector should agree and embed a consistent definition of what is considered to be a disability, including mental health conditions, and publicise more widely how the process of disclosure works (including being clear on how parties will share and use the information if a disability is disclosed);
2. The sector should encourage and/or develop initiatives which celebrate the work of disabled scientists, recognising the positive impact of role models, especially senior academics but also early career scientists who are pursuing a research pathway;
3. The sector should undertake work to challenge the culture that currently anticipates early-career research solely to be a full-time endeavour that will require uniformly high productivity and demand that researchers work more than 100% of full-time employment hours, such as aiming to introduce flexible working opportunities wherever possible;
4. The sector should undertake research to understand more about the use of research-only and teaching-only contracts, particularly to assess whether more disabled scientists are selecting teaching-focused pathways (and why) or whether circumstances are resulting in more of them being employed in such roles;
5. The sector should undertake further research work to investigate the reasons for the very low levels of disclosure at senior career stages, if necessary exploring barriers to doing so for senior scientists and what steps could be taken to enhance this.

Recommendations for HEIs:

6. HEIs should increase disability awareness training and inclusive recruitment/selection training for their staff involved in recruitment, progression decisions and line management. There is much to be learnt from sectors other than HE, which have made more progress towards inclusive progression;
7. HEIs should aim to collect systematic detailed diversity data on the number of disabled applicants/employees they have, as well as information on the number and quality of adjustments that have been sought and offered;
8. HEIs should provide clear guidelines on what types of reasonable adjustments are available and state clearly on job applications, as well as on relevant webpages for staff and applicants, some examples of the types of adjustments that can be requested (and

state that a wide range of possible adjustments can be offered in order to meet individuals' specific needs) to provide a flexible, inclusive approach;

9. HEIs should ensure they provide clear guidance for disabled staff and applicants on how to access support, information, advice, services, and funding, as well as providing specific information, training and assistance to line managers. Employers should do this collaboratively, working with trade unions and staff who are trained and supported to act as disability or equality contacts or co-ordinators within departments;
10. HEIs should support and increase the visibility of disabled staff networks to facilitate peer support and the ability of individuals to hold institutions to account in relation to access to reasonable adjustments. This could involve working with NASDN to do so;
11. HEIs should undertake research to ensure that advice and support provided by Research Offices is fully inclusive, whether they are supporting disabled external grant applicants, and how they are currently contributing to breaking down barriers or reinforcing perceptions of a lack of inclusivity from funders;

Recommendations for funders:

12. Funders should collect systematic detailed diversity data on the number of disabled applicants and awardees they have, as well as information on the number and quality of adjustments offered and taken up by applicants and awardees;
13. To support disabled applicants, funders should demonstrate a more proactive approach to inclusivity in the process of advertising grant/funding opportunities, handling applications and managing awards. This should involve providing clear guidelines on what types of reasonable adjustments are available to applicants within the application process itself, as well as for successful awardees within their funding;
14. Within the applications process, funders should clearly state a definition of what is considered to be a disability (including mental health conditions) in order to encourage disclosure at application stage, and offer adjustments such as providing additional time to apply and/or rolling deadlines, allowing for applications in different formats and providing room for contextualisation of CVs and research outputs;
15. Funders should promote the availability of specific adjustments in the support available to disabled awardees such as: allowing grants to be taken up on a part-time/flexible basis, potential for discrete additional funding for costs incurred specifically by disabled scientists, and clarifying with HEIs where financial responsibilities lie for providing different types of adjustments.

2. Aims, scope and methodology

2.1. Context

UK law defines a disability as an 'impairment' that lasts more than 12 months and affects day-to-day activities. Disabilities can be visible or hidden, intermittent or consistent, congenital or acquired, and the experiences of them can vary greatly between individuals. There is increasing support for the view that disability does not reside in or with an individual but arises from the interaction of that individual with an environment that is not suited to their needs. This has led to widespread adoption of a social model of disability which asserts that the barriers experienced by disabled people are the result of how the physical and social environment is structured, not by any inherent lack of ability on the part of the disabled individual. This is different from a medical model which suggests that difficulties experienced are caused directly by the limitations of those with disabilities. Adopting the social model of disability, in the context of this project, means we are considering the progression of disabled scientists rather than of scientists within disabilities.

Through UK law, disabled employees are entitled to work adjustments, but not all employees may want to disclose a disability (which is usually necessary to request or receive an adjustment). Disability can affect somebody who is well established in their job or career differently from someone just starting, who perhaps may not want to declare something that they think might hinder their progression or lead to perceptions that they do not add as much value to the employer as others. The social model places the issue of whether an individual discloses their disability, and the employer's response to it through adjustments, centre stage.

Significant progress has been made by the UK higher education (HE) sector in relation to increasing disclosure rates by disabled students and Disabled Students Allowance take-up. Figures from the Higher Education Statistics Authority (HESA) showed that almost 300,000 students in HE in England (14.3%) reported that they had some type of disability in 2018/19, which was 48% higher than in 2013/14 (when it was 10.4%).¹ The position for STEM subjects was only fractionally different from overall, with 14.1% of students reporting a disability in 2018/19 (up from 10.1% in 2013/14).

The most commonly reported disabilities were a specific learning difficulty followed by a mental health condition. By far the largest increase in these five years has been in the numbers of students reporting a mental health condition, that proportion tripling from 1.3% to 3.9%, while social or communication disorders have also increased markedly. The proportions reporting a learning difficulty have not risen in the last five years, while the level of sensory, medical or physical conditions reported has gently risen.

In parallel, progress has also been made in relation to the proportion of disabled students obtaining a good degree (i.e. the gap between their attainment and overall has been narrowing) and there is now no greater likelihood of non-completion by disabled students than overall. Overall, major strides have been made by providers in offering a more inclusive learning environment and a range of support for disabled students.² The proportion of students registered to receive Disabled Students Allowance almost tripled in the 12 years to 2015/16.

¹ Equality and diversity data, Office for Students 2020: <https://www.officeforstudents.org.uk/data-and-analysis/equality-and-diversity/equality-and-diversity-data>

² *Models of support for students with disabilities*, Institute for Employment Studies, 2017

There is evidence that rates of disability disclosure are much lower amongst HE staff, including those working in science and research, than amongst students. It is also broadly acknowledged that there is more university support for disabled students than there is for staff,³ in response to which the National Association of Disabled Staff Networks (NADSN) facilitates networks of disabled HE staff and publishes a variety of resources and insights. Prior research has investigated staff disclosure in HE institutions, looking at the support received by disabled staff and the barriers and factors influencing whether or not they disclose their disability.⁴ Much of this relates to the perceived balance between potential benefits from disclosure (principally that it enables adjustments to be requested and supported) and anticipated negative consequences (fear that it will damage advancement and career prospects, but also social stigma). It is also widely acknowledged that two people with the same impairment can experience it completely differently and that some staff have difficulty in identifying with the term 'disabled'.

Underlying this study is the key question of whether the current scientific environment (the UK HE research system and culture) restricts the opportunity of those who might or do disclose a disability to progress within it and realise their potential. Gaining insight into disabled scientists' career experiences and understanding disclosure of disability – how rates vary and, crucially, why – are vital in being able to develop a more inclusive research environment.

2.2. Project aims, research questions and scope

Diversity is an essential part of the Royal Society's mission to recognise, promote and support excellence in science, and the Royal Society is committed to increasing diversity in science by encouraging the participation of excellent scientists from under-represented groups.

The Royal Society and others have established that disability disclosure rates amongst HE staff are generally lower for those working in STEM subjects than others. While it is known that disclosure rates tend to increase with age, within HE staff and people in general, it has also been recognised that they may vary inversely with seniority/progress in a scientific career (Royal Society, 2019). On the basis of the statistical evidence available to date, there appear to be discernible decreases in the rates of those disclosing disabilities between some key stages in the academic progression pipeline for scientists: i.e. lower rates amongst doctoral students compared with undergraduates, and lower rates amongst staff than doctoral students, lower rates at more senior staff levels than early career positions. Rates of disclosure also vary quite strongly by discipline (for example, being higher in medicine and biological sciences than, for example, physical sciences or engineering. How experiences of disability (and/or rates of disclosure) intersect with other protected/personal characteristics, including gender, is another important factor, as is the issue of identity – not least for those who become disabled during their career.

In 2019, as part of work to address barriers to participation and success in STEM, the Royal Society commissioned the Careers Research & Advisory Centre (CRAC), supported by the Clear Company and our expert advisor Nicole Brown, to undertake a qualitative research project to explore these issues in relation to individuals' experiences. More specifically, the aims of the project were to:

³ <https://www.sciencemag.org/careers/2017/05/survey-highlights-challenges-disabled-academics-face-and-what-can-be-done-address-them>

⁴ *Disclosure and support issues for disabled staff in Higher Education*, Equality Challenge Unit, 2008

- Identify barriers which affect whether scientists disclose a disability and how these relate to progression, i.e. different career stages, and other characteristics/circumstances;
- Seek to understand why there are differences in the attitudes of disabled scientists to disclosing their disability in different contexts and broad disciplines;
- Identify and propose potential interventions that the Royal Society could make to address barriers to disclosure of disability in a range of different personal and career contexts.

In order to address these project aims we developed a series of research questions, which enabled us to focus on key areas of inquiry. These research questions were:

Barriers to disclosure

1. What drives disabled scientists to disclose a condition (or not), in different contexts – i.e. formally to their employer, or via an institutional survey, vs. informally to colleagues or confidentially to independent bodies?
2. What are the potential barriers to disclosing disability and how and why do they vary for the different groups, career stages and contexts above?
3. How do these issues vary for different types of disability and when it is experienced?

Understanding disability disclosure

4. What are the key trends in rates of disclosure for different groups of scientists across career stages, science disciplines and employment contexts?
5. Why do those differences exist? What are the factors which contribute to this?

Possible solutions

6. What works in terms of supporting disability disclosure and what are the key adjustments that enable scientists with disabilities to progress?
7. How are institutions communicating with their disabled employees about their inclusion commitments? Is their monitoring of data aligned with best practice?
8. What is the role of other actors in the research environment such as funders? What interventions could the Royal Society undertake or influence that could address barriers to disclosure of disability in these different personal and career contexts?

2.3. Methodology and sample

Our approach to this research was first to collate relevant existing knowledge within the HE sector and beyond, as presented in the evidence review in chapter 3, together with undertaking a small number (7) of scoping interviews with experts who had specialist knowledge and experience. These interviews were conducted by telephone with key members of the Royal Society Diversity Committee's sub-group on disability, as well as selected other individuals working to support disabled scientists at institutional or funder level. A further interview was undertaken with an individual working on disability disclosure within the NHS as a useful potential comparator outside the HE sector.

Undertaking the evidence review and these 'expert interviews' informed our approach to the qualitative research with disabled scientists, confirming the scope and allowing us to deepen our understanding of potential issues pertaining to disability disclosure within the current UK HE research environment and refine our areas of inquiry ahead of the main interviews.

As a parallel strand of evidence-gathering, we gained access to HESA staff record data which enabled selective analysis to be conducted to verify trends previously observed, assess current statistics and attempt some more detailed and specific analyses. This is reported in chapter 4.

For the main strand of primary research, a call for interview participants was circulated in February 2020, using a variety of relevant groups and professional bodies to aid recruitment of potential interviewees. Our main recruiting mechanism was through NADSN, which has more than 50 UK universities as members. In addition, the call for participants was circulated on mailing lists and via social media by organisations including the Royal Society of Chemistry, the Royal Academy of Engineering, the Royal Society of Biology, Wellcome Trust and the Royal Society.

Interested individuals were invited via the call for participants to complete a short, pre-interview online screening questionnaire, which asked for details such as individuals' career stage, current role, subject area and contract type. It also asked respondents to describe their disability briefly and indicate whether or not they had disclosed their disability to their employer, enabling us to select participants with a range of different experiences and generate a stratified sample of interviewees. The questionnaire also allowed respondents to express their preference for either a face-to-face or telephone/Skype interview, with an option to submit a written response also provided, acknowledging that telephone or Skype may not be the ideal mode of communication for some. After a first round of recruitment and discussion with the Royal Society, we instigated a more targeted call for participants which focused on attracting male, neurodiverse scientists to represent these groups more thoroughly in the interview sample, which resulted in a slight increase in participants from these groups, though despite our efforts women are over-represented within the sample (see Table 2.1). However, this is in line with data which highlights how women are more likely to disclose disabilities (AdvanceHE, 2019).

Responses to the pre-interview questionnaire generated a number of interesting insights, alongside its main purpose as a recruitment and stratification tool. It was evident that many who had clicked on the link to participate in the questionnaire were reticent to give personal details such as their current institution. This can be inferred from the observation that 136 individuals gave a response to the first question (which informed respondents that the questionnaire would ask for some personal information about them and that they should first indicate their consent for this information to be collected). However, only 62 individuals chose to give any further details through the subsequent questions.

In terms of the scope of the project, interview participants were those who either currently or had recently worked at a UK higher education (or related) institution. In agreement with the Royal Society, we developed a variety of employment and personal characteristics that we hoped to reflect in the sample of interviews, including different career stages, disciplinary areas, and who self-identified with a range of disabilities, conditions and learning difficulties.

We hoped to speak to those employed on different types of contracts, and with different modes of employment. We also aimed to interview participants who had disclosed a disability to their employer as well as some who had not done so. At inception, it was agreed that gaining insight into the experiences of those who had left academic science would also be of interest, which was taken into account when sampling participants. A purposive approach to sampling was undertaken in order to obtain a reasonably representative sample of interview participants from those who gave details in the pre-screening questionnaire.

From the sample of 62 individuals who responded fully to the questionnaire, 25 were considered outside scope as they were either PhD students or worked outside the UK. Based on the intended sample design, we elected to approach 28 individuals for interview from the eligible 37 individuals. However, 3 individuals did not respond to follow-up requests to schedule an interview, so 25 interviews were achieved in this phase. It is worth noting that the 3 individuals who did not respond to personal interview invitations had all disclosed in the questionnaire that they had mental health conditions.

Gender	Male (8) Female (17)
Type of disability	Physical disability or health condition (15) Neurodiversity (4) MH condition (1) SpLD (2) Multiple types of disability: Physical disability/MH condition (1) Neurodiversity/MH condition (2)
Career stage (defined as below) Early Career Academic (up to 8 years post PhD, e.g. postdoc) Mid-Career Academic (8+ years post-PhD, e.g. Lecturer/ Senior Lecturer/ Research Fellow) Senior/Late Career Academic (e.g. Reader/ Professor/ HoD)	Early career (8) Mid-career (8) Senior/ late career (4) Other: Prof services (1) PT prof services/ PT academic (1) non-academic (2) non-science academic (1)
Contract type and mode of employment	Open-ended (16) Fixed-term (9) Full-time (18) Part-time (7)
Identify as disabled?	Yes (17) No (3) Other – unsure, dependent on circumstances etc (5)
Tick disabled box on grant applications?	Yes (12) No (5) Other – unsure, dependent on circumstances etc (8)
Disclosed disability?	Yes, to employer and colleagues (18) Yes, to selected colleagues only (5) Yes, to employer only (1) No (1)

Table 2.1 Overview of characteristics of interview participants (n=25)

Practically, by mid-March, it was clear that the UK was about to experience the Covid-19 pandemic (something likely to have a greater impact on disabled academics, as a subsequent NADSN paper⁵ highlighted) and the wisdom of pursuing further fieldwork seemed questionable. Whilst we had originally planned to undertake c.35 interviews with disabled staff (across a range of circumstances, characteristics and conditions), it was decided at that point with the Royal Society that further recruitment should not be undertaken. As the 25 individuals who had responded to an invitation to interview represented a good range of the different experiences sought, it was decided to cease recruitment effort and work solely on the basis of this sample. It would have been possible to interview more individuals from the existing volunteer pool, but this would not have expanded the range of types of individual in the sample.

Interviews took place via telephone and Skype in February and March 2020, with a small number of individuals (n=3) submitting written responses. In agreement with the Royal Society, interview questions focused on perceptions of attitudes of employer, managers and colleagues towards disability; experiences of seeking adjustments to workplace, employment and working patterns; perceptions in relation to career progression of disabled people in science/research and barriers to it; attitudes to sharing information about disability, including barriers to formal and informal disclosure; experiences of positive support and overcoming barriers to disclosure, and ideas of additional support that the Royal Society or other funders could provide.

Thematic analysis was undertaken of interview data using Nvivo software, after transcription of all 25 interviews. An iterative approach to analysis was used, which involved a combination of inductive and deductive coding. This approach used the initial research questions to systematically develop themes and categories, such as barriers to disclosure, and institutional support, which provided a number of themes into which interview data were categorised and coded. However, incorporating an inductive approach was also necessary to allow additional themes to emerge from the data, resulting in other codes such as additional time and labour, and imagined career impact. These additional codes provided further insights into the issues pertaining to disabled scientists' career experiences as well as their experiences of disclosing their disability.

Using this approach to analysis enabled a number of key themes to be identified. The development of 12 specific codes also allowed themes to be compared in terms of which came out most strongly from the data. These themes are presented in sections 5 and 6 and discussed in detail under each sub-heading.

⁵ https://nadsnuk.files.wordpress.com/2020/05/nadsn-covid-post-lockdown-position-paper_version-6-for_release-3.pdf

3. Evidence Review

In order to inform our approach to the research, we conducted a rapid evidence review of published literature and professional knowledge about disability and its disclosure, within the HE sector as well as other employment sectors. This was a purposive exercise, guided by our expert advisers, designed to gain insight into issues around disclosure rates (including differential levels of disclosure) and adjustments, in order to steer and contextualise our investigations into how these issues are experienced by disabled scientists.

We have presented our findings of this brief review firstly in relation to disability within UK employment more broadly, before a discussion of the main issues relating to disability within the UK higher education (HE) sector. We then explore the issue of disability disclosure in relation to both the HE and other employment sectors, before reflecting on research which looks at disability specifically within STEM careers and finally, considering literature which presents recommendations and best practice as to how to support disabled scientists.

3.1. Disability and UK employment

According to the disability equality charity, Scope⁶, there are around 13.9 million disabled people in the UK and nearly a fifth of working age adults are disabled. However, there is a distinct disability employment gap; disabled people are more than twice as likely to be unemployed as non-disabled people. Barriers to employment often relate to perceptions of a lack of understanding and a fear of potential discrimination by employers. Schemes which aim to support disabled individuals in the workplace include the UK government's Access to Work scheme, which may include a grant to help cover the costs of practical support in the workplace, though this requires the direct involvement of employers to authorise payments. The Disability Confident scheme, another UK government initiative, aims to get employers to commit to undertake inclusive recruitment as well as develop more supportive practices for existing employees, by subscribing to the scheme. According to recent data, around 100 universities are currently signed up to the Disability Confident scheme⁷.

Recent research commissioned by Evenbreak⁸, a social enterprise run by and for disabled people, found that a significant barrier to employment for disabled people was the difficulties they faced in knowing which employers may be positive about recruiting disabled candidates. In their survey of over 700 disabled candidates, over 82% of disabled individuals stated that their main barrier to employment is finding truly disability-friendly employers. Further, confidence in employers' understanding of disability was low; 71% of disabled candidates rated employers poorly when it came to their empathy and understanding of disability. This translated into a lack of faith in recruitment and selection procedures, with the interview process being viewed as the biggest barrier. There was a lack of confidence in their own abilities, which linked to concerns about how potential employers might perceive them and fears that they may be discriminated against.

For those with a range of neurodiverse conditions such as autism, dyslexia, dyspraxia and ADHD, research from CIPD⁹ suggests that a change in culture is needed for greater understanding and acceptance of neurodiversity within workplaces. Whilst neurodivergent

⁶ <https://www.scope.org.uk/media/disability-facts-figures/>

⁷ <https://www.gov.uk/government/publications/disability-confident-employers-that-have-signed-up>

⁸ <https://blog.evenbreak.co.uk/2020/03/03/the-real-barriers-to-employment-faced-by-disabled-people/>

⁹ https://www.cipd.co.uk/Images/neurodiversity-at-work_2018_tcm18-37852.pdf

individuals are estimated to represent more than 10% of the UK population, only 16% of autistic adults in the UK are in full-time employment, according to the National Autistic Society. For those in employment, some individuals with neurodiverse conditions report being subject to disciplinary action or performance review because of their condition, often because managers were unaware of their condition or the extent of its impact¹⁰.

Across a number of employment sectors, disabled employees face barriers to career progression including discrimination in the workplace. For example, a recent survey undertaken by Foster and Hirst (2020) with disabled people in the legal profession in England and Wales, found that disabled individuals within the sector often did not receive the workplace adjustments to which they were entitled to, due to fears of the consequences of making such a request. Among those who did request adjustments, over 80% reported that the process caused stress and anxiety. These experiences had an impact on individuals' progression, as many expressed reluctance to move role or organisations for promotion, as they were concerned they might lose agreed adjustments. Thus, the experience of discrimination, as well as the anticipation of future discrimination, acted as a barrier to disability disclosure but also to career progression. In both the civil service and the NHS, similar trends are observed to those in HE, with disability disclosure higher amongst more junior staff and falling for those in more senior positions. Recent figures indicate that of those civil servants working at the most junior level, 10.6% identified as disabled, in comparison to just 5.4% of those working at the most senior level¹¹. For clinical NHS staff, 3.1% of those working in the most junior grades disclosed a disability, compared to just 1.8% of those working in the most senior roles¹². Clearly, then, this pattern can be observed across a number of employment sectors.

3.2. Disability within HE

Within the HE sector, many of the same issues come to bear on disabled staff and students. Whilst HESA data showed that over 94,000 new students with a disability started university in England in 2017/18, representing 13% of new entrants, there is evidence that rates of disability disclosure are much lower amongst staff working in UK HE.

The way in which staff disability data is collected and recorded within institutions does not reflect the way in which student disability data is captured. The Office for Students' recent review of support for disabled students in the UK¹³ indicated that as well as the system for collecting disability data at the pre-entry and application stage, the vast majority of institutions encouraged disclosure of a disability or condition at each stage of the student life-cycle. Further, nearly two thirds of institutions had developed processes whereby disclosure of a disability via a digital platform would automatically notify disability support services. In comparison, HESA data for staff disability is recorded on the basis of the member of staff's own self-assessment, with this dataset being published based on the statistical returns that HEIs make to HESA each year. Further, whilst all disabled students, including PhD students, are entitled to related benefits such as Disabled Students' Allowance and support from their institution's disabled students' office, which may encourage individuals to disclose, staff do not have straightforward access to this type of support. For disabled staff, support would be

¹⁰ [https://archive.acas.org.uk/media/4655/Neurodiversity-at-work/pdf/Neurodiversity_at_work_0916\(2\).pdf](https://archive.acas.org.uk/media/4655/Neurodiversity-at-work/pdf/Neurodiversity_at_work_0916(2).pdf)

¹¹ <https://www.instituteforgovernment.org.uk/explainers/disability-civil-service>

¹² <https://www.england.nhs.uk/wp-content/uploads/2020/03/nhs-wdes-annual-report-2019.pdf>

¹³ <https://www.officeforstudents.org.uk/media/a8152716-870b-47f2-8045-fc30e8e599e5/review-of-support-for-disabled-students-in-higher-education-in-england.pdf>

accessed directly from the university as their employer, potentially making it more challenging to disclose a disability.

It is widely acknowledged that far more support exists for disabled students than for staff,¹⁴ in response to which NADSNI coordinates university networks of disabled HE staff and publishes a variety of resources and insights. Research undertaken by the Equality Challenge Unit (ECU, 2011) has highlighted that in UK universities, processes for collecting disability data are variable and inconsistent. In their report, the ECU observe that each institution often had a variety of methods for collecting this data, including HR monitoring forms, referrals to occupational health and self-service applications. Further, the timing of data collection often varied, sometimes taking place at application stage, at interview stage, during employment, or following time off. Through a survey of disabled staff in UK institutions, the report highlighted that negotiating these institutional procedures in order to disclose a disability could be both time-consuming and challenging for individuals (ECU, 2011). It is perhaps unsurprising, therefore, that disability disclosure rates remain low across UK institutions.

Whilst institutions are required to provide reasonable adjustments for disabled staff as well as students, research highlights disparities between institutional policies and disabled staff members' experiences in practice, as well as inconsistencies in the levels of understanding and awareness of issues faced by disabled staff across departments and teams¹⁵. Funding arrangements also vary by institution, with some having a centralised funding model from which reasonable adjustments are funded and others taking a departmental approach to funding adjustments. Whilst disabled staff may be entitled to the UK government's Access to Work scheme, this requires the involvement of HR and it is often not enough to cover all the costs of adjustments. Some institutions combine Access to Work funding with institutional funding in order to cover the costs of reasonable adjustments, such as the provision of equipment or a personal assistant. There is some evidence to suggest that due to the variation in how institutions and individual departments fund reasonable adjustments for staff, the process of navigating institutional processes such as the government's Access to Work scheme and occupational health referrals, are not straightforward (Sang, 2017). Indeed, applying to the Access to Work scheme has been described as less accessible than the equivalent process for applying for Disabled Students' Allowance (ECU, 2011).

Existing research on life as a disabled academic reveals experiences of ableism (defined as discrimination in favour of non-disabled people) within day-to-day work, such as expectations of sustained periods of academic productivity, and full-time working patterns (Sang, 2017; Leigh and Brown, 2018). Researchers have argued that ableism is normalised within HE and that disabled academics often internalise this discrimination, meaning that it can be more difficult to disclose disabilities and request reasonable adjustments (Brown and Leigh, 2018). A recent report commissioned by the Wellcome Trust exploring academics' perceptions of research culture¹⁶ found that respondents with disabilities reported experiencing ableism within the culture of academic research. Disabled academics perceived barriers to career progression in HE such as the prevalence of short-term, temporary contracts during the early career stage, difficulties in accessing funding through existing processes, and the perception

¹⁴ <https://www.sciencemag.org/careers/2017/05/survey-highlights-challenges-disabled-academics-face-and-what-can-be-done-address-them>

¹⁵ *Enabling equality: furthering disability equality for staff in HE*, Equality Challenge Unit, 2011

¹⁶ <https://wellcome.ac.uk/reports/what-researchers-think-about-research-culture>

that as disabled academics they were less productive than able-bodied colleagues. Further, disabled academics were more likely to both experience and witness bullying or harassment in the workplace than their non-disabled colleagues.

Establishing a career in HE may therefore be challenging due to the persistence of ableism and pragmatic challenges in negotiating institutional systems and processes. Moreover, in her research on disability and academic careers, Sang (2017) found that disabled academics encountered difficulties in fulfilling expectations of what was perceived as the ideal, non-disabled academic, who worked full-time and was prolific in terms of producing research outputs. Thus, expectations of research productivity in academic STEM, combined with assumptions of full-time working, may be a further barrier to sustaining a career in HE for disabled scientists, who often expend considerable amounts of time managing their conditions or negotiating institutional support processes to secure necessary adjustments.

3.3. Disability disclosure

Whilst UK law requires employers to make reasonable adjustments to ensure that individuals with disabilities, or physical or mental health conditions are not disadvantaged, there is no requirement of individuals to share this information with current or potential employers. Whilst there have been critiques of the term 'disclosure' to refer to sharing of information about disability with an employer, and other terms such as 'declaring' a disability have been used in the past (see ECU, 2011; Nash, 2014), disclosure is now generally the most commonly accepted term. It is considered to be more than simply information sharing, because it is linked to a public statement of needs. Most academic and grey literature now refer to this sharing of information about disability with an employer as disclosure (see Brown and Leigh, 2018; ECU, 2014; Sang, 2017).

There may be a number of barriers to individuals feeling able to disclose their disability, not least the fear of discrimination. The UK charity Scope examined disabled people's experiences of discussing disability at work¹⁷ across employment sectors. They found that nearly half of survey respondents (48%) worried about sharing information about their impairment or condition with an employer for fear of it having a negative impact on how they were perceived or treated. Research in the HE sector suggests that the decision of an individual to disclose a disability is akin to a cost/benefit analysis, where the potential benefits such as access to support and adjustments are weighed against the possibility of encountering stigma and discrimination (Brown and Leigh, 2018). Despite a recent increase in the numbers of students disclosing mental health conditions, and a rise in academics seeking mental health support through university counselling and occupational health services (Morrish, 2019¹⁸), evidence suggests that staff find it particularly challenging to disclose these conditions (ECU, 2014¹⁹).

There is also often a lack of clarity in who will have access to disability data, once an individual has disclosed, and what the employer will use this data for. In her research with employers and disabled employees across the public and private sector, Nash (2014) found that a considerable proportion of disabled employees did not know why their employer asked for information about disability or understand how their employer would use this information. It has

¹⁷ <https://www.scope.org.uk/campaigns/lets-talk/>

¹⁸ Morrish, L. (2019). *Pressure Vessels: The epidemic of poor mental health among higher education staff*. Higher Education Policy Institute.

¹⁹ *Understanding adjustments: supporting staff and students who are experiencing mental health difficulties*, Equality Challenge Unit, 2014

been suggested that disability awareness training for employers may contribute positively to disclosure rates. Particularly in relation to neurodiverse employees, the CIPD (2018) recommend that employers undertake neurodiversity awareness training in order to encourage proactive disclosure from employees, rather than reactive disclosure as a result of performance-based interventions. It would appear, therefore, that employers have considerable work to do to not only reassure disabled applicants and employees that they will not be discriminated against, but also to effectively communicate the purpose of collecting disability data to employees and encourage proactive disclosure.

There is evidence to suggest that the way in which individuals are asked about their disability has a considerable impact on disclosure rates. In the HE sector, it appears that some independent surveys obtain significantly higher disclosure rates than those recorded by institutions of their staff and reported by HESA, despite the HESA definition of disability being fairly wide²⁰. For example, in a recent survey by Vitae on research integrity, 16% of respondents reported that they were disabled which is higher than levels recorded by HESA for similar types of staff. In terms of STEM, there have been efforts made to gather best practice on collecting data on disability. A new collaboration called Equality, Diversity and Inclusion in Science and Health (EDIS), founded by The Francis Crick Institute, Wellcome Trust and GlaxoSmithKline, recently released guidance²¹ on gathering diversity data, which recommends asking multiple questions about disability and explaining the reasons for asking these questions within any questionnaire or monitoring form. The issue of framing questions on disability was evident in the Wellcome Trust's recent survey on research culture; though just 6% of respondents answered that they considered themselves disabled, 13% indicated that they lived with a health condition that was a barrier to performing day-to-day activities. Further, 32% of respondents recognised that they had a disability, long-term health condition or mental health condition, suggesting that some may be reluctant to self-identify as disabled, despite having health conditions that often affected their ability to work. This reinforces literature which argues that feeling, or identifying, as disabled is not straightforward (Barnartt, 2010²²; Brown and Leigh, 2018; Nash, 2014).

The experience of disclosing a disability is likely to be very different depending on the type of disability. Disclosure is therefore variable and subjective (Brown, forthcoming²³); for individuals with physical disabilities, the visibility of their condition and often the necessity of securing reasonable adjustments in the workplace, means that disclosing their disability to an employer is not a choice in the way that it is for those whose disabilities are not visible. Further, disclosure is likely to be experienced differently for those with inherited conditions compared to those who acquire a condition later in life, who may be less likely to consider themselves disabled (Brown and Leigh, 2018). Sang (2017) argues that disclosing a disability is not a binary action, but rather an ongoing, context-specific process. For example, individuals may choose to disclose to colleagues and/or a line manager in order to secure necessary adjustments, rather than formally through institutional reporting systems. However, this meant that changes to line

²⁰ https://www.hesa.ac.uk/collection/student/datafutures/a/disability_disability

²¹ <https://edisgroup.org/wp-content/uploads/2020/01/DAISY-guidance-version-Jan-2020-1.pdf>

²² Barnartt, S. N. (2010). Disability as a fluid state: Introduction. In: Barnartt, S. N. (ed.). *Disability as a Fluid State: Research in Social Science and Disability*, Vol 5. Bingley: Emerald Group Publishing, 1-22.

²³ Brown, N. (forthcoming). Disclosure in academia: A sensitive issue. In: Brown, N. & Leigh, J. S. (eds.) *Ableism in Academia: Theorising Experiences of Disabilities and Chronic Illnesses in Higher Education*. London: UCL Press

management arrangement could result in the loss of these adjustments and the need to re-disclose (Sang, 2017).

Research undertaken by the Equality Challenge Unit (ECU, 2011) has highlighted that in UK universities, processes for collecting disability data are variable and inconsistent. In their report, the ECU observe that each institution often had a variety of methods for collecting this data, including HR monitoring forms, referrals to occupational health and self-service applications. Further, the timing of data collection often varied, sometimes taking place at application stage, at interview stage, during employment, or following time off. Through a survey of disabled staff in UK institutions, the report highlighted that negotiating these institutional procedures in order to disclose a disability could be both time-consuming and challenging for individuals (ECU, 2011). It is perhaps unsurprising, therefore, that disability disclosure rates remain low across UK institutions. It is also worth noting that good practice from other employment sectors, particularly in the private sector, could be drawn on in order to improve processes used in HE.

3.4. Disability and academic careers in STEM

Disabled academics in STEM subjects may encounter particular challenges during their career arising from the culture of these disciplines, as well as the structure of academic STEM careers, linked to the way in which STEM research is funded. The competitive nature of the academic job market and the disparity between the number of doctoral students and the comparatively few postdoctoral and Lecturer positions, means that opportunities for progression are already limited. Further, there is some evidence to suggest that disabled STEM academics are more likely to leave academic science than their non-disabled counterparts due to a perception of the culture as not being inclusive (RAEng, 2018).

Within academia in STEM subjects, where career progression is largely determined by individuals' ability to secure external research grants, the application and selection processes for obtaining research funding are likely to be significant in their impact on the ability of disabled scientists to progress their careers. A new campaign group, the Inclusion Group for Equity in Research in STEM (TIGERS in STEM²⁴) has recently formed to attempt to address some of these issues.

Given the significance of securing external funding and grants for research and career success in STEM subjects, clearly the extent to which these opportunities are accessible to disabled scientists impacts on individuals' career progression. A recent request made in 2019 by the Science and Technology Select Committee to UKRI for detailed diversity data on grant applicants and awardees showed that applications data for disabled scientists are very limited, perhaps indicating that disabled researchers are not disclosing their disability to their funding body. Moreover, available data indicate that the success rate for disabled researchers applying for grants has been consistently lower than the success rate for non-disabled academics over the last 5 years²⁵. Recent work undertaken by Boland (2019) on behalf of the TIGERS in STEM group highlighted that the guidance, application and interview processes for UK research council funding are often inaccessible, with platforms lacking basic disability tools such as screen-reading capability or audio descriptions for figures. This is supported by research undertaken by Sang (2017) which found that disabled academics faced particular difficulties in

²⁴ <https://www.tigerinstemm.org/>

²⁵ <https://www.nature.com/articles/s41578-020-0177-1>

completing grant applications, such as the time needed to process large amounts of information in a short time period for those with dyslexia, as well as difficulties using technology. There is clearly a need to ensure the accessibility of web-based grant application systems in order to facilitate inclusivity in access to research funding.

Beyond the issue of funding, it appears that there are broader issues pertaining to the culture of STEM research which can negatively impact on disabled scientists' career experiences. The Wellcome Trust's report on research culture published in 2020, based on a survey of over 4000 scientists, highlighted that for disabled scientists' experiences of the current research environment were less positive than their non-disabled peers. This was particularly evident in relation to bullying and harassment, where disabled respondents were more likely to experience and witness these behaviours (Wellcome Trust, 2020). This finding that research cultures in STEM are less inclusive for disabled scientists is echoed in a report commissioned by the RAEng in 2018, which found that disabled respondents reported a less inclusive experience of the engineering profession than their non-disabled colleagues. One ongoing project which aims to address some of the issues facing disabled scientists is the Disability Inclusive Science Careers (DISC²⁶) project, funded by EPSRC in 2018. This project aims to improve the recruitment, retention and progression of postdoctoral disabled scientists through the provision of immersive virtual reality games for line managers and research leaders, giving an insight into the lived experiences of disabled employees. Initiatives such as this one, which involves disabled researchers, managers and employers, may help to address some of the issues which contribute to disabled scientists' less positive experiences of working in STEM.

Prior research undertaken by Sang (2017) on the career experiences of disabled UK academics found that the career structure, along with the demands of scientific research may impact on the direction of individuals' career trajectories. In this study, some academics from engineering or physical science backgrounds shifted their work from the sciences into the social sciences, where it was perceived there was greater flexibility or a lesser demand for physical exertion within the research itself²⁷. This may have implications for the pipeline of talent in STEM if early career disabled scientists observe senior academics leaving academic STEM.

3.5. Supporting disabled scientists

Examining a range of research and reports on the experiences of disabled academics, including disabled scientists, indicates that a number of measures could be introduced by institutions, employers and funders, to improve the support provided for disabled scientists.

One area where there could be significant improvement is in the collection of data on disabled academic staff, as existing methods appear patchy and not fit for purpose. Despite its broad focus, the UK charity Scope have produced a guide for employers²⁸ with useful recommendations for how to report on disability and employment, which could be taken up by the HE sector. Their advice recommends that employers not only collect data on the number of disabled people they employ, but also information on the number and quality of adjustments offered and a comparison of average earnings between disabled and non-disabled staff. In

²⁶ <https://gtr.ukri.org/projects?ref=EP%2FS012117%2F1>

²⁷ <https://migrantacademics.wordpress.com/2017/05/18/its-like-having-a-second-job-disability-and-academic-careers/>

²⁸ <https://www.scope.org.uk/campaigns/research-policy/employers-guide/>

terms of best practice in collecting data on disability, Scope advise that it is key to explain to disabled employees why they are collecting this data and also to clearly communicate how it will be used to help disabled employees in their job. This would need careful consideration for how best this could work in practice with academic staff, given the comparative distance of HR in relation to other employment sectors, and it may be that line managers would have a larger role to play in communicating these messages to disabled staff.

An additional area for improvement in employers' support for disabled scientists is the provision of relevant information, which can help to create a positive culture that encourages disclosure. Making available information such as types of support and adjustments that can be offered to employees has been shown to encourage disclosure, as shown in the ECU's report on academic staff and disclosure of disabilities (2009)²⁹. Within this report, a number of case studies are cited where these actions have been taken, including Aston University who improved their disclosure rate by giving better information about what is involved and providing ongoing opportunities for staff to disclose through the completion of an online monitoring form (ECU, 2009). In their subsequent work on furthering disability equality for HE staff, the ECU (2011) recommend that institutions undertake a number of actions to improve their information provision. These include creating a dedicated webpage for disabled staff with information about assessments and how to access information, advice, services, support and funding, as well as providing specific information, training and assistance to line managers (ECU, 2011). A key method of facilitating access to this information is working with trade unions and staff who are trained and supported to act as disability or equality contacts or co-ordinators within departments (ECU, 2010). These groups are well placed to communicate with disabled staff, including those who have not already disclosed a disability. Further, these individuals have the relevant expertise to be able to advise institutions on the most appropriate and effective forms of communication.

A further area where changes could be made to improve the support for disabled scientists is in the area of anticipatory adjustments, meaning that a proactive approach is taken in terms of making reasonable adjustments for disabled staff, without necessarily requiring disclosure of disabilities. In their 2010 report on making reasonable adjustments in HE³⁰, the ECU highlight that universities already take a strategic approach in planning reasonable adjustments that can be provided for disabled students. Actions that institutions could take to move towards an anticipatory approach to adjustments include proactively engaging with disabled staff, drawing on responses of disabled staff to institutional surveys and directly addressing their feedback. The ECU (2010) describe the multiple possible benefits of this approach; not only helping the development of a more inclusive culture, but also having the potential for long-term cost and efficiency savings.

For funders, it appears from the literature that there are a number of improvements which could be made to the processes for allocating research funding. These can be categorised into three key areas. Firstly, the application process could be changed in order to improve accessibility and encourage applications from disabled scientists. This could include altering the structure and format of grant applications, such as refining platforms to ensure compatibility with screen-readers. The timeframe for applications could also be addressed, eliminating short turnaround times and deadlines within the application process and potentially moving to a rolling system

²⁹ *Developing staff disclosure*, Equality Challenge Unit, 2009

³⁰ *Managing reasonable adjustments in higher education*, Equality Challenge Unit, 2010

of applications to allow more time. In addition, a range of examples of reasonable adjustments for disabled applicants could be promoted within the scheme guidance, in order to encourage applications. This could include the allowance of extra costs for reasonable adjustments outside of normal working routine on grants (e.g. costs for a research assistant or specialist equipment). Secondly, in considering funding applications, committees could take into account individuals' circumstances including alternative career paths when assessing the research track record of individuals, allowing for impact of part-time working patterns and career breaks on research outputs when making funding decisions. Further, disability awareness and unconscious bias training could be provided to all members of interview and peer review panels, along with potentially a move towards explicitly inclusive recruitment training. Finally, in relation to reviewing the applications and success rate for funding schemes, funders could undertake regular analysis of the diversity of applicants and awardees to monitor the success rate of disabled researchers, as well as those from other under-represented groups. This would enable a focus on how access to funding schemes can be widened, in order to be more inclusive for all scientists.

4. New analysis of statistical data on disability disclosure in HE

4.1. Overview

A key part of the rationale for this project was recognition from previous analysis of HESA data that the level of disability disclosure is lower for HE staff than amongst students and also appears to fall with academic progression (i.e. it is lower for staff at more senior levels). Variations in rates of disclosure have also been observed in different academic fields and disciplines. Some evidence for these trends can be found in Advance HE's annual compendia of data about the diversity of staff (e.g. Advance HE, 2019).³¹ The apparent decreasing rate of disclosure with career stages in science, from first degree to professor level, was highlighted in a Royal Society diversity data analysis (Royal Society, 2014)³² based on HESA data for 2011/12.

In parallel with this project, the Royal Society has obtained relevant HESA staff record data for the years 2012/13 to 2018/19 and this was made available to us for potential analysis. We undertook a range of analysis of these HESA data in order to provide figures for the most recent year available (2018/19) to contextualise the qualitative findings of this project but also to investigate some of these apparent trends in more detail. While the reporting by Advance HE of diversity data about HE staff, including disability, is systematic, it is somewhat generic and the intention here is to provide analysis which is more closely tuned to the context of the Royal Society and the lens through which it sees the scientific workforce and progression pipeline.

For brevity, results shown here are for academic staff in UK HE institutions in the 2018/19 academic year (the most recent available) and for certain comparative purposes equivalent data from five years earlier (staff in the academic year 2013/14).

4.2. High-level results and trends

High-level analysis of the data indicates that 4.1% of academic staff (4800 people) working in STEM fields reported a disability in 2018/19 (Table 4.1). However, this proportion continues to be lower than for all academic staff (4.7%). Comparative data for 2013/14 confirms that these proportions are rising with time, although the gap between STEM and other (i.e. non-STEM) staff appears to be widening as both proportions increase (as can also be seen from successive annual data reported by Advance HE). It should also be noted that the total size of the academic workforce has increased during this period, so the increase in number of disabled staff rises faster than the proportion of that expanding workforce.

	2018/19		2013/14	
	% with known disability	Number	% with known disability	Number
STEM	4.08%	4800	3.53%	3680
Other	5.46%	5345	4.77%	4335
Total	4.70%	10145	4.11%	8010

Table 4.1 Academic staff in UK HE institutions recorded as having a disability

³¹ *Equality + higher education, Staff statistical report 2018*, Advance HE, 2019

³² *A picture of the UK scientific workforce*, Royal Society, 2014

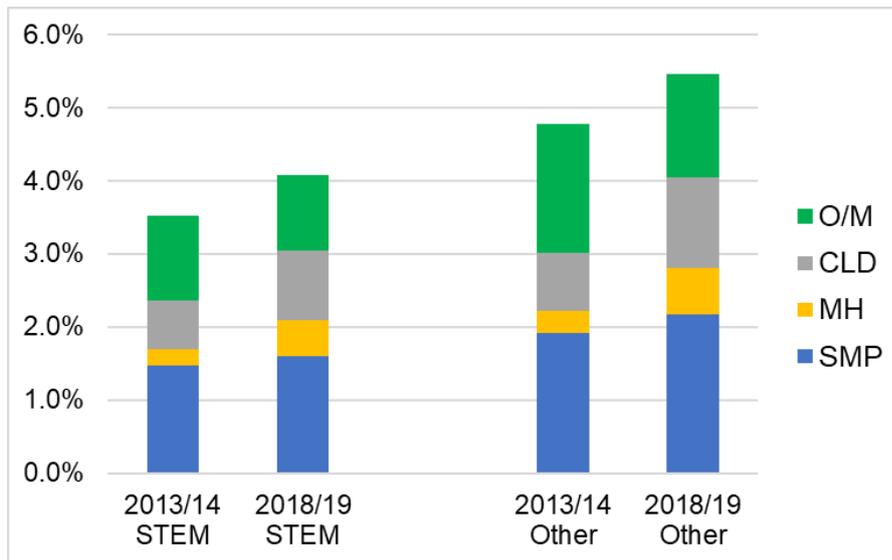


Figure 4.1 Proportions of STEM and other academic staff with different disability types, in 2018/19 and 2013/14 (SMP – sensory, medical and physical conditions; MH – mental health; CLD – cognitive and learning difficulties; O/M – other or multiple disabilities)

Figure 4.1 shows proportions of academic staff with disabilities of certain types (and some groupings of types) recorded by HESA. These groupings, as we will see, prove to be very useful in comparative analysis, including when comparisons are made with students. For example, unlike the case for students where the most common reported categories of disability are cognitive (learning differences/difficulties) and mental health conditions, the position for staff is different, with sensory, medical and physical conditions (SMP) being most common.

Figure 4.1 also shows that the proportions of all these types of disability (as well as overall) increased between 2013/14 and 2018/19 to varying extents, as well as some differences between STEM and other staff. However, the overall increase in disclosure of disability appears to have been driven most strongly by higher disclosure of mental health conditions and cognitive/learning differences, both within STEM and other fields.

Our analysis of disclosure of disability at different career stages differs somewhat from that by the Royal Society (2014), as we have used HESA's 'levels' of role within the HE staff record. The categories (identified with letters) for academic staff range from Vice-Chancellor (A) downwards to low-level administrative roles (P), although letters G and H are not used. In practice, academic staff tend to be clustered and in this analysis we have grouped roles into 'senior' (D-F: which includes Heads of Department (D) and Professor (F)), 'mid-career' (I & J: including Principal Research Fellows, Readers, Senior Lecturers, Senior or named Research Fellows) and 'early' career (K-M: including Junior Lecturers and postdoctoral researchers). Data on academic employment function, based on type of contract, is used in some further analysis of certain key science career clusters later in this chapter.

Figure 4.2 shows results for the STEM progression pipeline including first degree, doctoral researcher and early, mid and senior career stages for STEM academic staff, all for the 2018/19 year. While this is a snapshot not a longitudinal view, the chart demonstrates the much higher rates of disclosure by STEM students and postgraduates compared with academic staff, and the anticipated decrease in disclosure for staff with seniority. Comparison

with data from those outside STEM (not shown in the chart) reveal that at every stage the level of disclosure is lower by those in STEM than other subjects (and overall).

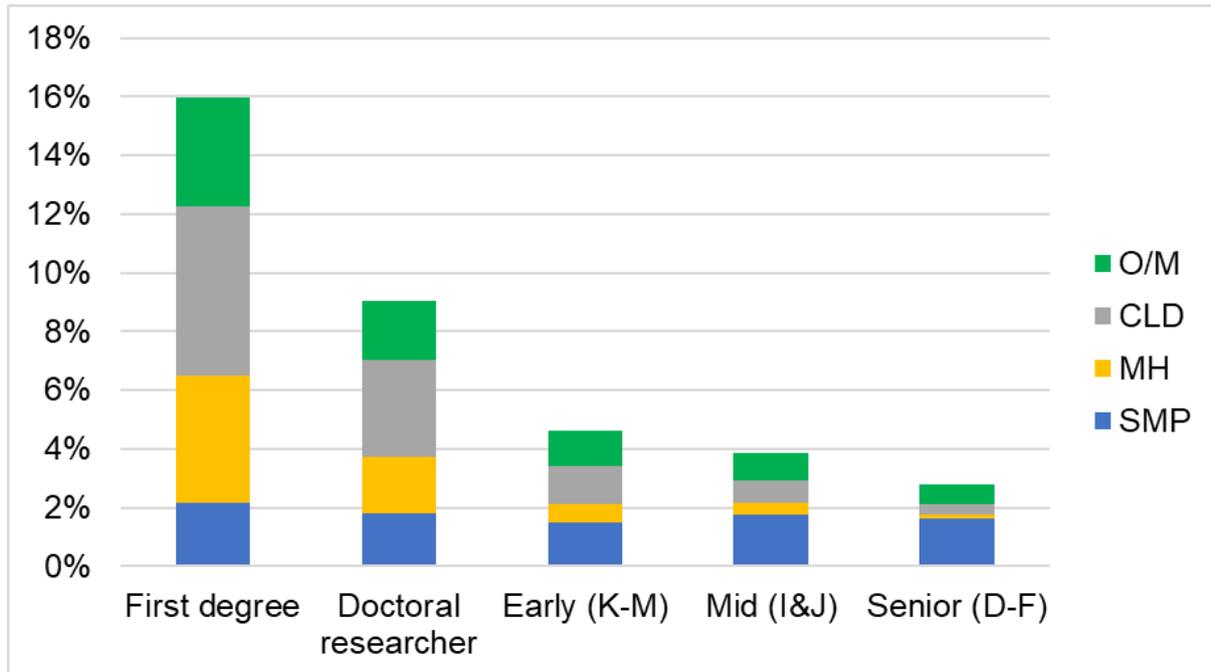


Figure 4.2 Proportion of STEM students and staff disclosing a disability, with type of disability, for academic year 2018/19 (SMP – sensory, medical and physical conditions; MH – mental health; CLD – cognitive and learning difficulties; O/M – other or multiple disabilities)

The results in Figure 4.2 also begin to shed some light in terms of links between career stage and type of disability. For example, the incidence of sensory, medical and physical conditions is quite similar for students and staff and only varies slightly with staff career stage, showing some increase between early and later career stages for staff (as might be expected if progression relates to age). On the other hand, the extent of disclosure of mental health conditions and cognitive/learning difficulties, and to a lesser extent multiple disabilities, is much lower amongst staff than students, and also falls for staff with seniority. The extents of reported mental health-related and cognitive disabilities are several times higher amongst early-career staff than their senior counterparts. Reporting of mental health conditions, in particular, within the most senior D-F group was extremely rare. Taken together, it can be seen that the overall decrease in reported disability with progression in a STEM academic career is driven by the extent of reported mental health and learning conditions; the very low disclosure of these by senior academics more than outweighs slight increases in the levels of other conditions by more senior staff (which might be expected amongst those of greater age).

When a time dimension is added to this analysis, for STEM academic staff, Figure 4.3 illustrates that the extent of change between 2013/14 and 2018/19 for those in senior roles has been far less than for those in an early-career stage, in fact for the former very little has changed in those five years. However, amongst early-career staff, there were distinct increases in the extent of reporting of all three of the main types of conditions analysed, although a reduction in other or multiple conditions. It should also be noted that similar trends were observed for these sub-groups of academic staff overall between these two years.

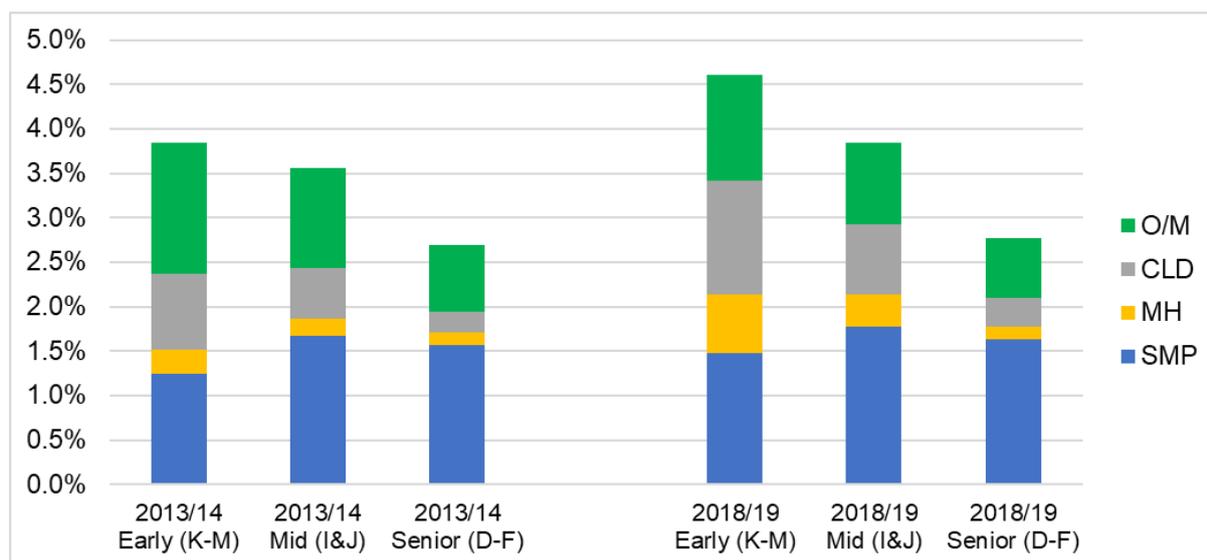


Figure 4.3 Proportions of STEM academic staff in different career stages reporting disabilities, for 2018/19 and 2013/14 (key as for Figure 4.1)

To summarise, this initial analysis confirms that rates of disability disclosure are far lower amongst STEM academic staff than students, and there is an overall decrease with progression to and in a STEM academic career. That decrease is mostly driven by much lower reporting of mental health and cognitive/learning conditions by more senior staff. The picture is changing somewhat over time, with broadly rising rates of disability apparent (other than for the most senior staff), again driven mostly by increasing rates of mental health and cognitive/learning conditions. Disclosure by STEM staff is consistently somewhat lower than staff working in other fields, and this difference appears to be persisting.

4.3. Intersections with age and gender

Advance HE (2019) has begun to provide a range of diversity analyses for HE staff which demonstrate significant intersectionalities between different personal characteristics, some of which are relevant to this investigation. For example, it describes a broadly positive correlation between age of staff and disability disclosure, which is also seen in the general population. This is as expected given that some conditions emerge with age and/or have more impact at higher ages, either of which may lead to disclosure. However, importantly, their analysis (which is for all HE staff, not just academic staff) suggests that levels of disability are highest for those under 25 and 56-60, and lowest for those aged 31-35, which is a more complex picture than a simple increase with age.

In our analysis we have used broad age groups for staff (under 35, 35-49, 50-65 and over 65) and investigated rates of disability for a variety of sub-groups as well as all STEM academic staff. Results in Table 4.2 for 2018/19 parallel the trend obtained by Advance HE in the most recent years, i.e. that of an inflected curve which is relatively high for the youngest and older groups, and in our case lowest for those in mid-career (35-49).³³ This pattern is similar for academic staff in STEM and overall. However, results for 2013/14 show a somewhat different pattern which is a simpler rise with age, with the lowest rate in the youngest category. It seems

³³ Results for those aged over 65 have not been shown as this is a relatively small population.

likely that this change with time reflects higher rates of disclosure generally by young adults recently, which are beginning to feed through into the early-career stages for academic staff.

	Under 35		35-49		50-65	
	% with known disability	Number	% with known disability	Number	% with known disability	Number
STEM 2018/19	3.92%	1355	3.67%	1755	4.82%	1540
STEM 2013/14	2.75%	855	3.00%	1280	4.98%	1400
Total 2018/19	4.52%	2410	4.22%	3725	5.45%	3595
Total 2013/14	3.15%	1520	3.53%	2825	5.55%	3365

Table 4.2 Proportion of academic staff disclosing a disability, with age group

From Table 4.2 there is also a hint that changes with time are not consistent across all groups within HE staff, as significant rises in disclosure between 2013/14 and 2018/19 are seen for those in the youngest and middle age groupings, but not for those aged 50+. Again, this occurs for both STEM and across all subjects.

More detailed analysis with age also revealed interesting trends in relation to different types of disability, which to some extent mirrored the trends seen with seniority. The incidences of sensory, medical and physical conditions have been greater for the higher age groups, while disclosure of mental health and cognitive/learning conditions were lower in these older groups. We infer, again, that this may well reflect ongoing cultural change of a greater willingness to disclose such conditions, especially amongst young people, which with time is gradually feeding through to people of greater age.

Another key intersectionality is gender. Advance HE has noted that women are over-represented amongst HE staff (not just academic staff) who disclose mental health conditions and sensory/medical/physical impairments, whereas social or communication impairments (admittedly much less common) are somewhat more highly reported by men. We undertook systematic analysis of disability rates for academic staff by gender in order to understand more clearly the linkage between gender and rates of disclosure by STEM academic staff, given that some STEM subjects are highly gendered (as is progression within them, to some extent). Table 4.3 summarises these results, confirming that rates of disclosure were higher by women than men for all academic staff and those working in STEM, overall and for all the types of disability analysed here. More detailed analysis suggested that these differences persist within each of the age ranges studied, overall and in STEM, although rates of disclosure by women were markedly higher for those aged 50-65 (for example, 6.15% for women and 3.94% for men, in STEM).

These consistent differences with gender need to be taken into account when comparing disability rates in different STEM disciplines where staff populations are strongly gendered, i.e. a discipline such as engineering with men in the majority might be expected to display lower overall disability than, for example, biological sciences (which has a more even gender profile), purely on account of its differing gender profile. This is explored further in section 4.6 where we show that disciplinary differences exist independent of gender but could be exacerbated by different gender profiles. There are gendered patterns within diagnosis of different types of disability, too, with women being more likely to be diagnosed with chronic conditions (Leveille,

Resnick and Balfour, 2000³⁴) and mental health conditions (Mental Health Foundation, 2020³⁵) than men. On the other hand, more men and boys are currently diagnosed as autistic than women and girls (National Autism Society, 2020³⁶), which is considered to be due to a range of factors, including gender differences in behaviour and the tools used to assess autism being based on male characteristics, leading to under diagnosis in females.

	% with known disability	Number	Sensory, Medical & Physical	Mental Health	Cognitive / Learning	Other / multiple
STEM						
Men	3.50%	2365	1.33%	0.42%	0.86%	0.89%
Women	4.84%	2430	1.98%	0.57%	1.32%	0.97%
Total						
Men	4.11%	4735	1.60%	0.49%	1.00%	1.02%
Women	5.38%	5405	2.16%	0.61%	1.18%	1.43%

Table 4.3 Disclosure of disabilities by STEM and all academic staff, 2018/19, by gender

4.4. Further insights into disability and STEM progression

Given these intersectionalities, we undertook more detailed levels of analysis to understand with more clarity the link between progression in academia in STEM and disability disclosure, in order to remove effects of (for example) age or gender, or both.

For example, analysis of the disclosure rates for those of similar age but different grades did reveal lower rates of disclosure at the more senior grades independent of age (Figure 4.4). For STEM staff aged under 35, the proportion reporting disability in grades K-M was just over 4%, whereas it was just under 3% for those at grades I and J. Similarly, amongst those aged 35-49, the rate for those in grades I and J was 3.3% while it was only 2.2% for those in the more senior grades D to F. The same pattern could be seen for both men and women. Figure 4.4 shows the results overall and for men and women separately in these sub-groups, indicating that the lower reporting of disability at more senior grades is not accounted for purely by any differing gender profile of these groups.

Detailed observation of these results by key types of disability revealed that these differences were driven mainly by differences in disclosing mental health and cognitive/learning differences, although there were also more modest differences in the extent to which sensory, medical and physical conditions were disclosed. The almost complete absence of disclosure of mental health conditions by those aged over 50 in professorial and more senior roles (F-D) was particularly stark. These results go some way to suggest that there is a genuine issue with low rates of disability disclosure with progression in STEM, irrespective of any underlying differences in the profile of these groups of staff by age or gender.

³⁴ Leveille, S. G., Resnick, H. E., & Balfour, J. (2000). Gender differences in disability: evidence and underlying reasons. *Aging Clinical and Experimental Research*, 12(2), 106-112.

³⁵ <https://www.mentalhealth.org.uk/statistics/mental-health-statistics-men-and-women>

³⁶ <https://www.autism.org.uk/about/what-is/gender.aspx>

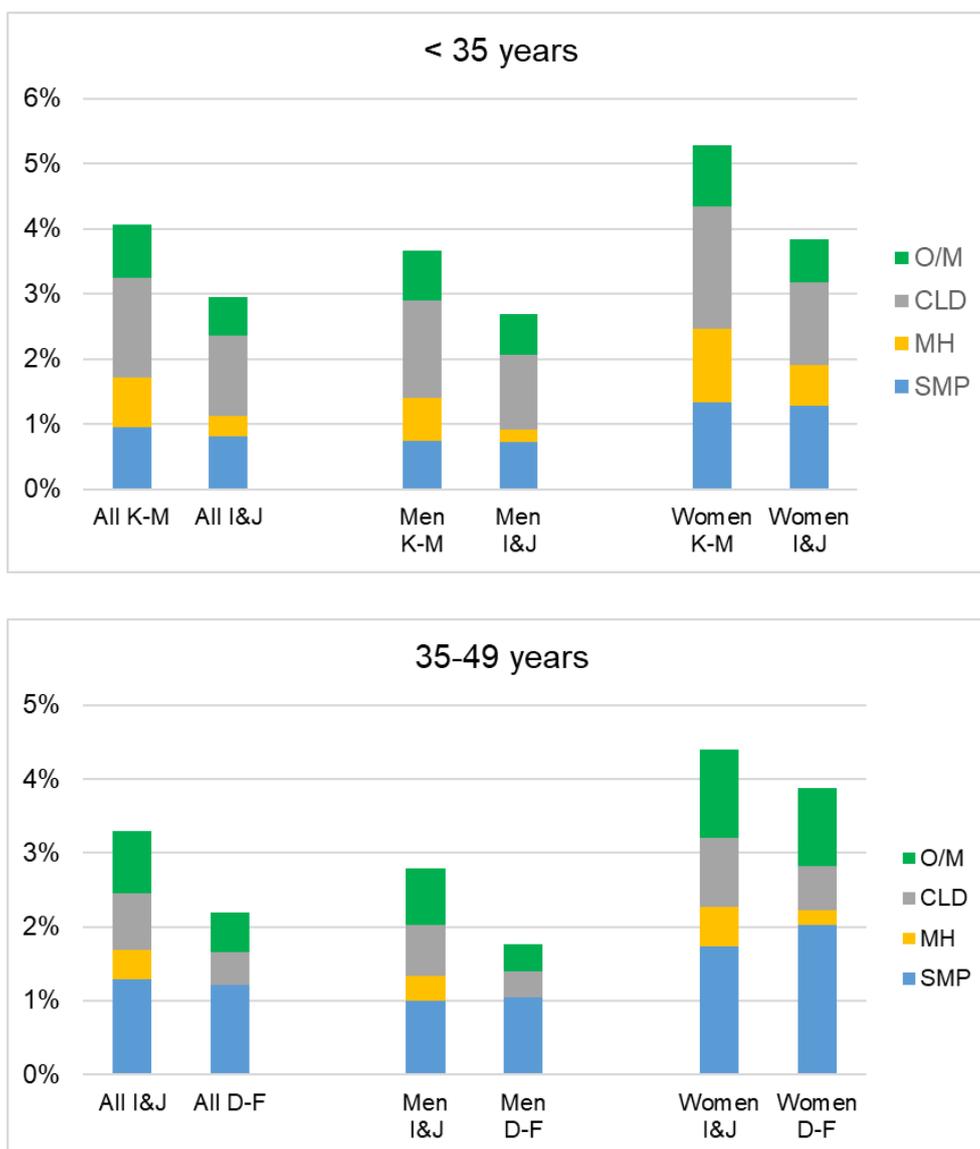


Figure 4.4 Proportions of STEM academic staff in 2018/19 disclosing disabilities by gender and career stage: (a, upper) under 35 years of age; (b, lower) 35-49 years old

4.5. Types of employment contract

Another aspect of interest within STEM progression – and which to some extent makes STEM different from other broad fields – relates to the type of employment contract held. Much of STEM research is undertaken in large, research-intensive universities in which the ‘mainstream’ trajectory for progression is postdoctoral researchers to be employed on fixed-term, research-only contracts from which they seek to progress (in some cases through a research fellowship) to a permanent academic position which most commonly also includes teaching and then upwards to a professorial position (again, mostly on a research and teaching contract). Clearly, some academics do not follow this trajectory and after their doctorate may instead obtain a teaching-only contract, after which they may or may not achieve progression to permanent senior academic roles which predominantly combine research and teaching.

These different trajectories can be identified through distinct clusters of staff at particular levels with certain types of contract; for example there is a large population on research-only contracts at grades M-K (and a smaller but significant population perhaps half this size on teaching-only contracts at these levels). Meanwhile, two thirds of staff at grades I and J are on

a research and teaching contract, as are the vast majority at grades F-D. Outside STEM, there are relatively few academics on research-only contracts at any level, and staff at grades M-K are dominantly employed on teaching-only contracts (whereas the picture at more senior levels is similar to STEM in terms of most being on combined contracts).

We undertook analysis of disability rates within some of these key clusters in the STEM progression trajectory, with the results in Table 4.4 for the 2018/19 year. Results are only given for groups of over 5000 staff (for the UK). What is notable is the difference in disability disclosure rates between STEM academic staff on research-only and teaching-only contracts at levels M-K. The rate in the 'mainstream' trajectory at only 3.4% is only just over half that amongst those with teaching contracts (6.7%). The same pattern is seen for STEM academics at grades I and J, albeit the numbers on these types of contracts at these levels are lower. Comparison with the picture for other (non-STEM) subjects suggests that this same broad pattern is observed, although the differences between those on research-only and teaching-only contracts are less marked.

We hypothesise from these results that one explanation of the low rates of disability disclosed by those in senior positions in STEM could be that many have pursued the (arguably most esteemed and competitive) trajectory from a research-only position, within which disclosure of disability is low, and/or some could have removed themselves from this trajectory or from academic progression entirely. By contrast, more of those who have taken a teaching-focused role when an early career academic, have disclosed a disability. This begs the question of why rates are so low for postdoctoral scientists on research-only contracts, and whether access to external funding is a factor here. It also raises the possibility of whether higher proportions of those with a disability are either choosing or ending up in a teaching-only route instead.

	Grades M-K		Grades I&J		Grades F-D	
	% with known disability	Number	% with known disability	Number	% with known disability	Number
STEM						
Research only	3.44%	1140	2.70%	210		
Teaching only	6.68%	1160	4.96%	410		
Research & teaching	5.20%	310	3.84%	1120	2.70%	370
Other						
Research only	4.93%	325				
Teaching only	6.45%	1965	5.64%	515		
Research & teaching	5.48%	460	5.08%	1485	4.15%	420

Table 4.4 Proportion of 2018/19 academic staff disclosing a disability, with contract type and career stage (data only presented where population is over 5000 individuals)

A related factor in this discussion could be the duration of the employment contract, as there is common concern about the precarity of employment of postdoctoral researchers who have fixed-term contracts rather than open-ended. In fact, analysis of disability rates in relation to this aspect of their contract did not reveal simple trends. For all academic staff aggregated together, the rates of disability for those with a fixed-term contract were somewhat higher than

for those with an open-ended contract, and the same was the case for STEM staff analysed in this way. However, fixed-term contracts are by far most common for those at early career levels, so it was important to disaggregate this analysis by grade of role. Interestingly, when this was done for STEM staff on research-only contracts at grades M-K (i.e. the majority at that level), there was almost no difference in disability rates between those on fixed-term or open contracts, at least at this aggregate level. By contrast, however, there was some difference for those on teaching-only contracts, amongst whom the rate of disability was significantly higher for those on fixed-term (7.5%) than open-ended (5.5%) contracts.

It is tempting from these observations to infer that relatively higher proportions of disabled scientists are pursuing an academic career through a teaching-only contract, in many cases of a fixed-term nature, rather than the arguably mainstream route starting with a research-only contract. However, this is to some extent conjecture and cannot be proven, or disproved, by these quantitative data or trends.

Separately, it was also clear that rates of disability were consistently higher amongst part-time staff than full-time; this was the case for all sub-groups investigated, within STEM and overall, and for both men and women. It seems likely that disabled staff are more likely to be employed part-time because some may have to manage their conditions and symptoms and cannot take on full-time jobs, or because they have been advised medically or managerially to "pace themselves" and step or scale back. It is not clear from these data the extent to which this is a driver in STEM progression for disabled staff, i.e. to what extent working part-time impacts on their ability to progress. This sort of issue is further investigated within our qualitative research on individuals' experiences.

Two other factors which have not yet been taken into account here are nationality of staff (although Advance HE reports that disclosure is higher amongst UK nationals than others) and type of institution. Brief exploration of the latter issue was undertaken simply by comparing key results for those in Russell Group institutions with the aggregate results presented so far.

The Russell Group institutions account for just over half of all STEM academic staff (52%) in the UK, but only 42% of those reporting a disability, indicating immediately some difference within this group. Analysis of rates of disclosure for 2018/19 staff in many groups were lower in Russell Group institutions than all institutions combined; for example, this was the case for all STEM academic staff and also non-STEM (Table 4.5). Similarly, focusing on STEM staff, rates of disclosure for early-career (levels M-K) staff and mid-career (I and J) were lower in STEM than overall, although there was no significant difference for senior staff. Interestingly, rates of disclosure by those who had research-only contracts at levels M-K (potentially a key STEM pipeline sub-group) were similar in the Russell Group and overall, and this could also be seen for those in levels I and J. In contrast, rates at these levels for staff on teaching-only or research and teaching contracts were lower in the Russell Group institutions.

	All institutions		Russell Group institutions	
	% with known disability	Number	% with known disability	Number
All STEM academic staff	4.08%	4800	3.26%	2000
All non-STEM academic staff	5.45%	5345	4.06%	1185
Seniority (STEM only)				
Levels F-D	2.77%	420	2.61%	235
Levels I & J	3.84%	1735	2.98%	635
Levels M-K	4.61%	2615	3.65%	1130
Contract type for STEM M-K				
Research only	3.44%	1150	3.46%	880
Teaching only	6.67%	1155	4.90%	220

Table 4.5 Proportions of key groups of 2018/19 academic staff disclosing a disability, overall and in Russell Group institutions

It should also be borne in mind that the proportion of early-career staff on research-only contracts is significantly higher in the Russell Group institutions (over 80%) than overall (59%), so the impact of low disability rates within this particular group presumably contributes to the lower rates overall for the Russell Group. Thus, these data seem to suggest that rates of disclosure are generally lower in Russell Group institutions (than overall), other than at the most senior levels and also the key pipeline sub-group of early-career staff on research contracts.

Given that rates of disclosure appear to vary in relation to a wide range of both personal characteristics and employment-related factors, a full and systematic analysis of disability disclosure amongst HE staff (including potentially a regression analysis) was beyond the scope of this project – within which this quantitative analysis was intended only ever to be a minor and contextualising part.

4.6. Disciplinary differences within STEM

The Royal Society (2014) report highlighting differences in rates of disclosure of disability for academic staff working in different disciplines used 2011/12 HESA staff data, which were then based on subject-related cost centres. That analysis included some consideration of career stage, specifically ‘researcher’, ‘lecturer or senior lecturer’ and ‘professor’. It suggested that the highest rates of disclosure were by staff in nursing and paramedical studies (at around 5%), while rates in some branches of engineering (but not all) and physics were particularly low (at around 1-2%). However, it has to be said that there was significant noise in those results and that consistent disciplinary trends were not evident.

Since that time, HESA data collection for staff has been revised to incorporate role grades fully (as used already in our analysis of progression) and also utilising subject disciplines more closely tied to the JACS subject classification used for students. In our study, we first analysed disability data for STEM staff based on the Royal Society categorisation of ‘A’-side subjects (which are broadly the physical sciences and engineering) and ‘B’-side (biological and biomedical). Figure 4.5 shows that the extent of disclosed disability was slightly higher for academic staff working on B-side subjects (and higher for each type of disability shown). Closer

inspection showed that most of this difference was due to higher rates amongst those working in Subjects allied to Medicine (which includes disability-related studies, as well as nursing, and within which the level of disclosure was close to for non-STEM subjects). Overall, the rates across B-side subjects are higher, but only fractionally so if this sub-group is omitted.

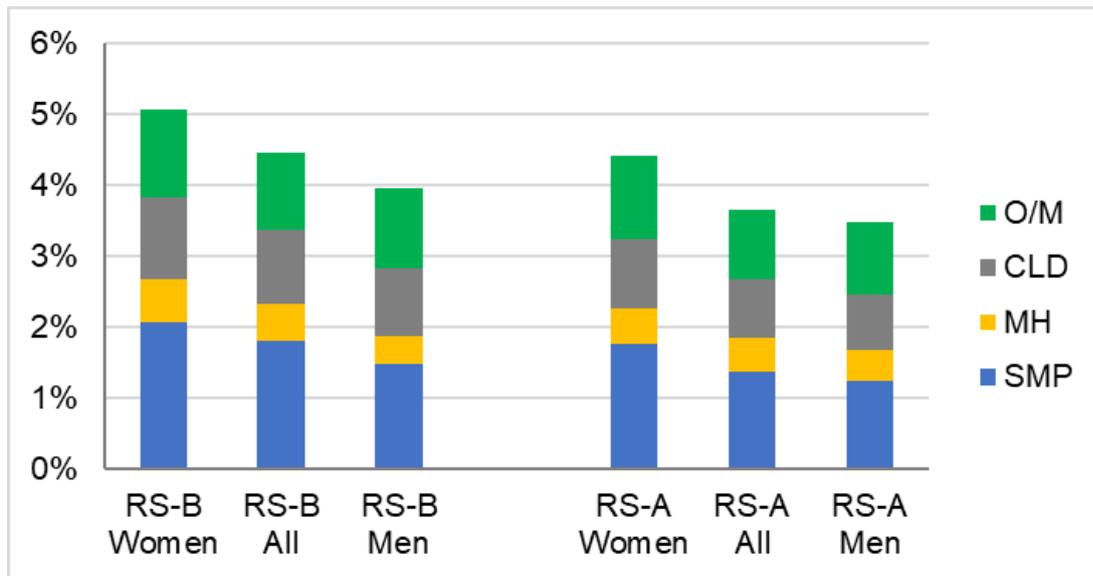


Figure 4.5 Proportion of academic staff working in subjects within Royal Society 'A' and 'B' subject groupings, 2018/19

Figure 4.5 also illustrates that within either of these broad subject groupings, disclosure by women was consistently higher than by men (overall and for each of the disability types shown). Equally, results for men in A-side subjects were lower than men in B-side subjects (and the same trend for women).

However, these trends confirm that the differences in rates between the subject groups are not a function purely of any differences in gender profile between them (as a result of inherent differences in rates of disclosure by gender). Thus, there does appear to be some difference by broad discipline, albeit some of that difference on account of higher levels of disclosure in Subjects allied to Medicine.

Analysis of rates of disclosure in particular career stages or by contract type within these broad subject groupings showed that some differences persisted, but to varying extents. While the results for those on research-only contracts at levels M-K were only slightly lower for those in A-side subjects (3.3%) than B-side (3.5%), there were more substantial differences in some other sub-groups (such as teaching-only contracts at levels M-K, or combined contracts at levels I and J, for both of which there was a difference of around a full percentage point). This seems to suggest that the disciplinary differences are not straightforward when the subjects are aggregated in this way.

Therefore, we undertook analysis at a more detailed subject level for the progression pipeline in STEM including selected student data. Figure 4.6 shows the results, confirming that for all subjects studied the rate of disclosure is lower for staff than students and, broadly, falls with seniority amongst academic staff. A number of possible trends are evident, bearing in mind this is a snapshot of the 2018/19 populations and not a longitudinal analysis. For engineering

and also medicine and dentistry, rates of disclosure are particularly low throughout. The rate for physical sciences is amongst the highest for students but close to lowest for staff. The trend for subjects allied to medicine is highest for established staff, higher than at early career (and the only subject where this appears to be the case).

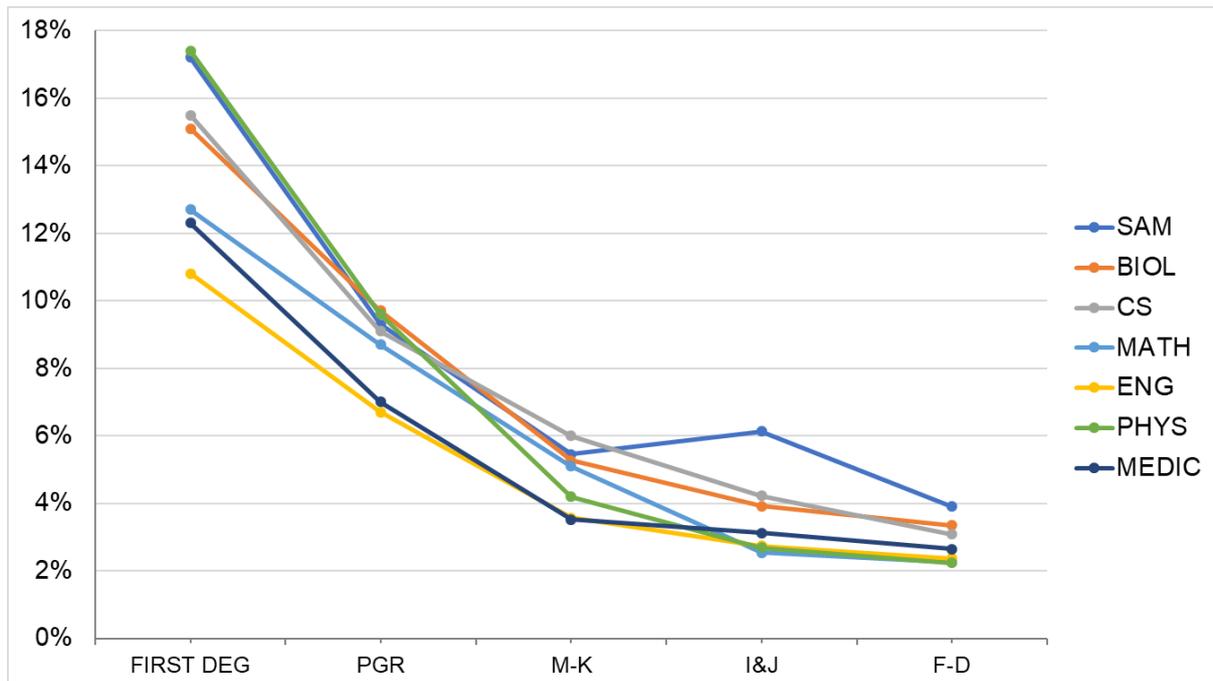


Figure 4.6 Proportion of 2018/19 students and academic staff disclosing a disability, with subject (SAM – subjects allied to medicine; BIOL – biological sciences; CS – computing science; MATH – mathematics; ENG – engineering & technology; PHYS – physical sciences; MEDIC – medicine & dentistry)

Detailed focus on the early career stage (role levels M-K) showed some complexity of results, with higher rates of disclosure by those on teaching-only contracts than research-only contracts, in all subjects. It was notable that the relatively high levels of disclosure by computing science and mathematics staff at this level were in large part driven by the much higher proportions of those staff on teaching-only contracts (up to half) than in engineering or physical sciences (around a quarter), amongst whom rates of disclosure were higher. We infer that this may reflect different balances of research- and teaching-focused trajectories within different subjects, which may be linked to rates of disclosure.

Overall, the picture is not simple and a more sophisticated analytical approach, ideally with longitudinal aspects, than possible within this study could be valuable to understand some of these differences with discipline.

4.7. Summary

Summarising what this new data analysis has confirmed or revealed anew, there is evidence of the following trends in terms of rates of disability disclosure. Rates of disclosure are lower amongst academic staff than doctoral students and much lower than first-degree students. They are also lower amongst senior academic staff than at early-career stages. In the key early-career stage for staff, disclosure rates are also particularly low amongst those on research-only contracts. However, disclosure is generally increasing with time, other than at

the most senior levels where little is changing. This overall increase is largely due to more common reporting of mental health conditions, especially, and cognitive/learning differences, while there is little increase in the level of some other types of condition. Disclosure rates are lower amongst more senior staff than early-career, or students, mostly on account of differences in disclosure of those particular conditions, especially mental health – currently there is almost no reporting of mental health conditions by senior staff in STEM subjects.

There is evidence of disciplinary differences in disclosure rates, with disclosure being lower in STEM subjects than outside STEM. Further, disclosure is particularly low for staff in certain subjects, such as engineering, medicine and physical sciences. Further, disclosure rates are lower in Russell Group institutions (taken together) than outside this group, other than at senior levels and for early-career staff on research-only contracts.

In addition, certain trends are also seen that exist more widely in the general working population, including rates of disclosure being higher amongst women than men; higher with greater age (notably for some disabilities, especially sensory, medical and physical conditions, but which can be outweighed by lower reporting of some other conditions), and higher amongst those working part-time than full-time.

5. Experiences of disabled scientists

This section presents our analysis of the career experiences of disabled scientists, drawing on interview data gathered through 25 interviews with disabled scientists. We have provided some detail as to individuals' career stage, gender, subject area and a broad categorisation of their disability, as selected by participants in the pre-screening questionnaire, in order to provide a context for their comments. In some cases we have provided less detail in order to ensure that individuals are not identifiable. Findings are presented thematically under the sub-headings below and summarised in the section 5.5.

5.1. STEM academic/research culture

The challenges of the research culture in STEM for disabled scientists have been identified in a range of literature, most recently in the Wellcome Trust's report. This report found that disabled academics were less likely than non-disabled colleagues to feel that the research culture was inclusive, and highlighted experiences of ableism and discrimination faced by disabled scientists.

Interview participants observed that some structural features of academic science posed particular challenges to disabled scientists, some of which were specific to certain disciplines or sub-disciplines:

"I think lab work is a challenge right, especially the hours that it requires."
(Female, Mid-Career, Biology, Physical disability or health condition)

"Fieldwork poses particular challenges – travelling to face-to-face interviews and to see research sites made me ill – I am just in a lot of back pain, so if I am carrying a suitcase, sitting or standing for long periods causes the pain to spiral which is very draining." (Female, ECR, Health Research, Physical disability or health condition)

One participant observed that across many disciplines, the processes of experimentation and testing could have a particular impact on individuals with mental health conditions:

"In science, there is a lot of failure because you are testing things all the time. Keeping up with that level of failure hits people hard, it just might be extra hard for those with mental health. If you don't have successes or small wins happening it can be hard."
(Male, Non-academic STEM role, Medical Science, Neurodiverse)

Others, struck a more positive note, noting the possibility for inclusion that working in STEM offered for disabled researchers:

"You get some very different characters in science – people who are quirky and would be seen as very different by normal standards but they can be well respected because they may not be seen as 'normal' but they are very good scientists. Science can be very tolerant of that." (Male, ECR, Medical Science, SpLD)

"In science there are an above average number of neurodiverse people so you will quickly find you aren't the only one." (Female, Mid-Career, Psychology, Neurodiverse)

However, for those who were neurodiverse, a significant issue within the culture of research in STEM was the need to network, attend conferences and funding events and increasingly to undertake public engagement or outreach work. The social expectations of this kind of activity could be difficult to navigate, and there was a feeling that STEM increasingly rewards socially confident and outgoing communicators. Whilst this was particularly challenging for those who were neurodiverse, it was also difficult for those with conditions which made communication more challenging:

“Deaf people are left out in group meetings, conversations – basically networking so deaf people cannot form effective networks in applying for funds.”

(Male, Mid-Career, Chemistry, Physical disability or health condition)

“Increasingly, being successful in research, especially in getting funding, requires skill in social interaction or social competition. Researchers do not simply write and submit bids. You must influence the priorities of the funder and of your subfield. Particularly if you are from outside the golden triangle (as I am) you must try to attend funders’ scoping and shaping workshops, apply for sandpits and build consensus while boozing at the conference bar.”

(Male, Senior/Late career, Neurodiverse)

“In the past I think scientists were more introvert but now the competition is so fierce there is need to be far more extrovert. They spend more time talking about it than doing the work itself. Interviews can be designed so as to attract these kind of people – like those who broadcast on Twitter. Presenting can seem more important than the work itself.” (Female, Mid-Career, Geoscience, Neurodiverse)

Other elements of the research culture in STEM, such as the focus on productivity and outputs and a high level of competition for academic roles and grant funding, could be experienced as a challenging environment for many disabled scientists. This could reflect the finding in the data analysis of a particularly low rate of disclosure amongst early-career STEM academics on research contracts, as well as the more general observation of higher rates amongst those who work part-time. Particularly for ECRs, the competitive nature of academic science caused concern that they would not be able to match their peers in terms of research productivity, with negative long-term career implications:

“I simply cannot work the long hours that I did before I was unwell. I have ongoing fatigue alongside heart issues, some (thankfully fairly minor) memory problems, and compromised immunity. This makes it extremely challenging to be as productive as I used to be. I am certain that this will affect my ability to publish and “keep up” with my contemporaries, and so I suspect that this will affect how I am compared to others when applying for a permanent academic role and grants.”

(Female, ECR, Chemistry, Physical disability or health condition)

Even for those further on in their career, employed on permanent contracts, there were perceived to be challenges in meeting expectations of research outputs. It was noted that whilst colleagues may be able to dedicate more time to applying for research grants and publishing papers, this capacity was difficult to replicate for disabled scientists, particularly those with conditions which caused fatigue.

The Research Excellence Framework (REF) was cited as a particular issue which mid-career scientists needed to negotiate, as the process of being submitted for the REF had a significant impact on career progression. One participant observed how the process of calculating her research outputs in terms of metrics meant that on paper she compared unfavourably with her colleagues:

“The reality is that because my disability comes with a lot of fatigue and associated brain fog...it means that I am not able to do as much evening and weekend working as my colleagues do. I lose equivalent of about a day a week relative to their 6 days a week working. Now I know that is toxic and all the rest of it, but the pragmatics of it is I have not written as many papers or grants as another colleague might have done. Whilst I meet the standard metrics, so I am REF-able, and I have been for the last 3 REFs and all the rest of it, you know I haven’t achieved what I might have achieved with my set of talents and skills and bloody mindedness that I would have done otherwise.”

(Female, Mid-Career, Health Research, Physical disability or health condition)

Further, individuals perceived the ways in which the REF measured productivity and recorded disability as not fit for purpose, though there was some recognition that the more recent REF had improved the way in which disabled researchers could acknowledge impact on research productivity. The metrics used within the REF to measure productivity, however, were viewed as overly reductive in terms of the allowances made for the impact of disabilities on individuals’ research outputs:

“For the purposes of the REF this time I do actually get marked as a disabled member of staff for the first time I am actually recorded. I do not get a reduction because I haven’t taken time off and it is substantial amounts of time you are talking about at least 6 months sort of level...the REF has very, very blunt way of recording whether or not your research has been impacted by my disability. Yes it massively has. Yes I should get a discount. No I don’t qualify so I don’t even bother...They are actually recording metrics this time which they haven’t previously. So I am actually recorded but previously 3 previous REFs I have gone in and I have been invisible again.”

(Female, Mid-Career, Health Research, Physical disability or health condition)

Though being able to disclose a disability as an “equality-related circumstance which may significantly constrain the ability of submitted staff to produce outputs or to work productively throughout the assessment period”³⁷ was viewed as a useful option within the REF, there is a risk that individuals may internalise the implication that they are somehow less successful:

“Some of the formal stuff is frightening because the, you know the REF thing came back and basically they asked me kind of what do you estimate your reduction in research effort was over this period and I gave them a percentage but then what they did is they took that time and they multiplied it by the percent and suggested that I had 20 months lost, which was like it makes it look like I didn’t work for 20 months.”

(Female, Mid-Career, Biology, Physical disability or health condition)

³⁷ https://www.ref.ac.uk/media/1092/ref-2019_01-guidance-on-submissions.pdf

An additional aspect of research culture in STEM which was experienced as particularly challenging for disabled scientists was the expectation to work outside normal working hours, and the cultural assumption that all were able to work in this way. This was observed by participants across all career stages and was perceived to particularly disadvantage individuals with chronic conditions, who needed time to rest and recuperate:

“There’s an expectation that you can always pick up an extra task and if you are working hard at pacing and managing your time and energy levels or balancing a lot of plates, because you have time in the day that’s just spent on staying well, it’s harder to just take an extra plate and say I’ll do that this evening, because you’re in bed this evening.” (Female, ECR, Health Research, Physical disability or health condition)

“There is also quite a lot of just assumptions that people will check their e-mail in the evenings or be able to work over the weekend and they’re things that I can’t do. I know there has been things like I have been on a programme committee of conferences and the papers will be out on Thursday and then they want the reviews in by Monday thinking they are giving us 4 days. I think I once even had one where the reviews were due Sunday and I was like that is not happening. I think one even came out with like Friday I was like I am going to pretend I didn’t even see this e-mail and I will check it on Monday.”

(Female, Mid-Career, Biology, Physical disability or health condition)

A further assumption within the culture of STEM that could negatively affect disabled scientists was the view of the normal academic working pattern as full-time, with part-time working being perceived as an aberration. For some participants, their condition meant that full-time working was not possible, and being able to work part-time provided the flexibility to continue in their careers. However, this was not always well received by employers:

“A lot of the jobs, that I have applied for I have said I can only work part time, so I will often apply for a full time role, on that basis and say this is my situation can I do this on a part time basis, and don’t even get a response back to some things. So, yes that has definitely been a problem.”

(Female, Mid-Career, Health Science, Physical disability or health condition)

For one individual who had not disclosed their disability, their condition meant that they had taken the decision to work part-time. Higher rates of disclosure are consistently seen amongst those working part-time, presumably reflect this. They recognised that being supported to work more flexibly would be helpful:

“I work part-time currently. If people knew about my condition, they might consider how my schedule might impact on me. I am actually really good in the mornings but I’m not so effective in the afternoons. If my 4 days could be more flexible and perhaps being able to work from home one day a week would help.”

(Female, ECR, Applied Health Research, Physical disability or health condition)

The assumption of full-time working patterns as the norm meant that others were very resistant to switching to part-time working, instead managing to secure agreements which meant that they could work flexibly instead. Being able to work from home on a regular basis and having

flexible work patterns enabled some participants to maintain full-time employment, but meant that periods of rest could be incorporated into the working week:

“I work very, very flexibly. My Fridays are usually working at home now and working at home can include an entire day of sleeping and I am still working. I refuse to go down to part time because my faculty is completely useful at managing its part time people and as far as I can see the majority do a full time load and get paid less. So, I refuse, until I am done for capability I am not going down.”

(Female, Mid-Career, Health Research, Physical disability or health condition)

“I arranged flex time so I have half a day off a week, I work for full time in that and I can take a week off during teaching weeks which I just desperately need because otherwise I just kind of get zombie like.”

(Female, Mid-Career, Biology, Physical disability or health condition)

These experiences indicate the need for more flexible approaches to work in order to support disabled scientists to continue in their careers. Beyond institutions offering part-time and flexible employment contracts, funding bodies could also consider how allowing grants to be undertaken on a part-time basis may contribute to a more inclusive culture in STEM.

Whilst some participants felt academic STEM had the potential to be an inclusive environment, some aspects of research culture, such as increasing expectations of networking and public engagement work, posed barriers – especially for those who were neurodiverse. Further, assumptions of full-time working patterns as the norm, and the expectation of working outside normal working hours was difficult for disabled scientists who often needed to work more flexibly in order to successfully continue in their careers. The need to publish significant numbers of research outputs and sustain periods of productivity to meet expectations of employers and funders - particularly in context of the REF - was also experienced as challenging. Though contextualised REF submissions were helpful in allowing disabled scientists to participate by submitting a reduced number of outputs, the metrics used were viewed as not entirely fit for purpose. Further, it is important that contextualised submissions are normalised in order that individuals do not internalise discourses of inadequacy. Research funders, institutions and research leaders have important roles to play in improving these aspects of research culture to make it more inclusive for disabled scientists.

5.2. Institutional support and accessing adjustments

In terms of the visibility of disabled scientists, the majority of participants were unaware of any activities undertaken by their institutions to celebrate disabled scientists, though a couple of individuals mentioned the presence of disability staff networks and some one-off events relating to UK Disability History Month. Whilst some felt that anything which increased the visibility of disabled academics was helpful, not all participants were sure they wanted their institution to focus on this:

“It would be nice to see [disability in science] celebrated but at the same time I feel that that could also be a tiny bit shallow, and by that I mean it is great to just uphold something as good but if there are no practical changes then this is kind of pointless...what is going to make me stay in academia is whether someone pays me

to do research, it is not whether someone says being a disabled researcher is great and then does nothing else about it.”

(Female, ECR, Physics, Physical disability or health condition)

“I am not sure we should be celebrated – I consider myself as a good scientist and would prefer to be judged on that.”

(Male, Mid-Career, Chemistry, Physical disability or health condition)

In general, there was a feeling that simply celebrating diversity was not as helpful as concrete actions institutions could take to improve working conditions for disabled staff and students:

“They make a big hoo-ha about diversity – they are really proud of their attitude to diversity, but they are rubbish. We have a very new campus and students in wheelchairs can’t reach to activate the doors and gates and it’s humiliating because they have to ask others. This has been going for a year – nothing has been done. Some have to travel in the goods lift because other students occupy the main lift. It’s even more difficult for those with invisible disabilities because no one wants to talk about it because it’s messy.”

(Female, Mid-Career, Psychology, Physical disability or health condition)

Further, some expressed concerns about a perceived tendency of universities to talk generally about diversity rather than addressing the particular concerns of marginalised groups, including disabled staff, but also women and LGBT staff:

“They generally exhibit a performative, superficial approach to inclusion and diversity, except perhaps for their LGBT+ stance which seems more genuine.”

(Male, Senior/Late career, Neurodiverse)

In terms of accessing support and adjustments, there were a wide range of both positive and negative experiences. Whilst there were instances of discrimination, there were also a number of accounts where reasonable adjustments had been secured and which had made a significant, positive impact to individuals’ experiences. One example of this was an individual whose manager had been very supportive when the department was moved into a new workspace, taking time to consider the impact on her:

“They look out for situations that might be difficult for me – they understand my need for routine like when we moved offices my department manager videoed the office space so he could show me what it actually looked like, things like that minimise stress. For him, it wasn’t a hassle, it was just something he did because he knew that it would be easier for me. My department do things that enable me to thrive.”

(Female, Mid-Career, Psychology, Neurodiverse)

Other positive experiences of adjustments included support in accessing helpful technologies:

“I now use an online work planning tool called Notion as a way of bringing all of my tasks together. It helps me to organise all aspects of life – its literally been life changing.” (Female, ECR, Computer Science & Design, Neurodiverse and mental health condition)

Further, an important adjustment for some was a reduction in teaching load. Taking on a full teaching load could be challenging, particularly for those with chronic conditions, and thus this adjustment could make a significant positive difference:

“After I teach I am really wiped out and really, really tired and sometimes...this term I have been less well and so sometimes I am in the lecture and I am just so, so I have struggle with fatigue. I have trouble putting words together, so it feels very much like being extremely sleep deprived which means I have trouble doing anything else. But my department has been very nice, and they have let me not have me teach as many lectures as I am supposed to and so I am still working full time but I am doing other things so I have a bit more admin responsibilities than I would normally have at this stage but then I am lecturing one less module.”

(Female, Mid-Career, Maths, Physical disability or health condition)

Whilst securing a flexible working pattern was another helpful adjustment which was secured by some, one participant highlighted the expectation of employers that individuals would still undertake a range of academic duties, which could be challenging:

“I think sometimes universities are great at saying ok yes we will be flexible and give you part time work but the range of activity they want you to do in that time is still pretty much the same they just want you to do perhaps less of it. But you know they want you to be on committees, and they want you to do a bit of teaching and they want you to do all this variety of stuff, I find that yes, that’s really challenging it’s kind of like I can’t get around to do lots of different things so physically I feel a bit held back in that regard.”

(Female, Mid-Career, Health Science, Physical disability or health condition)

Despite the success that some participants had in accessing support and securing reasonable adjustments, this was not consistent across the interview sample. Some had much less positive experiences of requesting similar adjustments:

“Working in a big open space with lots of other people is a nightmare for me. I cannot focus, the noise annoys me a lot. I use headphones with music but that can difficult because I have to listen to music from 9 to 5. I asked to be moved still no response – people don’t understand the condition really. I didn’t ask for anything else because I didn’t know what other help they might or could give me. I wonder if it is because I am there a day and a half only – maybe it is not taken seriously.”

(Female, Mid-Career, Geoscience, Neurodiverse)

“When bulbs go that’s really dangerous for me – it can trigger a seizure but if I point out that a light is going there is no sense of it being important to put right – the culture is not disability orientated.”

(Female, Mid-Career, Psychology, Physical disability or health condition)

Further, not all participants were able to secure the adjustments they needed. One particular difficulty raised was the lack of technicians or interpreters with specialist scientific expertise. This challenge was also noted by two of the experts interviewed as part of this research, who acknowledged the difficulty for disabled scientists in accessing appropriate personal support,

such as a PA or assistant, who was able to provide the level of relevant expertise in STEM required to conduct experiments or convey precise terminology. This meant that those who might have benefited from support of this kind were unable to access it:

“There is no such thing as interpreter support for the chemistry research I do. I have tried many aids – interpreters, notetakers, palantypists – they are basically hopeless.”
(Male, Mid-Career, Chemistry, Physical disability or health condition)

Accessing equipment could also be challenging, particularly when individual members of staff were given responsibility for overseeing the procurement process and were not perceived as approachable or supportive:

“I went to my manager and I said my chair is dying is it possible to get a new one, but then it just became a huge fight because the person in charge of ordering equipment kept making you try all the old knackered chairs that everyone else had thrown away. I don’t know why. I think she had a real personal chip about it or something because it wasn’t just me that she did this to, it was everybody. So if you have an issue, after going to occupational health then you kind of have to go through all the old equipment before you are given some new equipment...she just seemed to put barriers up all the time. And when I went to see her to talk about it she would tell me about all her own medical issues and her own problems and that she just got equipment herself and didn’t see why we, well she didn’t say overtly didn’t see why we needed equipment but it was implied.”
(Female, Mid-Career, Health Science, Physical disability or health condition)

This account highlights how institutional processes for accessing support as a disabled member of staff were often not clear or transparent, with the potential for access to reasonable adjustments to be compromised by the attitude of the individual approached.

Indeed, often informal rather than formal adjustments were secured through disclosing to an approachable individual, with supportive line managers often being crucial in accessing the required adjustments. However, this meant that disabled members of staff felt that their adjustments could be threatened by changes to staffing arrangements, meaning more formal (often perceived as intimidating) requests would have to be submitted:

“Within university settings your relationship with your immediate management team has far more relevance to you than any institutional level policies or documents or otherwise. I have been very lucky with the people that I have worked with who have usually been able to allow me to work as flexibly as I have needed to and that sort of thing.” (Female, Mid-Career, Health Research, Physical disability or health condition)

“It is just basically based on the head of school agreeing to it and I think if I got a head of school who didn’t want to agree to it, I would have to but maybe I could just put a little flexible working request directly in through HR but they might request an occupational health assessment which hopefully would not find I couldn’t do my job.”
(Female, Mid-Career, Biology, Physical disability or health condition)

Inconsistencies in the institution's approach to funding reasonable adjustments could lead to disparity in the experiences of disabled staff across departments, with some confusion as to whether department funds or Access to Work funding should be drawn on:

“Each department handles people with disabilities different. There is not really a standardised policy which is not great because one person in one department could get treated really poorly and another one really good. It is not uniform across the university, so it is very difficult to then get advice from other people because they don't know how your department does it so actually it gives the people who order stuff huge amounts of power because they can essentially do it how they like. They didn't want me to go to Access to Work...they said they would rather spend the departmental money which meant I couldn't, I didn't have anybody battling for me really and it meant I was really limited to the amount of money I could spend.”

(Female, Mid-Career, Health Science, Physical disability or health condition)

For the majority of participants, the process of securing support and reasonable adjustments was not straightforward. There was often low awareness of where to go within institutions for advice or support, with confusion around the reporting process between line managers, occupational health and HR. The additional labour and time involved in negotiating these processes could be burdensome:

“It should be easy and transparent where to go for support and also the information should evoke a confidence that disclosure and seeking support will be met be a positive response. The waiting time for occupational health is pretty high and it's tiring when you have to repeatedly state your case, going back to occupational health and asking for adjustments again and again.”

(Male, Senior/Late Career, Environmental Science, Physical disability or health condition and mental health condition)

It was felt that for the most part, the onus was on the individual member of staff to request exactly what they needed, rather than a range of possible options being offered. Within expert interviews, the issue of a more proactive approach from institutions was also raised. Experts highlighted that publishing guidance as to the range and type of possible adjustments available for disabled staff would be a key improvement that institutions could make to their support for disabled staff, facilitating disclosure and making the process more straightforward for individuals. One interview participant indicated how this could work in practice:

“After being accepted I sent them an e-mail going like hey can I have a monitor arm, and they immediately directed me to the one of the administrators who ordered it for me. So, but it was the, the initiative was on me was the impression I had and so, it could be nice maybe to extend, to have a more formal if you ticked a box maybe someone can just send you an e-mail saying hey you ticked this box, can we help you.” (Female, ECR, Physics, Physical disability or health condition)

There was a general perception that institutional provision of support for students was far greater, more comprehensive and easier to access than for staff:

“Access to support is easier for students. For staff, support is not all in the same place but scattered across the campus – the disability office, the building manager’s office, various support offices etc. For the students it is a one-stop shop. The two disability functions don’t talk to each other.”

(Female, ECR, Computer Science & Design, Neurodiverse and mental condition)

Some noted the irony of the expectation that as academics they would accommodate a range of adjustments for students, whereas securing reasonable adjustments for themselves as staff was much more difficult:

“I don’t even know how many people are over in student support, it is 30 or 40 people and we have one person. I mean we do have quite a few, you know we have got something like 8,000 students but we also have 1,800 staff and so the ratio is quite off. And you are expected to provide accommodations for students basically no questions asked and do it and you talk to the experts about what accommodations do I need to give and then you listen to them. Whereas for staff there isn’t, there isn’t such a thing it is kind of everybody for themselves.”

(Female, Mid-Career, Biology, Physical disability or health condition)

Further, it was perceived by one participant that the provision specifically of mental health support for staff was particularly poor, especially compared to what was available for students:

“As a student, I was aware of them being concerned and signposting the supports. As a staff member, I’ve not been asked anything about any disability – in the research institute they wouldn’t be aware of my disability. I think as staff you are seen as having responsibility for yourself and they leave you to search out support for yourself. I don’t even think that there is any support for mental health for staff members.”

(Female, ECR, Public Health, Physical disability or health condition)

Interestingly, it was evident that some participants had taken on additional advocacy or ambassadorial roles alongside their academic post in order to try and improve support for disabled students, with varying degrees of success and frustration:

“I have privately tried to advocate for improved access for visually impaired undergraduate students through a website and a podcast as well as creating guidelines for conference organisers to improve access for visually impaired people.”

(Female, ECR, Physics, Physical disability or health condition)

“I’m one of the faculty disability co-ordinators so every student with a disability in the faculty comes by my desk. We are always encouraging the students, but I also encourage staff to come to me if they need to discuss anything, but they never do. Recommendations get sent to a higher group, but nothing gets done, it’s pointless. I’m also only allotted five hours a year to fulfil this role, even though there are four meetings a year which are two hours each.”

(Female, Mid-Career, Psychology, Physical disability or health condition)

There were a range of suggestions as to what institutions could do to better support disabled staff. These included the need for better awareness and understanding of reasonable

adjustments amongst line managers and heads of department, as well as the desire for a more proactive approach to providing support and examples of adjustments that could be made, and more support for staff disability networks and for those who were applying for external funding:

“Be more serious about reasonable adjustments. Publish examples of reasonable adjustments. Try to suppress your illogical biases about some reasonable adjustments (for example sole office, nice IT kit) being high-status and reserved for management.”

(Male, Senior/Late career, Neurodiverse)

“It’s not enough to have the policies, the relevant staff need to know that they exist have to feel confident to implement them. It needs to be a core element of LM training.”

(Male, Senior/Late Career, Environmental Science, Physical disability or health condition and mental health condition)

“Provide training for writing bids – how to organise your ideas.”

(Female, ECR, Environmental Science/Professional Services, SpLD)

“There is not a disabled network at either institution I have worked at, but there is a network for everything else. Women’s, BAME, LGBTQ+ and allies. Allies would be great for disabled staff too. I just wish they would put in the same efforts.”

(Female, Non-science academic, Physical disability or health condition)

“Instead of treating disclosure as a requirement for disabled staff to prove that they can still do the job fully, ask what support you could provide and review this every so often.” (Male, Senior/Late career, Neurodiverse)

Participants’ accounts highlight that though some had positive experiences of accessing institutional support and securing the reasonable adjustments they needed, for many, the process of accessing this support was inconsistent and rarely straightforward. This often resulted in individuals instead requesting adjustments informally, which meant relying on the support of an approachable head of department or line manager, causing ongoing concerns that these adjustments might eventually be lost. There were a range of interventions that participants felt institutions could introduce in order to better support disabled staff, largely requiring a more proactive approach to offering support, thus reflecting the approach to providing adjustments for disabled students. Significantly, these included publishing guidelines as to the types of adjustments which could be requested so that individuals could see the value of disclosing, as well as providing training for those in positions of responsibility.

5.3. Access to funding

Many participants expressed a desire to apply for external grants or funding, often highly aware that this was key to their career progression. However, multiple barriers were perceived in being able to engage in applications. These ranged from inaccessible platforms used to host application forms and tight deadlines for applications, to the perceived lack of flexibility in most grants in terms of being able to undertake them on a part-time basis. Related to issues raised in section 5.1, participants were also often discouraged by the need to demonstrate consistent periods of productivity, which was more challenging for disabled scientists.

As well as these broader issues, one participant indicated that the types of research that funding bodies chose to fund could pose a barrier for disabled scientists from engaging with grant applications, noting that the history of some scientific research (particularly medical research) was often discriminatory and ableist in its aims. This individual indicated that witnessing research of this kind continuing to be funded was problematic:

“Stop funding research with a eugenics driver. There are several groups holding large grants to find biomarkers for autism with an explicit application in foetal screening. The largest global autism-specific research charity has recently removed a public aim to eliminate autism from our species but has not reduced its funding for this line of research. This work is distressing and offensive to most autistic people.”

(Male, Senior/Late career, Neurodiverse)

Beyond this, similarly to views of the types of support that institutions could offer disabled staff, it was felt that funders should provide clarity on the types of adjustments that might be available within the application process, but also within the grant application itself. Individuals indicated that there was a lack of overt inclusivity of funders, meaning that the onus was on individuals to request adjustments. Publishing guidelines which highlighted the sorts of adjustments that would be possible was felt to be a key way of encouraging applications from disabled scientists:

“Be more explicit about the type of support they can offer. Having discretionary funding for applicants who need additional support to mitigate a disability. Being explicit that extensions are possible. It’s a point of equity. It’s about removing barriers because weirdly – its makes it easier for everyone.”

(Female, ECR, Professional Services, Mental health condition)

One practical way of removing barriers to the grant application process for disabled scientists was considered to be ensuring that all application forms, websites and online systems are accessible, as some were found to be challenging to navigate:

“It would be helpful if it was clearly stated that adjustments were available if needed and there were clear formats and forms. It can take me half a day just to get it in a format I can deal with.”

(Female, ECR, Environmental Science/Professional Services, SpLD)

“We need websites to be accessible, I have seen some of the funding websites have tiny font that nobody can read. The language is terrible.”

(Female, Mid-Career, Health Science, Physical disability or health condition)

A common issue raised by participants which posed a considerable barrier to many was the pragmatics of applying for grants which had fixed, short deadlines for applications to be submitted. This caused difficulties particularly for those with chronic conditions and were particularly challenging when deadlines coincided with periods of ill health, or holiday periods which were often spent recuperating from term-time:

“Short deadlines and dates which clash with Christmas and Easter for example, for submitting proposals can be particularly challenging. People with a disability may

simply need more time to put these applications in. Allowing submissions in different formats – e.g. a video application.”

(Female, ECR, Professional Services, Mental health condition)

A number of participants also noted the negative impact that short deadlines could have on those with caring responsibilities, likely to be women:

“I see grants with a very short time frame and that's just not possible for anyone who has a health problem or even a child. This gives an advantage to those people that can turn around things quickly.”

(Female, ECR, Health Research, Physical disability or health condition)

“Firm deadlines are really not great either for disabled applicants or for applicants with young women, for women who might have children. My understanding is ECSRC does not have deadlines anymore. So it means that when you do have the energy you can write it and submit so I think this kind of flexibility although I have not managed to do it yet, knowing that whenever I am ready I can just submit is a bit freeing.”

(Female, Mid-Career, Maths, Physical disability or health condition)

Changes to grant processes which allowed more time for applications to be submitted, particularly which enabled applicants to submit proposals at any time, on a rolling basis rather than before a fixed deadline, were considered to be a useful way of supporting disabled scientists to apply.

The possibility of introducing more flexibility into the ways in which grants could be taken up was felt to be a key improvement that funders could make. Potential changes such as offering the option for individuals to undertake a grant part-time, or to pause funding during periods of ill health (something perceived to be particularly important for those with mental health conditions), were amongst suggestions made by participants:

“I think there are way too few grants for part time, some of them have an option. Dorothy Hodgkin fund is the only one I know of that officially advertises flexible options which makes it highly competitive. You are competing against non-disabled people. Grants should be available to encourage disabled scientists to apply.”

(Female, Professional Services, Physical disability or health condition)

“We need part time allowances. I know that NIHR has got better, and they have recently changed their fellowships so that you can now do them on a part time basis but prior to that I think it was much more you had to request it rather than it just being the norm that it was fine.”

(Female, Mid-Career, Health Science, Physical disability or health condition)

“If someone goes off because of a kidney infection, everyone understands. EPSRC now pays sickness benefit. But I wonder how much sympathy mental illness issues attract.” (Female, ECR, Professional Services, Mental health condition)

“I think that mental health issues is probably an area that does need help. One thing that would be useful in that area would be to be able to pause, take time out without that having a detrimental effect on your funding and the length of programme.”

(Male, ECR, Medical Science, SpLD)

Further, it was considered that funders could make available additional funding for disabled applicants who required adjustments which incurred extra costs, such as additional funds for travel, specialised equipment or support. Yet from wider conversations with funders, it was evident that there is a lack of clarity as to whether these additional costs should be funded by the university, as the employer, or the funding body. Participants felt that there could be an option within applications themselves to include a line in the budget for expenses relating to necessary adjustments, or funders could ring-fence a separate budget for this, which applicants would be able to access as needed:

“I have never asked for more travel money even though I know I need it. You know I have never tried that one on, and that is partly because I don’t want to draw attention to it, I don’t want to, I think you know I would have been embarrassed to have a line in the travel funding saying this may seem a lot but it is because I need it because I am disabled, because I wouldn’t have wanted to draw attention to that and maybe that’s bad, maybe I shouldn’t worry about that.”

(Male, Senior/Late Career, Environmental Science, Physical disability or health condition)

“It should not be a component of is this grant application a good value for money...it should allow diversity of what you are using it for, so they should accept that BSL interpreters, there is only so much you can get on access to work and they won’t necessarily travel with you and all the rest of it for free and stuff. But if you need a carer, if you need specialist equipment like a hoist or things like that then...there should be some flexibility on that, there should be some quick grab funds for doing that sort of stuff. It shouldn’t all be locked down and detailed into a grant, that actually is stupid because we would end up having to detail more than we would actually spend.”

(Female, Mid-Career, Health Research, Physical disability or health condition)

Another practical change that it was felt funders could usefully implement was the introduction of an option to add contextual notes within the application, particularly in relation to their publishing track record, to ‘explain’ periods of lower productivity. Participants from all career stages observed the difficulties of being viewed as less successful than their colleagues due to having needed to take periods of absence from work. It was felt that providing an option to contextualise their track record with details of their disability and how this had affected their work, would allow individuals who had needed to take time off or work on a part-time basis, still to be recognised as valid candidates:

“They want to see people on a rising trajectory, and I am not going to do one of those I am just not capable of rising at the speed that they want someone to rise at. You know so things like looking over a longer period and is there a consistent good work as opposed to how many papers have they published in the last 2 years.”

(Female, Mid-Career, Biology, Physical disability or health condition)

“In a grant application they will look at whether I have 15 publications versus someone who has 20 that number, because it is so metricised that number will make a difference. So for example, I have already come across fellowship applications where there was a box saying how many publications do you have, and to me that doesn't, that is a very silly way of quantifying research because someone might have one fantastic publication compared with 3 bad ones for example. So, I think a very rigorous metric punish disability but then you are faced with the problem would you disclose the disability in the grant application so might that bias the panel for example.” (Female, ECR, Physics, Physical disability or health condition)

“It is very hard to be competitive when I simply cannot work the same hours as non-disabled scientists without damaging my health. I have also had several periods of formal medical leave, alongside interrupted working when back at work full time (having to accommodate ongoing scans/tests/appointments/treatments). This can be difficult to quantify. On paper, I simply look like I have been far less productive than my peers.” (Female, ECR, Chemistry, Physical disability or health condition)

“A lot case for funding is based on prior funding applications. That means your track record of receiving money, building a portfolio is important and some of those are travel grants. If you are disabled, travel becomes a more significant outlay or not feasible. There is indirect discrimination there.”
(Male, Senior/Late career, Biology, Physical disability or health condition)

Within the recruitment and selection processes, there were also perceptions that funders could introduce changes which would make the process more inclusive and accessible for disabled scientists. Possible improvements suggested by participants included ensuring that panel members receive disability awareness training and/or training in inclusive selection, in order to reduce potential bias:

“The interview process is still difficult for neurodiversity. Especially because the panel would find it hard to understand, they could easily get you wrong. They should be mindful of track record and how it could be affected by life circumstance, assess grants where you aren't the applicant. There should be training for assessment panel on inclusion, so the panel are considering these things and understanding them.”
(Male, Non-academic STEM role, Medical Science, Neurodiverse)

“Be more generous in the allowances made for those who have disabilities. Instead of only considering formal periods of leave taken, enable applicants to set out periods where their productivity may have been compromised by an ongoing condition. Inform and educate panel members and reviewers about what this means and how this should be accounted for.”
(Female, ECR, Chemistry, Physical disability or health condition)

Participants suggested a range of adjustments which could be made by funders in order to make grant applications more inclusive for disabled scientists. These included flexibility in the way grants could be undertaken, improvements to the accessibility of the platforms used to submit applications, as well as the possibility of allowing additional funds to be made available for disabled applicants who required reasonable adjustments. Once again, participants

generally felt that more could be done by funding bodies to take a more proactive approach to publicising what adjustments could be offered to disabled applicants, i.e. presenting a more inclusive face which proactively welcomed applications from a diverse range of applicants including disabled scientists and demonstrated the flexibility that could be available, rather than putting the onus on applicants to seek out what might be possible.

5.4. Impact on career progression and trajectories

Almost all participants felt their disability or condition had negatively impacted on their career, particularly on their ability to progress. With the benefit of hindsight, and having had longer academic careers, participants who were mid/late career scientists were often more able to articulate the ways in which they felt either their own careers had been affected, or how they perceived disability affected disabled scientists' careers more generally:

"I should now be going for professorial level and going for larger grants, but I now don't have the opportunity to do that. I don't have the level of energy for that. It started catching me in the evenings, I am shattered from the day at 6pm. Academia does mean you have to work 12-13-hour days."

(Male, Senior/Late career, Biology, Physical disability or health condition)

"In my immediate department I have mostly been lucky that I have worked with a trusted colleague for most of my career. While we have gradually shaped the local culture into something collaborative and nurturing, he is very much the public face and got promoted much faster than I did. I'm OK with this, since he promotes my ideas and helps me make contacts with others. I think it does sometimes mean that I am seen within my university as an unoriginal drone who tags onto my starry colleague."

(Male, Senior/Late career, Neurodiverse)

"Moving PhD to post doc is tough but doable. Short term contracts are more common now, it has gone from 3 years to 18 months. They are trying to squeeze into deadlines. Post docs have to waste longer time on applying for the next job rather than focussing on their research. This has most impact on disabilities. It is stressful time. The first post doc is not so bad, but then you are on the mill and it is high pressure. The issue is how competitive it is, the level is negative for anybody who has a reason why they can't compete. Children, caring commitments, disabilities – anything like that, you are fighting for every millimetre. I am not sure how you mitigate that because of the level of competition."

(Male, Senior/Late career, Biology, Physical disability or health condition)

Significantly, though often more senior scientists had mostly managed to develop strategies and achieve career success, some with more recently acquired conditions still struggled and had not ruled out leaving academic science altogether:

"[Institution's] failure to operate and/or follow reasonable adjustments and is making my condition worse and having struggled to keep working for a number of years, it is having a major implications for my mental and physical health. I've reached a position where it's time to spend time on my health rather than on my career."

(Male, Senior/Late Career, Environmental Science, Physical disability)

"I have considered leaving but I truly love my teaching and research. I know I am good at both. My work is a very significant part of my identity."

(Male, Senior/Late career, Neurodiverse)

Some participants described their desire to progress while their good health lasted, but indicated that this generated pressure to reach certain career stages and succeed before conditions worsened:

"I am almost in a bit of a rush to get my career as far as I can while I can. And I don't know if other people feel that way or not but while I feel like, there is that how much can I do now and will it make me worse versus let me do as much as possible so that if I can't do more I am in a more senior place and a place that it is easier to do less in because you have got lots of people working for you, it is easier for you to obtain grants." (Female, Mid-Career, Biology, Physical disability or health condition)

"I haven't been disabled for long enough to consider leaving academia; I still want to persevere and see if I can find a compromise between what I want to do and what I physically can achieve. If this allows me to work at an acceptable level, and my employer is sympathetic, then I hope to continue. If my health suffers and I can't keep on top of my workload, then I will need to consider alternative career options." (Female, ECR, Chemistry, Physical disability)

For those at an early stage of their career, they recognised that how they were perceived by colleagues and funders would have significant implications for their career, particularly for individuals working on insecure, temporary contracts:

"I've never used my disability to take time off of work, even when experiencing significant symptoms. I feel as a young person, this would not be well received by my colleagues among whom I'm still trying to establish professional confidence."

(Female, ECR, Public Health, Physical disability or health condition)

"I feel that I am at a crossroads, if I can't get my own funding then I am not sure how much longer I can carry on in F/T contracts."

(Female, ECR, Applied Health Research, Physical disability or health condition)

It was felt that a further impact of disability on individuals' academic careers was the reduced ability many disabled scientists had to exercise the geographical mobility expected in STEM careers. Experts interviewed alongside participants also noted the difficulty of employers and funders often expecting individuals to have moved institutions multiple times during a scientific career, with the feeling that this indirectly discriminated against disabled scientists who were less likely to have moved around for jobs. Participants indicated a number of reasons for not wanting to move institutions, often due to having secured reasonable adjustments at their current workplace and the fear that conditions elsewhere would not be as positive, as well as the need to stay in secure employment:

“It is kind of known in the department I have had to ask people to do things for me because I just couldn’t. I don’t see myself moving to another institution coming with this baggage and knowing that the department I have now is supportive. I would be really worried about trying it out somewhere else.”

(Female, Mid-Career, Maths, Physical disability or health condition)

“I don’t know who the next head of school will be and because it is an informal agreement I am unsure what is going to happen because I had, I had suggested doing this flexible working arrangement through HR but that requires a change to your contract and none of the heads of school really wanted to change my contract...it makes me more wary of moving. I do really like it here the people here are very nice, but it would make me wary of kind of being a new person somewhere.”

(Female, Mid-Career, Biology, Physical disability or health condition)

“Promotion is not the biggest thing, the getting a permanent contract was the biggest thing and once you have got it you don’t want to move.”

(Female, Mid-Career, Health Research, Physical disability or health condition)

Many early and mid-career participants struggled to envisage how they would embody the ‘ideal’ scientists’ career trajectory, which manifested itself in an individual who was able to sustain long periods of significant research productivity, was highly mobile, and successful in securing large external grants. This could be why rates of disability disclosure appear to be higher amongst those focused on a teaching rather than research trajectory. Participants detailed the ways in which they anticipated their career progression would be, or had already been, affected:

“I am really, really worried about not being able to progress. I really worry about just being a lecturer for the rest of my career.”

(Female, Mid-Career, Maths, Physical disability or health condition)

“I have pushed against being a PhD supervisor for now because if I were to have a very bad year which would mean that I couldn’t support someone else. Now in STEM, they are expecting you to run a team and given my history, I am not sure when I will be ready to do that.”

(Female, ECR, Computer Science & Design, Neurodiverse and mental health condition)

“My inability to be able to work alone is a limitation. Having sufficient brain power to be able to do research, to be able to focus for that long, to be able to put in all the hours...I get very tired, it’s one of the effects of the brain tumour...it isn’t really acceptable in science, you need to have that energy and be always on it. Having time off is frowned upon. Colleagues are able to read through 2 or 3 papers in a day, whereas it would take me a week. My current role does not have this requirement. I don’t think it was fair that I was moved out of my previous role, but I can see their point of view – they have a lot of research to get done and published within a given time but it has pushed me away from research. I feel like a failure as I pictured myself as a career researcher.”

(Female, ECR, Medicine, Physical disability or health condition)

For some, their experiences so far in their careers meant that they had changed direction, either moving away from research into teaching, or a professional services role, or in some cases leaving academic STEM altogether, reinforcing findings highlighted in Sang's (2017) work on disability in the context of academic careers. This pattern was also noted by experts who were interviewed alongside participants, who indicated that disabled scientists were more likely than their non-disabled peers to have changed career focus:

"I have got around networking difficulties by focusing on the things I can do well. I get really good teaching feedback from the students I teach. I have been nominated for Student Choice Teaching Awards. Students have written to my HofD to say how much they enjoy my teaching. The Teaching Fellow route is easier – because the focus is on your effectiveness as a teacher not on how many presentations you have given at conferences." (Female, Mid-Career, Psychology, Neurodiverse)

"I had hoped to be an academic, but in practice I wanted a different career and realised I don't want to carry on. I had realised that 'I don't have the publication record for this', and I could do without the stress and mental health impact." (Male, Non-academic STEM role, Medical Science, Neurodiverse)

"I've gone from being a healthy PhD student to needing to move away from research into technical services due to struggling with the demands of research." (Female, ECR, Medicine, Physical disability or health condition)

"During my first post-doc I got my MS diagnosis, which led to reflection phase where I looked at my career and whether I was happy. I changed career, I probably would have done it anyway but was forced to consider this earlier...It isn't what I thought but with hindsight but the moves I have made have been the right one. My role now is futureproofed. Geoscience work was a lot of travelling, a lot out in the field. Nothing was MS proofed in that world. Knowing the university wasn't accessible and a lot of things I couldn't do anymore. I can now work from home more." (Female, Non-science academic, Physical disability or health condition)

Another aspect of STEM careers which participants viewed as having been impacted by their disability was the possibility of participating in academic conferences, which are important for networking and career progression. Individuals observed the high costs that were required in travel arrangements, the impact of travel on fatigue, and the time taken to organise the necessary adjustments. For some, this meant they were less likely to attend, and indeed some felt unable to participate:

"Networking is vital so research conferences etc would be useful if I could participate." (Male, Mid-Career, Chemistry, Physical disability or health condition)

"Unfortunately, those informal connections have an impact in science. You can't evade that. It is part of human endeavour so it is important, but it is harder and harder for me to integrate. Using a mobility scooter makes you someone who needs to be cared for rather someone who has something interesting to say at a conference. I have pulled back from conferences; the bills rack up and it takes a lot of planning." (Male, Senior/Late career, Biology, Physical disability or health condition)

"I give a lot of talks I go to conferences, I travel a lot and there I couldn't do that...without people who are inviting me being prepared to pay a little bit extra for because trains are difficult if I have got luggage, sometimes there is distances to walk where I would get a taxi you know where they are expecting people to walk. You know lunch will be in such and such a place, and it is just 5 minutes away well that is 15 minutes away for me, to do the distance. So there are things like that, which affect your ability to do the job, which aren't obvious."

(Male, Senior/Late Career, Environmental Science, Physical disability or health condition)

"The additional cost of me going as a person with disabilities is huge. I won't travel by the Easyjets of the world because they have the worst reputation for damaging the kit. I have to have accessible transport, accessible accommodation, and usually because I cannot guarantee even being able to roll down a pavement and have a drop kerb in an international setting, I have to stay at the hotel the conference is at. You know how expensive those are... my additional costs are going that just doubles and triples up etc, so my additional costs of going to conferences internationally I would say it is treble...But there is nothing in most grant applications that allow you to ask for additional separate funds for disability accommodations."

(Female, Mid-Career, Health Research, Physical disability or health condition)

Further, conferences and events could be particularly challenging for neurodiverse individuals, or those with mental health conditions, to navigate:

"I have run off from several conferences when I can't stand the social exclusion and general difficulty and I quite often don't turn up to events when I can't face the social stuff." (Male, Senior/Late career, Neurodiverse)

"The requirement to go to conferences and present is just horrible for me, too many people, so the traditional networking routes are out."

(Female, Mid-Career, Psychology, Neurodiverse)

"It took me 3 years to figure out how to network with people – mostly in very loud bars with a lot of people causing me to have an anxiety attack – so not great. Conferences are super challenging. These things can be challenging for anyone but the challenge it is heightened by disability."

(Female, ECR, Computer Science & Design, Neurodiverse and mental health condition)

As well as broader issues of career progression, participants also noted the ways in which their disability had a practical, everyday impact on their work and lives, which had a cumulative impact on their careers over time. Women in particular observed how having children, combined with their disability had affected their careers:

"I have a son so you can see in my CV a 13 year gap for me being at international conferences because initially I had no energy to do it, and once I did of course I wasn't being invited."

(Female, Mid-Career, Health Research, Physical disability or health condition)

“It has really kind of just limited my ability to do stuff especially after maternity leave... I didn't realise how much rest outside of work I was doing and I now don't have that capability because I now have a child who requires attention...my best working time is the morning but two hours out of my morning are spent getting her to school. Getting her breakfast, getting her to school and that's kind of my prime working time. I try to get up and work an hour, an hour and half before she wakes up but especially in the winter that is really hard when its dark outside...it wasn't until after I had a child and I couldn't sleep as much as I did before that I really realised.”

(Female, Mid-Career, Biology, Physical disability or health condition)

“We have a son and in my previous position in [HEI in midlands] so my husband is in [northern HEI], and I was going 3 days a week to [HEI in midlands] every week, and this was a lot of work for both of us and I didn't stay in [HEI in midlands] despite having the facility to because we couldn't sustain this for our careers so I continued to look for work and I found this position now in [northern HEI] which is closer and we are living together, but the fact that we are not at the same place means that we have put our base in [northern city] because for me the commuting daily would be too much energy and I would be too tired and not being able to work. But it means that I have to do, I have a lot of the parental responsibilities now. Which ideally, we would share, we would be in the same location and have short commutes, but this is just not possible.” (Female, Mid-Career, Maths, Physical disability or health condition)

Further, others at an earlier career stage observed how even in their careers so far they had noted how they lost time and energy simply to managing their condition and developing alternative coping strategies:

“I count how many days I have lost, just going to the doctor or hospital – so that's the frustration.” (Female, ECR, Public Health, Physical disability or health condition)

“There is almost a time cost, and I found this especially when doing my undergrad in that you have to plan ahead a lot more so you have to put in the time to ensure that lecture material and so on is accessible to you and you have to reach out to lecturers, you have to talk to lots of people, prepare exams and so on and that time you spend doing that is time you could have been studying or socialising and so on, so there is a time cost and I think my research for example I probably read a bit slower than others. I haven't found that it makes a massive difference yet but in the long run in say 20 years, the number of research papers someone else can get through it probably adds up.” (Female, ECR, Physics, Physical disability or health condition)

These accounts highlight the various barriers faced by disabled scientists in progressing their academic careers, allowing insight into the factors which affect disabled scientists' academic career trajectories.

5.5. Summary

Attending to the career experiences of participants has generated a range of insights into how disabled scientists face particular challenges within STEM academic research culture, and in accessing institutional support and external funding, which had an impact on individuals' career trajectories. Disabled scientists reported finding the competitive environment of academic STEM difficult in terms of the underlying assumptions about academics' working practices

based on expectations of consistent, significant levels of research productivity, the successful accrual of external research funding, the expectation of full-time working patterns and regular presence at conferences and networking events. It was evident that whilst some participants had successfully managed to secure the adjustments that they needed in their workplaces, for the majority negotiating access to institutional support was not straightforward and often there was little faith in formal reporting processes, with individuals being more likely to ask approachable line managers for informal adjustments instead.

It was felt that both institutions and funders could be more proactive in terms of developing measures which would better support disabled scientists. These included the need for better awareness and understanding of reasonable adjustments amongst line managers and heads of department, as well as the desire for a more proactive approach to providing support and examples of adjustments that could be made, and more support for staff disability networks and for those who were applying for external funding. In terms of funders, a range of adjustments, such as flexibility in the way grants could be undertaken, improvements to the accessibility of the platforms used to submit applications, as well as the possibility of allowing additional funds to be made available for applicants who required reasonable adjustments, were suggested in order to make the process of grant applications more inclusive for disabled scientists.

In the next section, we present our analysis of interview data which provides insights into how these issues informed participants' experiences of disclosing disabilities, exploring the factors which affected disclosure of disabilities to employers, colleagues and funders, including the factors which facilitated or acted as barriers to disclosure.

6. Disclosing disabilities

In this section, we present our analysis of participants' experiences of disclosing their disabilities, as well as considering the factors which affected individuals' decisions about whether or not to disclose, including any barriers or enablers to disclosure.

6.1. Experiences of disclosure

The vast majority of interview participants (n=24) had disclosed either formally to their employer, informally to colleagues, or both. A small number (n=5) had chosen not to formally disclose their disability, instead disclosing only to selected colleagues. These participants were either neurodiverse, or had a mental health condition, SpLD or chronic condition, and their reasons for not disclosing more formally were largely related to concerns of being discriminated against, either by potential or current employers:

“Sharing with a colleague means they will understand if I have a misspelling or something has wrongly autocorrected in an email or something like that. Colleagues know you, they know your work and worth. If you disclose to an employer like in job applications...it may be a misperception, but I don't want anyone to misunderstand. They don't know what I am capable of and I don't them to see me as being less employable. I have never disclosed I am dyslexic because I don't feel it has impeded me and I'd want to avoid giving someone who doesn't necessarily understand what it means and overlooking me when they are looking through hundreds of applications. I don't want to give them a possible out or a possible black mark.”

(Male, ECR, Medical Science, SpLD)

Of the majority of participants who had formally disclosed (n=19), only around a quarter (n= 5) had positive experiences of disclosure, with supportive responses from those involved in the disclosure. Being able to request and obtain reasonable adjustments, such as flexible hours, were perceived as key benefits of disclosing:

“I disclosed after my application was successful, to my line manager who was very supportive. He said that I should have a single office and also gave me the option to ask for specific time slots for classes which was helpful. For me if I have had 2-3 weeks when I am not doing well, I know that I won't meet deadlines and it just seems easier to disclose rather than to let people think that I'm incompetent.”

(Female, ECR, Computer Science & Design, Neurodiverse and mental health condition)

Interestingly, of those participants who had the most positive experiences of disclosing their disability, two were no longer working in academic roles. Thus, their positive experiences of disclosure had taken place largely in other contexts:

“I have always been open and honest about my disability. I have been able to discuss it with my employer, and over the past three or four years I have shared more. More from going through a difficult time, I felt like I had to. I had to ask for further adjustments. Your age says a lot about what you disclose, too. Now things are becoming more recognised, now it is flavour of the month it is easy to discuss without the stigma. I think as I have got older, I see it as a great attribute.”

(Male, Non-academic STEM role, Medical Science, Neurodiverse)

“In my past job, I didn’t disclose for two years. It was really because I was managing it quite well. Then it got difficult in my personal life. It became more of a necessity. I wished I had disclosed it sooner because it was a really positive response from them.”
(Male, Non-academic STEM role, Engineering, Neurodiverse)

Experiences of disclosure appeared to vary considerably across institutions. A number of participants contrasted the different experiences of disclosing at their current institution compared to past institutions at which they had worked. One individual described moving from a STEM academic post into an academic role in another discipline at a different institution, observing the significant difference in the reaction of her previous PI with her current line manager to her disclosure:

“My previous PI was not supportive, didn’t know about rules and regulations, reasonable adjustments, nothing. He didn’t want to educate himself, neither did the University encourage him to. When I got the offer, I talked about it openly and encouraged questions. I was starting treatment soon. He said your illness is your problem. The next thing was I had hospital appointments, I would leave a bit earlier. He would say I hope it isn’t serious. I would tell him what they were, but he wasn’t really interested... He couldn’t understand working at home adjustments or travel. One adjustment example was for long haul flights I would get an extra leg room seat, I struggle with my legs and not being able to sleep. Someone else implied I was getting favours. I had to do a lot of work to educate others. I was surprised by HE, how ignorant and unwilling they were to do that. It was a shock. Now to contrast to that, my first day here the equipment I had asked for wasn’t there. They hadn’t told my manager about the details, she said what do I need to do to support you. She was really warm and brilliant ever since...There are supportive people out there, but they are few and far between.”

(Female, Non-science academic, Physical disability or health condition)

For the majority of participants who had disclosed, experiences of disclosing their disability were not straightforward. Those who had worked in other employment sectors expressed surprise and disappointment at the lack of awareness and understanding they encountered in seeking support after disclosing disabilities:

“This was the first job where I’ve disclosed my disability to my employer. Disclosing in the private sector is a very different story, I thought that it might be a reason not to get a job whereas when I got a job with a university, I actually thought they’ve got rules about this kind of thing and they actually have to stick to them. But there was no response at all – nothing from HR. My supervisor knows because of my research but there has never been a conversation about is there anything you need, or I can help you with, or does this hold you back in any way.”

(Female, Mid-Career, Psychology, Physical disability or health condition)

This account, as well as the one that follows, indicates that particularly when disclosure involved more formal reporting to HR at institutions, there was often a lack of clarity in the process of requesting and securing reasonable adjustments, which could cause distress and concern:

“Disclosing to my employer has been frustrating and worrying. HR referred me to their occupational health supplier for an assessment. The occupational health report said that I would be able to continue in my role if I could retain my own room. The employer has not responded to this in two years, so I worry that perhaps they would find it less trouble to get rid of me.”

(Male, Senior/Late career, Neurodiverse)

It is perhaps not surprising, therefore, that generally disclosure was only undertaken when considered to be absolutely necessary (for example to secure reasonable adjustments) and seen by individuals as unavoidable. Where possible, participants chose to disclose informally to a line manager/head of department or colleagues, rather than formally, highlighting a wider culture which is not inclusive.

Further, most did not disclose until after they had secured their job and significantly, the vast majority of participants would not recommend other disabled scientists to disclose their disability unless it was unavoidable. This is likely a contributing factor to the lack of senior academic scientists who disclose either mental health conditions or SpLDs, given that these disabilities are not visible. Significantly, of the four senior/late career stage participants (all of whom were male), none of them would recommend others to disclose a disability. One of these participants reflected on his interactions with an early career scientist who he had supervised, who was hoping to secure a permanent position at the institution:

“I had a postdoc who has depression, he started off as a PhD student with me then a postdoc and then he got his own postdoc, an independent postdoc and then he became a lecturer and so on, so his career progressed. He only told me about this depression towards the end of his postdoc when he was going on to this independent postdoc and I said to him well ideally you would disclose this but I am not going to tell you to do it because I didn't know, I still don't know how the head of department that we had then would have dealt with that. Because at the end of his independent postdoc he became a permanent member of staff but that wasn't definite then you know, and I said, I don't know what I would do in your situation...I don't think he did disclose in the end.”

(Male, Senior/Late Career, Environmental Science, Physical disability)

Even those at the mid-career stage perceived that disclosing a disability was to be avoided if at all possible, particularly at the pre-application stage. One participant described how she directly instructed other disabled scientists not to disclose their condition before a formal job offer had been made, in order to avoid any potential for discrimination:

“When I am talking to people, particularly confidentially if they have an invisible disability I say do not disclose. I say, if you need to disclose to get some accommodations to allow you to work well, you do not disclose until you have a signed contract in your hand. You never disclose throughout the entire interview process and then you do and then you ask for a separate interview where you discuss what your access needs are, and you sort out access to work and all the rest of it. But you do not disclose at interview unless you have to. I have gone through various stages of going through a lot of job interviews and I have to disclose, and I know that meant that I wasn't chosen quite a few times you can see it. You could see how scared and ignorant they were about your disabilities and what they would do for you and they just perceived it

as additional work they would have to do... It is regarded as a problem always and never as an advantage.”

(Female, Mid-Career, Health Research, Physical disability or health condition)

There is evidently a significant issue if mid/late career scientists are overtly recommending that more early career scientists do not disclose their disability to employers because of the potential for discrimination. It is likely that this is based on their own previous experiences and perceptions of persistent stigma within the academic environment. Yet the implications of this are that rates of disclosure, particularly of less visible disabilities, are unlikely to change without a significant culture shift. It may also mean that younger generations may choose to avoid a career in which disclosing a disability remains stigmatised, resulting in a loss of scientific talent in academic STEM.

Disclosing a disability was not viewed as a one-off, binary process, but rather was acknowledged to be an ongoing consideration which had a range of implications depending on the context. The need to continually disclose to new collaborators or line managers was challenging, particularly for ECRs who were more likely to have to move institutions more often to try and secure a permanent job:

“When you are setting up collaborations or you are working with somebody and then you have to explain that I can’t get back to you over the weekend. And kind of keeping in my head who knows and who doesn’t it is hard sometimes, it is like who have I mentioned it to already.”

(Female, Mid-Career, Biology, Physical disability or health condition)

“The culture of short term contracts is an added stress because each time you move to a new position you have to start all over again, disclose again, explain it all again and fill out the forms again. You have to go through it every year.”

(Female, ECR, Environmental Science, SpLD)

The challenges involved in disclosure meant that some participants deployed a highly strategic approach to deciding whether or not to disclose to colleagues, collaborators, or potential employers, depending on the potential costs and benefits they perceived:

“I use the term when I need to use it – when I have an issue and I need help – when it’s relevant I will tell them...It’s difficult because it’s about accepting something about yourself and I was not sure what the reaction would be. People generally find disability difficult or uncomfortable to talk about.”

(Male, Senior/Late Career, Environmental Science, Physical disability)

“I disclose when I think it can help me because people really do look at me like I am a circus freak and the amount of explanation needed to describe something so invisible and so personal, it’s just too much work.”

(Female, ECR, Computer Science & Design, Neurodiverse and mental health condition)

6.2. Factors affecting disclosure

When asked what would make it easier to disclose a disability, most participants felt that it should become easier to disclose once a more senior career stage had been reached, and some acknowledged that they had become more confident in disclosing over time:

“I have found it significantly easier to disclose my condition over time. It took me over a year to come to terms with the idea that people might think of me as weak, or not offer me opportunities to collaborate etc because they didn’t want to overburden me.”
(Female, ECR, Chemistry, Physical disability or health condition)

This is worthy of note, as it runs entirely counter to HESA data which indicates that disclosure rates fall at more senior levels, due to very low rates of mental health and SpLD disclosure. However, particularly amongst ECRs, there was a perception that disclosure would be more straightforward once a permanent role had been secured, particularly if the disability being disclosed was a mental health condition:

“I guess as you get more established and more secure in your identity as a researcher it might become easier to disclose.”
(Female, ECR, Health Research, Physical disability or health condition)

“Having security of tenure makes disclosure easier because career path isn’t at risk – particularly with mental health because there is still a lot of stigma associated with it – that you aren’t capable. In the earlier stages of your career, if you disclose that sort of stuff, it follows you around.” (Female, ECR, Professional Services, Mental health condition)

Indeed, many ECR participants who had disclosed were aware of the “*need to bang the drum of behalf of people coming up behind me*” (Female, ECR, Environmental Science/Professional Services, SpLD) and be role models:

“I would like to think that I would go onto keep disclosing it, because also the more of a role model you should maybe expect to be and I would like to, if that is a contribution I can make then I would like to make that.”
(Female, ECR, Physics, Physical disability or health condition)

“A lot of disabled young people still feel like there is no hope, that is why role models are so important. I do a lot work with young people and schools to really highlight it from my perspective.”
(Male, Non-academic STEM role, Engineering, Neurodiverse)

There was clearly a link between the visibility of other disabled scientists and disclosure. Generally, individuals reported being unaware of other disabled scientists in their discipline, which meant that they were not easily able to see others like themselves who had been successful:

“Beyond the department, some people don’t know how to react and find discussing a disability or long-term illness very awkward and challenging. There are no other people in the Department who are “public” about having a disability (I know of no one

else who is classified as disabled), so it makes it difficult to see different ways of managing my symptoms or managing high workloads with finite energy levels.”

(Female, ECR, Chemistry, Physical disability or health condition)

This meant that connecting with other disabled scientists through wider disability networks on platforms such as Twitter, as well as opportunities to meet other disabled academics at conferences, was valuable:

“I have sought out people that I know who have a disability and are still working because at one point I was thinking how am I going to keep doing this particularly as the condition I have is progressive. I was thinking like how am I going to, like at what point am I going to say I can't do this anymore. So, just seeing that other people do keep going and then seeing that other people don't.”

(Female, Mid-Career, Health Science, Physical disability or health condition)

These accounts highlight the importance of role models and the significance of visibility for disabled academics. A lack of role models may contribute to feelings of marginalisation, making it more difficult to request adjustments. It was particularly helpful for ECRs to see that career success is possible for disabled scientists; something also highlighted by experts interviewed alongside participants. One ECR participant described her desire for more senior disabled scientists to be more visible:

“My biggest fear – and what holds me back from disclosing my condition to the majority of my colleagues and collaborators – is that I will be stereotyped and overlooked; that no one will consider the person and they will only see the condition. I don't want to be perceived in that way. If disabled scientists who have well-established careers and are in senior positions could be more visible, that would be a tremendous help in breaking down the stigma associated with having a disability.”

(Female, ECR, Chemistry, Physical disability)

Conversely, witnessing others conceal their disabilities could normalise non-disclosure:

“My PhD supervisor who I saw...dealing with personal struggles...one day somebody said oh well she can't come because of the heat and that will bother her multiple sclerosis, I didn't know she had that you know, so she hadn't revealed it either. So that kind of the role model I had was that you just kind of soldiered on and didn't let people know unless it was essential.”

(Female, Mid-Career, Biology, Physical disability or health condition)

There was some awareness amongst mid/late career scientists that they could also act as role models for early career disabled scientists. Yet despite this, HESA data reveals that disclosure, particularly of mental health conditions or SpLDs, is very low amongst senior academics. Whilst some participants acknowledged their potential to be role models to others, not all were comfortable with this:

“A visible role model is very important, almost like having the language to describe what you want to do. This is now my main reason for being openly neurodiverse. Last year I introduced myself to a junior neurodiverse lecturer at a conference last year.”

When I said I was a neurodiverse professor, he responded, "I didn't know that was possible." As a shy, awkward person, this sort of self-promotion makes me squirm, though." (Male, Senior/Late career, Neurodiverse)

"I don't have any role models. I am the role model. I do what I call a lot of lay teaching as I roll across the campus with my name badge on."
(Female, Mid-Career, Health Research, Physical disability or health condition)

There was recognition that increased visibility of disabled scientists and access to positive role models helped to reduce stigma, particularly for neurodiverse participants:

"Seeing neurodiverse people succeed in any walk of life is incredibly important... Female role models are particularly important."
(Female, Mid-Career, Psychology, Neurodiverse)

"I now think that there is also an ethical imperative. If I can be fully open then I might represent a rare role model to students, PGRs and academics."
(Male, Senior/Late career, Neurodiverse)

The idea of the 'ethical imperative' on more senior scientists to disclose disabilities was echoed by one participant, who felt that not just scientists but those working in senior leadership roles in universities, also had a responsibility to be open about their condition:

"You have to have positive disclosure from senior people. And it is kind of, I am really sorry but one of the things that go with being senior vice-chancellors, pro vice-chancellors, senior research team leads etc, one of the responsibilities that go with that seniority is you no longer have the choice about whether you disclose or not. Actually, you have to because you need to be the role models that everybody needs."
(Female, Mid-Career, Health Research, Physical disability or health condition)

Despite the perceived value of increased visibility of successful disabled scientists, some participants indicated that role models needed to ideally reflect a range of experiences. For female participants especially, it appeared important that role models did not simply represent traditional success stories, reflecting the 'ideal scientist' career trajectory. It was also felt to be helpful to understand the strategies that individuals had developed to achieve career success:

"If we could see role models and people like that working in a more flexible way and that opportunity to work more flexibly that would be really helpful as well, so then you have not only an idea of yes people can succeed but how they succeed, how they make it work that would be really helpful."
(Female, Mid-Career, Health Science, Physical disability or health condition)

"The issue is role models can be used to show ideals. Most of them are more women scientists. All you see perfect life scenarios with happy marriages and kids. I have seen one talk where they were like me. That was someone who had a chaotic career path and life led them. Not the Hawkings, it should be everyday people not just the poster role models. We struggle to find those. Ideals are hard to achieve."
(Female, Non-science academic, Physical disability or health condition)

“Role models are always important to be able to see yourself so I am, as a woman in the Mathematics department I am already in need in of role models who are women in Mathematics departments...I know women who have made it, some of them with families and then I know some people with [condition] who are Professors. I don't know them very well so I don't know if they have made it to being Professors before, after or during, but it is always important to see others that are, that you can identify with.” (Female, Mid-Career, Maths, Physical disability or health condition)

Whilst having role models was perceived as helpful, it was also evident that not all those who were successful were necessarily positive role models. One participant who had left academic STEM described how witnessing the career trajectories of more senior scientists contributed to her decision to leave:

“I can remember looking at the role models above me – they were either professors, very driven without families or partners, or others with families who ended getting up shunted into teaching jobs. I looked at both routes and decided that I didn't want that.” (Female, ECR, Professional Services, Mental health condition)

6.3. Barriers to disclosure

Whilst almost all participants had disclosed their disability either formally or informally, one participant had not disclosed to anyone. They described their various reasons for choosing not to share this information with their employer or colleagues:

“I have fibromyalgia and Graves disease (in remission). Because this disease is not well understood and indeed misunderstood, I do not disclose it. However, it impacts on the energy I have and speed I can complete tasks and therefore has knock on effects in my work. For instance, writing grant applications require working outside of office hours and I cannot do this as I need to rest after work in order to be able to carry out my work responsibilities. This has meant that I have not progressed as I would have hoped in my career. This is also why I work part-time currently. I have had difficulties accepting this 'disability' myself...I haven't told colleagues either as there won't be any benefit, I won't get any support and since I'm on a fixed term contract, I will be in competition with them. I would struggle to think that they wouldn't say something because of the competition in academia.” (Female, ECR, Applied Health Research, Physical disability or health condition)

As well as not seeing any 'benefit' to disclosing her disability, reflecting the idea of disclosure relating to a cost/benefit analysis, it is clear that for this participant, the need to compete with their peers for a permanent contract is a major factor contributing to their decision not to be open about their disability. This demonstrates the significant impact of insecure employment on disclosure. The perception that decisions about disclosure were made alongside the fear that knowledge of their disability could be used against them by others, was echoed by another participant:

“It is competitive isn't it and anything is weakness so, I don't think everybody is like that but certainly in my lab, when I was doing the PhD there and you are going on and being a research fellow, in Psychology my God anything that you could reveal that somebody else might use as a sort of stepping stone to get past you would be

valuable to them. I certainly know there were people that I did my PhD with and worked with who had certainly mental health disabilities that they did not disclose."
(Female, Mid-Career, Health Science, Physical disability or health condition)

One female ECR described feeling more discouraged from disclosing her disability as a member of staff, compared to when she was a student. She indicated that as a female disabled scientist she would be more concerned about potential discrimination when applying for academic jobs:

"It didn't feel risky as a student, but now it feels more risky. When I am a young professional doing a consultancy that feels fine but if I were to apply for a job at a research institute and I was really hungry for that kind of position where you have that security, it would feel more risky then because being a woman with a disability – people might have the expectation that you will have more time off."
(Female, ECR, Public Health, Physical disability or health condition)

Indeed, stigma about disability and the fear of being stereotyped or discriminated against was a significant barrier for participants:

"I know that it will affect how people see me (whether consciously or not) and will potentially affect my ability to be involved in large scale collaborations or projects."
(Female, ECR, Chemistry, Physical disability or health condition)

"It is very difficult for anyone not to notice my disability. I don't declare it if I can help it. All it does is make people treat me as someone to avoid."
(Male, Mid-Career, Chemistry, Physical disability or health condition)

"I don't think that I would encourage anyone to declare before an interview or as part of an application process particularly if the disability is going to be visible to the people selecting. I might be entirely wrong, but I just see it as being sensible to keep that information to oneself. I think it could prejudice the decision."
(Male, ECR, Medical Science, SpLD)

The persistence of social stigma, particularly in relation to mental health conditions, meant that many participants felt that disclosing this type of disability would be very difficult, especially for ECRs in insecure employment. However, HESA data suggests that more senior academics, too, find it difficult to disclose these types of conditions. This supports existing reports which suggest that academics find it particularly challenging to disclose mental health conditions (ECU, 2014³⁸). Participants described the barriers they perceived individuals with mental health conditions encountered in academic STEM:

"There is a lot of ableism, some people can't be scientists is the view. I have had PHD students being told that if they have dyslexia or mental health issues, that they aren't strong or resilient enough for the career. They give the implication that mental health is a weakness and that people with dyslexia shouldn't be scientists."
(Male, Non-academic STEM role, Medical Science, Neurodiverse)

³⁸ *Understanding adjustments: supporting staff and students who are experiencing mental health difficulties*, Equality Challenge Unit, 2014

"I think the disclosure issue is significantly more of a problem for people with mental health problems. Because there is even less education, one of the problems with disability and discrimination of any sort I suppose, but with disability is lack of appreciation or lack of awareness, lack of education and that was the thing that the committee pushed, for the university to improve, you know some people now have to go on don online courses where they are asked about all aspects of diversity including disability. But our ignorance is greatest, I am including myself here, ignorance is greatest I think in terms of mental health issues."

(Male, Senior/Late Career, Environmental Science, Physical disability or health condition)

"There is still stigma, particularly around mental health. It is getting better though. You are seen as a minority, it isn't recognised how it can affect your productivity. How difficult it can be to do things others find easy."

(Male, Non-academic STEM role, Engineering, Neurodiverse)

Beyond perceived stigma and the potential for discrimination, a further factor which could prevent individuals from formally disclosing a disability was having had negative experiences of disclosing to employers or line managers in the past:

"My experience with my previous line manager put me off disclosing. I didn't feel that anything would come out of a conversation. I would have filled in the form when I applied for Daphne Jackson if I had felt that something would happen."

(Female, Mid-Career, Geoscience, Neurodiverse)

This was particularly the case where individuals had had difficult encounters with more formal institutional processes, such as HR. One participant described being told by a HR professional that if she had a formal assessment, it might result in her being deemed unable to fulfil the requirements of her role:

"I talked with my head of school who then sent me to occupational health which was not a good experience at all and that frightened me quite a bit. We had a discussion because one of the things that would help me because part of my issue is with blood flow, and if I can have my feet raised then I don't get as tired, so they said maybe you know we could get you a special stool or a sofa or something for your office so your feet can be up and so go to talk to occupational health they can probably you know do something...So I went there and you know she just kept repeating well we could do these but it might, it might show that you can't do your job. I was like I have been doing my job for 10 years now and maybe I don't want one of these and my head of school said ok yes you can buy a sofa for your office out of your funds, that's fine, so I just did that instead. So that made me a bit wary of the official processes."

(Female, Mid-Career, Biology, Physical disability or health condition)

Thus, the fear of institutional procedures being used in a way which was punitive, rather than supportive, was likely to result in individuals avoiding more formal disclosure and reporting processes.

An additional barrier to disability disclosure was the lack of clarity in who would have access to data if individuals did disclose. A number of participants described being unsure of how the data would be used and what the possible implications would be, acknowledging that a significant part of the reason they decided not to disclose was their fear of any possible negative consequences which might affect their career:

“I made a lot of applications to jobs and I never told anyone at that stage. Only at successful stage. At the time, there wasn’t adjustments necessary and didn’t know what was coming either, it was an unknown whether it would affect me in my career. I was also aware about the competition, I didn’t want to disclose anything which might have an impact. A lack of trust in the application process might be accurate but it was pragmatic view.”

(Male, Senior/Late career, Biology, Physical disability or health condition)

“I definitely remember sitting there and trying to decide whether or not to click the box. I didn’t know what consequences it would have. I didn’t know that I deserved the additional things they might offer me because my condition is mostly well managed.”

(Female, ECR, Public Health, Physical disability or health condition)

One participant who had not formally disclosed also acknowledged the lack of clarity in understanding how disability data was collected and monitored, describing her uncertainty in knowing who in HR might have access to this information:

“When REF came around I asked him [line manager] should I put in for REF special circumstances he was like well it is up to you but it might be useful, and so I did that and then in that process I engaged with a single HR person and she was like yes you can just click the disabled thing and so she also knows but I don’t know who else in HR knows... So I don’t know what has officially been disclosed so maybe that is official I don’t know.” (Female, Mid-Career, Biology, Physical disability or health condition)

These accounts underline the need for far more clarity from institutions about how disability data is recorded and used, given that this appeared to be a significant barrier to disclosure. A more proactive approach, in terms of publicising the ways in which disability data is used, combined with steps to provide support such as referrals to occupational therapists, may provide reassurance to those considering disclosing a disability.

From analysing participants’ experiences of perceptions of disability disclosure, it was evident that the additional time and energy involved in disclosing their disability or condition to employers, colleagues or collaborators was not an insignificant factor in individuals’ decisions about whether or not to share this information. Participants highlighted how this additional labour contributed to fatigue, and often required them to navigate ableist attitudes:

“It is a lot of disclosing, explaining and educating others on top of doing your job. Not just colleagues but everyone. I use a ‘please offer me a seat’ badge at a conference, everyone asks why have you got that badge, what does it mean instead of talking about your research.”

(Female, Non-science academic, Physical disability or health condition)

'I just don't want to get into it – they want to know what you have and why you have it...it's exhausting sometimes.'

(Female, ECR, Public Health, Physical disability or health condition)

Academics in disability studies refer to this additional work as 'crip work', a term which one participant draws on to describe the barriers that disabled academics face to disclosing a disability. One participant outlined how engaging in this additional work can be particularly challenging for those with mental health conditions, which may mean they feel unable to disclose their condition:

"You have to be incredibly confident and assertive to ask for your rights and make sure that you get them and that sort of thing and it is a lot of work and particularly if you are struggling with the mental health aspects, that can be beyond what you are capable of doing. You are perfectly capable of doing the job, but you are not necessarily capable of doing the additional crip work for having to deal with all of that assumptions and dealing with stuff."

(Female, Mid-Career, Health Research, Physical disability or health condition)

6.4. Factors which facilitated disclosure

Our analysis has highlighted that the factors which supported individuals to disclose a disability largely related to institutions and funders providing clarity; in terms of clear and comprehensive descriptors of what types of conditions were defined as disabilities, in relation to what benefits disclosure would generate, and in terms of how this information would be used and accessed.

When asked how disability disclosure might be encouraged amongst disabled scientists, it was evident that individuals valued clear terminology and guidelines as to what types of conditions 'count' as a disability. This reinforces findings from other recent work which has highlighted disparity in how individuals respond to questions about disability, particularly for those with mental health conditions (Wellcome Trust, 2020). This highlights the need to ensure multiple questions about disability are asked in any diversity monitoring exercise, as highlighted by EDIS³⁹. Participants with mental health conditions were particularly concerned with whether they should define their condition as a disability, and did not always know how employers of funders would view this:

"I'm not always sure if my condition counts as a disability – clearer definitions and clearer descriptions of what help might be available if you do disclose. It's super tricky – because most of the time I don't have a disability because I keep it under control. I don't want to abuse resources because I know they are scarce."

(Female, ECR, Computer Science & Design, Neurodiverse and mental health condition)

"Being explicit about what counts e.g. applying for jobs – do you have a disability – we include ...so they are including me in that category so therefore I will disclose. Disclosing to colleagues is different because you are disclosing to people you know and who know you." (Female, ECR, Professional Services, Mental health condition)

³⁹ <https://edisgroup.org/wp-content/uploads/2020/01/DAISY-guidance-version-Jan-2020-1.pdf>

Further, providing clear information about the types of adjustments that individuals who disclosed could expect to access was felt to be important, so that there were obvious benefits to disclosure:

“It might sound a bit Machiavellian, but I have applied for 2 jobs in the last 2 months. One guaranteed an interview if you disclose a disability and one was like we’ll organise an interview around your requirements – so I disclosed one and I didn’t the other.” (Female, ECR, Health Research, Physical disability or health condition)

“If there were examples, stories of how disclosure has benefited people because all I have heard is how it doesn’t. If a job could allow me to listen to my own body and give me some flexibility, I might function better.”
(Female, ECR, Applied Health Research, Physical disability or health condition)

Participants’ accounts also highlighted that having trust in the person to whom they disclosed was crucial in supporting them to disclose, though this could take time to develop:

“I only tell those I trust and know well...It was a challenging conversation, but once I told one person it became a little easier.”
(Female, ECR, Chemistry, Physical disability)

For those who remained at an institution where they had previously worked or studied, familiarity with institution could generate faith in its processes and thus facilitate disclosure:

I think at that point I was confident in disclosing it, but I think because of the circumstances in specifically being [institution], because I am familiar with the environment, I know what I can expect. But I think maybe I would have been a bit more hesitant if it is for environment I wouldn’t know so well.
(Female, ECR, Physics, Physical disability or health condition)

Yet it is worth noting that this may mean that individuals are less likely to move institutions, which could impede their career progression.

This trust is likely to be generated by faith that those involved in selection and management have a good level of awareness of disabilities and are trained in inclusive recruitment and management practices. One senior scientist felt that this was crucial in supporting disclosure:

“The fundamental thing is increasing awareness. Training and awareness, training to increase people’s awareness of disability issues and other diversity, not just but gender issues, race issues, religious issues and so on across all the diversity but to increase training to increase awareness. Without that you will still get patronised and you will still be discriminated against...it is the awareness issue that is the thing so that when they are interviewing people or when they are looking at CVs or when somebody in their lab develops a problem or someone in their department develops a problem they know how to deal with and don’t automatically think you know how can I get rid of this person.”
(Male, Senior/Late Career, Environmental Science, Physical disability or health condition)

Finally, it was also clear that having had previous positive experiences of disclosing themselves led to individuals feeling more able to continue disclosing in other roles:

“I am about to apply for an internal job, and I will tick the box because I have had positive experiences.” (Male, Non-academic STEM role, Engineering, Neurodiverse)

6.5. Summary

This section has presented our analysis of participants' experiences of disclosing their disabilities, enabling insight into the factors which affected disclosure, including barriers and enablers to disclosure. It was clear that individuals' experiences of disclosure were variable, with some having very positive experiences of securing the adjustments they needed in order to succeed in the workplace. For the majority, though, experiences of disclosure were more challenging. Participants reported a lack of clarity in the process of requesting and securing reasonable adjustments, and a lack of awareness and understanding when they sought support, particularly from formal sources such as HR. Generally, disclosure was only undertaken when considered to be unavoidable, and was more likely to be reported informally to a line manager rather than through more formal institutional reporting processes. Most did not disclose until after they had secured their job and the vast majority of participants would not recommend other disabled scientists to disclose their disability.

Interestingly, participants felt that disclosure would become easier once a more senior career stage had been reached, and some acknowledged that they had become more confident over time in disclosing their disability. Yet this does not correspond with patterns evident in HESA data for certain conditions, which show a decrease in disclosure between earlier and later career stages. It was clear that a significant factor which affected disclosure was the visibility of senior disabled scientists, who could act as role models for early career scientists.

Perceived barriers to disclosing a disability included persistent stigma around disability and the fear of both direct and indirect discrimination, particularly for those with mental health conditions, which was compounded for ECRs attempting to secure a permanent academic role in a competitive environment. Further, the lack of clarity as to who would have access to this information and how it would be used, along with the additional time and labour involved in disclosure, also contributed to decisions not to formally disclose disabilities. However, there were a number of factors which facilitated disclosure. These included institutions and funders providing clear and comprehensive definitions of disability as well as outlining the types of adjustments which would be available for those who disclosed. In addition, trust in those being disclosed to, which could be facilitated by increased awareness and training of recruiters and line managers, was important, along with previous positive experiences of disclosure, which gave individuals confidence that their needs would be sufficiently met.

7. Overall findings, issues and recommendations

7.1. Summary of findings

This research project set out to understand more about disability disclosure, to identify barriers that disabled scientists face in disclosing their disability to institutions and funders, and to gain insight into possible solutions. From our review of evidence from within and beyond the HE sector, new and bespoke analysis of HESA staff record data, interviews with 7 experts and, most powerfully, interviews with 25 disabled scientists, we summarise our key findings here.

Firstly, it is evident that many disabled scientists have different career experiences from those of their non-disabled colleagues. As others have suggested (Brown and Leigh, 2018; Sang, 2017), disabled scientists encounter what some have defined as ableism within STEM academic research culture, and face discrimination in their workplaces. The culture of academic STEM is seen by participants to reward those who can easily fit the mould of the 'ideal scientist' who is able to demonstrate consistent, high levels of research productivity, to secure significant external research funding, to work full-time and more outside normal working hours, and to communicate their research to wider audiences at conferences and other events/channels. For a considerable number of disabled participants, these expectations are challenging to meet and mean that they judge their own performance negatively, in comparison. Some others may judge them negatively too. It is evident that research cultures in STEM are experienced as less inclusive for disabled scientists (RAEng, 2018; Wellcome Trust, 2020), which has a considerable impact on career trajectories.

Secondly, based on our sample, there is evidence of huge disparity in whether or not individuals have been able to access support from institutions and funders. Whilst some participants had successfully managed to secure the adjustments that they needed in their workplaces, for the majority negotiating access to institutional support was not straightforward. There is a lack of clarity in how to seek support as a disabled member of staff, as well as little faith in formal reporting processes. Individuals are more likely to ask approachable line managers for informal adjustments than seek more formal arrangements, but this makes them dependent on particular individuals and more likely to remain at that institution, while many progression pathways have some expectation of mobility. Interviewees feel, and we infer, that both institutions and funders should be more proactive in terms of developing measures which would support disabled scientists better. These include the need for better awareness and understanding of reasonable adjustments amongst line managers and heads of department, as well as a more proactive approach to providing support and examples of adjustments that could be made. This could be brought together as a policy or set of guidelines on reasonable adjustments. There could also be more support for staff disability networks and for those who apply for external research funding.

In relation to funders, grant applications data for disabled scientists tend to be very limited, suggesting that disabled researchers are not disclosing their disability to their funding body. Further, available data indicate that the success rate for disabled researchers applying for grants has been consistently lower than the success rate for non-disabled academics over the last 5 years⁴⁰. It is clear that funders could do more to ensure that data in relation to disabled scientists' applications are effectively captured and recorded, in order to be able to better understand how disabled scientists are accessing external research funding and seeking

⁴⁰ <https://www.nature.com/articles/s41578-020-0177-1>

adjustments. Further, our research has highlighted that a number of changes to the way that grants are administered and undertaken could be made, in order to improve the inclusivity of grant-making. A range of adjustments, such as flexibility in the way grants could be undertaken, improvements to the accessibility of the platforms used to submit applications (such as ensuring compatibility with screen-readers), as well as the possibility of allowing additional funds to be made available for applicants who required reasonable adjustments, are all potential enhancements which would make the process of applications for funding more inclusive. Funders also need proactively to present an inclusive face to potential applicants, rather than putting the onus on the applicant to ask what might be possible. These findings reinforce the findings of other, recent research into disabled academics' experiences of applying for research funding (see Boland, 2019; Sang, 2017).

Thirdly, almost all participants feel their disability or condition has negatively impacted on their career, particularly on their ability to progress. The more senior scientists we interviewed or consulted have developed coping strategies and outwardly achieved career success, while some with more recently acquired conditions still struggled and had not ruled out leaving academic science. As well as facing challenges in attending academic conferences, important for networking and career progression, participants also observe the day to day impact of their disability on their work, which has a cumulative impact on their careers over time. Women in particular observe how having children, combined with their disability, has negative effects on their careers. Early-career researchers struggle to envisage how they will compete for permanent posts and external funding against non-disabled peers, who are more likely to work full-time, be more productive in terms of research outputs and undertake the geographical mobility expected in STEM careers. For some, the challenges and experiences of discrimination in academic STEM has meant that they have changed direction, either moving away from research into teaching, or to a professional services role, or in a few cases leaving academic STEM altogether. The HESA data on academic staff records higher proportions of disabled staff on teaching-only contracts than research-only, which could reflect some of these shifts in trajectory away from the mainstream STEM progression route of an early-career research contract, as well as lower levels of disability disclosure at more senior levels.

Fourthly, experiences of disclosing a disability were more often negative than positive. Whilst most participants in this study had disclosed either formally or informally, and some had successfully secured the adjustments they needed, the majority of experiences of disclosure were characterised by frustration at the lack of clarity in the process of requesting and securing reasonable adjustments. There are also concerns about discrimination (which pose a risk to employers, should a case be raised), fears about how formal processes might be used punitively, and for some, these concerns have meant that disclosure was often only undertaken when felt to be unavoidable. Often, individuals have chosen not to disclose their disability formally (and in one case, not at all). It is striking that most mid/late career scientists we interviewed would not recommend, or would even actively discourage, other disabled scientists from disclosure of conditions for fear of discrimination. This surely feeds into the lack of senior staff recorded to have disclosed mental health and learning conditions and, accordingly, an acute lack of role models at senior career stages.

Finally, it is evident that a number of factors affect disability disclosure. Interestingly, most participants felt that disclosure would become easier once a more senior career stage had been reached, and some ECRs acknowledged that disclosure had become easier over time,

perhaps indicating a shift in employers' attitudes, or more security through open-ended employment. However, this does not correspond with patterns evident in HESA data, which tend to show a decrease in disclosure of several key conditions between earlier and later career stages, especially mental health conditions. It is clear that a significant factor which affects disclosure is the visibility of senior disabled scientists, who could act as important role models for early career scientists, yet very few of them disclose mental health conditions.

Perceived barriers to disclosing a disability include persistent stigma around disability and the fear of discrimination, particularly for those with mental health conditions. This is compounded for ECRs, many of whom will be attempting to secure a permanent academic role in this highly competitive sector. The lack of clarity as to who would have access to this information and how it would be used also contributes to decisions not to formally disclose disabilities. However, we consider that higher levels of disability disclosure could be facilitated through a range of interventions, such as the provision of clear and comprehensive definitions of disability, as well as outlining the types of adjustments which would be available for those who disclosed, from funders and institutions. In addition, trust in those being disclosed to, which could be facilitated by increased awareness and training of those making selection decisions, is critically important, along with previous positive experiences of disclosure.

These findings indicate the need to address a number of specific issues, which are outlined below and followed by a series of recommendations for institutions and funders.

7.2. Emerging issues

Here we outline some of the key issues which emerge from the range of evidence gathered, including from our analysis of HESA staff record data.

Variations in disability disclosure

It is evident that, overall, the proportions of academic staff disclosing disabilities are increasing with time, largely due to more widespread reporting of mental health conditions and cognitive/learning differences, while there is little evidence for an increase in the level of reporting of many other types of condition, especially at more senior levels.

In relation to the key issue of STEM academic progression, which is a focus of this study, we note that levels of disability disclosure broadly fall with seniority reached, due largely to the lower disclosure of mental health and cognitive/learning conditions by senior staff. This appears to be a real trend as evidence suggests it is not related to age. This could be very important as it contributes to the absence of role models at senior levels. The significance of a more open culture in HE in relation to mental health can be seen in the UUK StepChange Mentally Healthy universities framework⁴¹, a key policy development which encourages those at senior management levels to declare mental health conditions.

From our research, what is also apparent is that rates of disclosure are particularly low for early-career staff employed on a research-only contract, which is considered by many to be the most esteemed and 'mainstream' trajectory for progression in STEM. This may contribute to low levels of disability at more senior stages. By contrast, levels of disclosure appear to be higher amongst those at a similar career stage who have a teaching-only contract. It may require further research to understand these trends better and determine whether disabled

⁴¹ <https://www.universitiesuk.ac.uk/policy-and-analysis/stepchange/Pages/framework.aspx>

scientists are actively seeking this pathway believing it to be more inclusive or accommodating, or whether other factors are driving these differences.

Whilst there is little evidence from our research of discipline-specific barriers to disclosure, our analysis of HESA staff data reveals that there are some particular disciplines in which there appear to be very low rates of disclosure, such as engineering and certain physical sciences, as well as medicine. Further, there is a clear gendered pattern evident in HESA data of disclosure being higher amongst women, in all disciplines studied and at all levels other than the most senior (where levels of disclosure are almost equally low). While our interview sample was small, very few men other than those who had successfully navigated their career emerged for interview, which may reflect continuing stigma.

Cultural change has started in the wider population so that disclosure of certain conditions including learning differences and mental health vulnerabilities is far more common amongst young people, witnessed in the much higher rates amongst first-degree students and doctoral researchers, in STEM and other fields. The wave is coming – there will be an expectation from young people entering STEM careers that it is normal to disclose conditions and that the system and their employer will welcome and accommodate them. Put bluntly, if they encounter the academic staff culture and support system as it is now, they may choose to work elsewhere and this could impact on the future supply of talent, at a time when strategically we are seeking not only more highly-skilled STEM scientists, but a greater diversity of them.

Access to support and adjustments

Experiences of disabled scientists' access to support and reasonable adjustments from institutions and funders were variable. Where reasonable adjustments such as flexible working patterns and reductions in teaching load had been secured, this had a significant, positive impact on individuals' ability to succeed in their roles. However, for the majority, requesting similar adjustments was problematic, and there is evidence to suggest high levels of inconsistency across institutions and funders in how support and adjustments are provided.

Within institutions, despite the duty of employers to make reasonable adjustments as set out in the Equality Act (2010), the process of securing support and adjustments was not straightforward. There was low awareness of where to go within institutions for advice or support and considerable confusion around the reporting process between line managers, occupational health and HR. Further, when individual members of departmental staff were given responsibility for overseeing adjustments, this could lead to access to reasonable adjustments being compromised by the attitude of the individual approached. Whilst support for disabled students was largely perceived to be straightforward, academic staff noted the irony of being expected to accommodate a range of adjustments for their students, whilst struggling to secure reasonable adjustments themselves as members of staff.

Generally, participants did not disclose unless they had to, and often chose to do so informally where possible in order to secure adjustments. Supportive line managers were often crucial in accessing the required adjustments. However, this meant that disabled members of staff felt that their adjustments could be threatened by changes to staffing arrangements, causing ongoing concerns that these adjustments might eventually be lost. It also means that they may be less likely to change institution, which could limit their progression.

Whilst many participants expressed a desire to apply for external grants or funding, often highly aware that this was key to their career progression, a range of barriers were perceived in applying. These ranged from inaccessible platforms used to host application forms and tight deadlines for applications, which caused particular difficulties. Changes to recruitment and selection processes, such as ensuring that panel members receive disability awareness training and/or training in inclusive selection, were suggested as ways of being more inclusive of disabled scientists. Further, the possibility of introducing more flexibility into the ways in which grants could be taken up is a key improvement that funders could make. Changes such as rolling deadlines for grant applications, offering the option to undertake a grant part-time, to add contextual notes within the application in relation to publishing track records to 'explain' periods of lower productivity, to pause funding during periods of ill health (something perceived to be particularly important for those with chronic and mental health conditions), or to access additional funds for adjustments which incurred extra costs, could be undertaken as part of a proactive approach by funders to demonstrating inclusivity.

From wider conversations with funders, it was evident that there is a lack of clarity as to whether these additional costs should be funded by the university, as the employer, or the funding body. This is an area which needs further exploration. Further, the role of Research Offices in institutions should be considered in future work in order to understand the extent to which they are able to provide inclusive support to disabled scientists seeking research funding. Most who apply for external funding are already employees of an HEI and are supported by the institutional Research Office when they make an application for a grant or fellowship. It would be worth exploring in future how the attitudes of those working in Research Offices are experienced by disabled applicants, and whether or not adequate support and advice is being given. The extent to which they perceive funders to be inclusive and are advising applicants to request adjustments will be significant in understanding the issues that disabled scientists face in applying for external funding schemes.

For both institutions and funders, publishing guidance as to the range and type of possible adjustments available is a key improvement which could be made to better support disabled scientists, facilitating disclosure and making the process more straightforward for individuals, and likely encouraging applications from disabled scientists. There is a need for a much more proactive approach to providing support and reasonable adjustments to disabled scientists if there is a genuine will to improve the inclusivity of research and wider cultures in HE.

Impact of disability on STEM career trajectories

There was considerable evidence that individuals perceived their disability or condition to have negatively impacted on their career, particularly on their ability to progress. This was compounded for mid-career female scientists who had taken maternity leave and had caring responsibilities.

ECRs anticipated that their career progression would be affected in various ways. They often struggled to envisage how they would embody the ideal career trajectory embedded in the culture of STEM, which manifested itself in an individual who was able to sustain long periods of significant research productivity, able to work both full-time and outside normal working hours, was highly mobile, and successful in securing large external grants. This could be why rates of disability disclosure appear to be higher amongst those focused on a teaching rather than research trajectory, though more research would be needed to explore this.

Certain wider cultural expectations within STEM, such as the assumption that scientists are geographically mobile, could be particularly challenging. For those who had secured reasonable adjustments at their current workplace, or who had a permanent contract, the fear that conditions elsewhere would not be as positive meant that they were less likely to move to take up different posts. Further, the need to take time off during periods of ill health, and potentially work part-time or flexibly had an impact on individuals' research productivity, likelihood of attending conferences, capacity for teaching and grant applications. These experiences led to a shift in some career trajectories, with evidence that some individuals either moved away from research into teaching, or a professional services role, or in some cases leaving academic STEM altogether.

In order to support disabled scientists to progress their careers in academic STEM, actions to support inclusive progression should be considered. A review of the processes by which academics are promoted and progress in academia could be undertaken to ensure that they are fair and inclusive. Beyond disability awareness and unconscious bias training, neither of which appear to be systematically undertaken or recommended by institutions to those involved in selection processes, a move towards inclusive selection techniques would present a clear commitment towards supporting diversity within the scientific community.

7.3. Recommendations for the sector, institutions and funders

Recommendations for the sector:

1. To encourage disclosure, the sector should agree and embed a consistent definition of what is considered to be a disability, including mental health conditions, and publicise more widely how the process of disclosure works (including being clear on how parties will share and use the information if a disability is disclosed);
2. The sector should encourage and/or develop initiatives which celebrate the work of disabled scientists, recognising the positive impact of role models, especially senior academics but also early career scientists who are pursuing a research pathway;
3. The sector should undertake work to challenge the culture that currently anticipates early-career research solely to be a full-time endeavour that will require uniformly high productivity and demand that researchers work more than 100% of full-time employment hours, such as aiming to introduce flexible working opportunities wherever possible;
4. The sector should undertake research to understand more about the use of research-only and teaching-only contracts, particularly to assess whether more disabled scientists are selecting teaching-focused pathways (and why) or whether circumstances are resulting in more of them being employed in such roles;
5. The sector should undertake further research work to investigate the reasons for the very low levels of disclosure at senior career stages, if necessary exploring barriers to doing so for senior scientists and what steps could be taken to enhance this.

Recommendations for HEIs:

6. HEIs should increase disability awareness training and inclusive recruitment/selection training for their staff involved in recruitment, progression decisions and line management. There is much to be learnt from sectors other than HE, which have made more progress towards inclusive progression;
7. HEIs should aim to collect systematic detailed diversity data on the number of disabled applicants/employees they have, as well as information on the number and quality of adjustments that have been sought and offered;
8. HEIs should provide clear guidelines on what types of reasonable adjustments are available and state clearly on job applications, as well as on relevant webpages for staff and applicants, some examples of the types of adjustments that can be requested (and state that a wide range of possible adjustments can be offered in order to meet individuals' specific needs) to provide a flexible, inclusive approach;
9. HEIs should ensure they provide clear guidance for disabled staff and applicants on how to access support, information, advice, services, and funding, as well as providing specific information, training and assistance to line managers. Employers should do this collaboratively, working with trade unions and staff who are trained and supported to act as disability or equality contacts or co-ordinators within departments;
10. HEIs should support and increase the visibility of disabled staff networks to facilitate peer support and the ability of individuals to hold institutions to account in relation to access to reasonable adjustments. This could involve working with NASDN to do so;
11. HEIs should undertake research to ensure that advice and support provided by Research Offices is fully inclusive, whether they are supporting disabled external grant applicants, and how they are currently contributing to breaking down barriers or reinforcing perceptions of a lack of inclusivity from funders;

Recommendations for funders:

12. Funders should collect systematic detailed diversity data on the number of disabled applicants and awardees they have, as well as information on the number and quality of adjustments offered and taken up by applicants and awardees;
13. To support disabled applicants, funders should demonstrate a more proactive approach to inclusivity in the process of advertising grant/funding opportunities, handling applications and managing awards. This should involve providing clear guidelines on what types of reasonable adjustments are available to applicants within the application process itself, as well as for successful awardees within their funding;
14. Within the applications process, funders should clearly state a definition of what is considered to be a disability (including mental health conditions) in order to encourage disclosure at application stage, and offer adjustments such as providing additional time

to apply and/or rolling deadlines, allowing for applications in different formats and providing room for contextualisation of CVs and research outputs;

15. Funders should promote the availability of specific adjustments in the support available to disabled awardees such as: allowing grants to be taken up on a part-time/flexible basis, potential for discrete additional funding for costs incurred specifically by disabled scientists, and clarifying with HEIs where financial responsibilities lie for providing different types of adjustments.

Qualitative research on barriers to progression of disabled scientists

**Report for the Royal Society by the
Careers Research & Advisory Centre (CRAC)**

**Careers Research & Advisory Centre (CRAC) Ltd
22 Signet Court
Cambridge CB5 8LA**

www.vitae.ac.uk