Improving the experience of disabled PhD students in STEM

A report by Disabled Students UK
and Pete Quinn Consulting Ltd.

DISABLED
STUDENTS
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Change through Collaboration

Contents

Executive summary

Our research reveals that PhD students have broadly positive experiences of the uniquely important relationship between supervisor and supervisee. However, only 33% of participants felt they had received the support they needed to be on an equal footing with their non-disabled peers. This report suggests 7 ways in which disabled students can be better supported going forward in order to improve admission, retention and progression:

1. **Address gaps in the provision of individualised support and clarify which bodies are responsible**

Less than half of disabled PhD students felt it was clear where they should get their disability support from. Compared to taught students, research students are falling through the cracks. We can improve the number of disabled students who receive appropriate disability support by:

- Ensuring all parties know which body is responsible for which support.
- Educating needs assessors and Disability Services (DS) staff about the specific needs and processes involved when supporting disabled PhD students.
- Ensuring students have a single point of contact for their access needs.

2. **Reduce the administrative burden associated with attaining support**

Reducing disabled students' administrative burden was the most requested change among our survey respondents. We can reduce the burden by:

- Making the support application process clearer.
- Resourcing DS to take on some of the burden currently shouldered by disabled students.
- Providing support based on need rather than diagnosis.

Survey respondents who had found the administrative process of setting up support quick and easy were 4.5 times more likely to state that they had the support that they needed.

3. **Resource decentralised bodies**

Decentralised bodies such as academic departments and doctoral training partnerships are responsible for implementing agreed support as well as promoting inclusion through universal design. We can enable a holistic approach to accessibility by:

- Investing in disability support and structures of responsibility within decentralised bodies
- Improving communication between DS and the staff involved in supervising, training, supporting and assessing doctoral students.
- Universities and funders creating accessibility teams which support decentralised bodies through guidance, training and advice.

Respondents who had not needed to intervene in order to have their agreed support put in place were 2.4 times more likely to feel they belonged.

4. Encourage structures and cultures of support

86% of respondents stated that conducting their doctoral studies had impacted on their mental health but this was significantly less common among those students who felt a sense of belonging at their institution. 44% of our survey participants felt they belonged at their institution. The number of disabled students who feel they belong can be improved by:

- Ensuring students have somewhere to turn when issues arise.
- Running campaigns and staff training which encourage a culture of support.

Students who felt they had somewhere to turn with disability issues were 3.7 times more likely to feel that they belonged.

5. Build on the positive aspects of the crucial supervisor-supervisee relationship while addressing possible difficulties

Our survey shows that the supervisor-supervisee relationship is uniquely important for disabled students' sense of support and belonging. We can empower supervisors by:

- Better connecting supervisors to students' other disability support.
- Training supervisors and providing better support for their needs.

We should also improve safeguards to prevent this crucial relationship going wrong. PhD students whose supervisors were accepting and supportive of their disability were 12.1 times more likely to have the support they needed.

6. Make the physical and sensory environment more accessible

The physical/sensory environment on campus was the aspect of the PhD experience that was found inaccessible by the largest number of survey participants (50%). Relatedly, students with mobility difficulties were the least likely to have a sense of belonging at their institution. The accessibility of the physical and sensory environment can be improved by:

- Using universal design to create enabling workspaces for staff and doctoral students with mobility and sensory difficulties.
- Funding ergonomic furniture and equipment

7. **Allow students to study at a pace that suits different bodies and minds**

Disabled PhD students are more likely to drop out than other PhD students. Funders can provide disabled students with the opportunity to study at a pace that does not negatively impact their health and wellbeing by:

- Adjusting their policies around sick leave and part time studies in keeping with common employment practices.
- Offering greater flexibility around extensions and part time studies.
- Offering full time stipends to disabled students who are unable to study full time.

Students who felt that their funder was flexible, accommodating and valued their wellbeing were less likely to say that undertaking their PhD had negatively impacted their health.

Introduction

Disabled doctoral students make valuable contributions to life science research, both through their research activities and their diverse and unique perspectives. However, many disabled doctoral students face a wide range of challenges at every stage of their doctoral journey, which could be more effectively addressed in order to ensure equitable outcomes. This has been recognised in UKRI's recently published report "A New Deal for Postgraduate Researchers" (UKRI, 2023e) which states that reviewing support for disabled students is one of UKRI's immediate priorities.

Since 2017/18 the proportion of Postgraduate Research (PGR) students in the UK who are eligible for home fee status, and who have a declared disability has increased by 54%, today making up 20% of PGR home students (HESA, 2023)[1].

The diverse nature of the doctoral student population, which includes international students, as well as students from groups that are currently under-represented in doctoral research, such as socioeconomically disadvantaged students and students from minority ethnic groups, means that many students come from backgrounds where disability and neurodivergence is less well-recognised or stigmatised, potentially leading to a higher frequency of non-disclosure or a lack of pre-existing diagnoses within these groups.

This also means that disability needs to be considered in an intersectional context, alongside other factors that affect student health, financial security and wellbeing. In general, doctoral students commonly face the prospect of becoming geographically isolated from existing support networks, including family, friends and medical professionals as they start their studies.

Existing data indicates existing inequalities. For instance, the Postgraduate Research Experience Survey found that disabled PGR students were less likely to

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[1] However, it should be noted that data on the numbers of doctoral students with disabilities is an underestimate: it is often generated based on information provided during recruitment or upon admission, and does not include students who choose not to disclose a disability. Nor does it always include those who acquire or are diagnosed with a disability (including chronic illness or neurodivergence) during their studies.

say that they were satisfied with their studies (72%) compared to their non-disabled peers (81%) (Neves, 2022).

In March 2023 UKRI laid out their EDI strategy, which includes a commitment to "*include and support a diversity of people and ideas through our funding and partnerships*" (UKRI, 2023b, Our Strategic Objectives). A specific action plan was also drawn up by the Biotechnology and Biological Sciences Research Council (BBSRC, 2023), committing to removing barriers to participation to address under-representation of disabled students in BBSRC programmes. This included understanding non-disclosure, understanding barriers to participation, providing clear communication of reasonable adjustments available and developing targets for change. BBSRC has committed to evolving existing schemes and integrating "diversity by design" into future funding programmes "*to ensure they are as inclusive as possible and do not inadvertently restrict access to groups or individual researchers, irrespective of their career path.*" This with the intention that *"BBSRC programmes and policies will have diversity built in from the outset, to stimulate creativity and to ensure a breadth of ideas from across the whole of the biosciences community*" (BBSRC, 2023, Introduction, para. 3).

Neither UKRI as a whole nor BBSRC has yet laid out a detailed action plan for disability inclusion in particular, despite the 'anticipatory duty' toward disabled people that is not applicable to other protected groups. However, UKRI recently commissioned an equality impact assessment of UKRI training grant terms and conditions, which has highlighted several areas that can be addressed that are specifically relevant to disabled students. This assessment is currently under review by UKRI, with further action expected (Pugh, 2023).

Unfortunately, there is currently little specific research into how disabled STEM doctoral students can be included and supported either by funders or research institutions. There have been influential studies into the experience of disabled students overall in the last years (Disabled Students UK, 2022; Higher Education Commission & Policy Connect, 2020), however these have tended to focus on taught students. There has also been recent attention to doctoral student wellbeing (as will be addressed in Chapter 4) which rightly acknowledges the pressures and challenges faced in this domain, however, the unique experiences of disabled doctoral students need to be given greater consideration.

Here, we wish to understand challenges faced by disabled doctoral students in STEM, as well as good practices encountered across the sector, in order to gain knowledge of how funders, research organisations and non-academic organisations involved in doctoral training can work towards improving the experiences of these students. To this end, Disabled Students UK, the Oxford Interdisciplinary Bioscience Doctoral Training Partnership and Pete Quinn Consulting Ltd have collaborated to evaluate the experiences of disabled doctoral students in STEM. We have collected data from two focus groups, ten structured conversations with doctoral training programme staff and associated colleagues as well as from a UK-wide survey of 192 doctoral students, providing us with much needed data on how to improve the disabled doctoral student experience going forward.

Although our report focuses on the lived experience of doctoral STEM students, the majority of the findings are also of direct relevance to organisations and individuals involved in supporting students who are working toward non STEM qualifications, and in some cases to STEM researchers more generally. In addition, while we focus here on the experience of disabled students in applying to and undertaking doctoral study, it should be noted that guidance and policies should also consider the needs of supervisors and staff involved in doctoral training, including disabled supervisors and staff, as well as considering factors affecting the progression of disabled doctoral students into both academic and non-academic careers.

Given the lack of research focused on disabled doctoral students, a significant proportion of the report is dedicated to laying out the specific responsibilities involved, with less attention given to topics which overlap with taught students, an area that is comparatively better researched. At the same time we have focused on the areas that the doctoral students surveyed themselves deemed to be most important in their recommendations to their institutions.

Although of necessity we focus on areas for improvement, we would like to highlight that many doctoral students spoke very positively of their experiences, particularly in terms of support from individual supervisors and other staff members. We hope that this report will help give a voice to disabled students and focus attention on an important issue in doctoral training that will benefit from further consideration and action, with long term benefits for students, the scientific community and society.

List of abbreviations

AtW - Access-to-Work
A UK government funded scheme designed to help disabled workers gain employment or stay at their work by providing practical support.

BBSRC – The Biotechnology and Biological Sciences Research Council
A UKRI Research Council and the biggest funder of non-medical bioscience in the UK.

DS - Disability Services
Units designed to provide guidance and arrange individualised support for disabled students within a research organisation.

DSA - Disabled Students' Allowance
UK government financial support aimed to cover students' study-related costs experienced due to disability.

EDI - Equality, Diversity, and Inclusion
An approach implemented to promote equal opportunities, recognition and respect of diversity, and the promotion of inclusive environments within different institutions and workplaces.

NUS - National Union of Students
A confederation of students' unions in the UK.

OH - Occupational Health
Services within a research organisation aimed at promoting physical and mental health and safety in the workplace.

PEEP - Personal Emergency Evacuation Plan
An assessment used to document and plan how a person would be evacuated during an emergency such as a fire alarm, either through direct assistance or planning for them to have the tools to escape unaided.

PGRs - Postgraduate Research Students
Students who are undertaking research degree programmes such as a PhD, MRes or MPhil.

STEM - Science, Technology, Engineering, and Mathematics

UKRI - UK Research and Innovation (UKRI)
A non-departmental public body sponsored by the Department for Science, Innovation and Technology (DSIT). UKRI brings together seven disciplinary Research Councils, Research England, which is responsible for supporting research and knowledge exchange at higher education institutions in England, and the UK's innovation agency, Innovate UK.

Measuring the experience of disabled PhD students

Of those survey participants who required support only 33% agreed that they had received the support they needed to access their degree on equal terms with their non-disabled peers. This is concerning considering that the duty to disabled students is to provide all reasonable adjustments which remove the substantial disadvantage they face compared to their non-disabled peers.[2]

Disabled student support can be roughly divided into three kinds:

1. **Individualised formal support**

Most institutions put in place individualised support by having a staff member from Disability Services (DS) engage with the student and co-create a plan for their support. With the consent of the student, and on a need to know basis, this plan is then shared with other staff members within the institution for implementation, and updated over time as the student discovers new access barriers. If the student is employed by the institution, or requires specific adjustments within their working environment, they may also have a workplace assessment by Occupational Health (OH). Other adjustments such as sick leave are approved by their academic department, doctoral training programme or funder, as appropriate. In the first half of this report we explore the approval and implementation of individualised formal support, addressing who is responsible for approval (Chapter 1), the application process (Chapter 2) and implementation of approved support (Chapter 3). Figure 2 shows the factors that were most correlated with whether a student felt they had the support they needed.

2. **Informal support**

Sometimes individualised support is provided without the student undergoing a formal application process. For instance, a supervisor may offer to speak more clearly or put action points in writing after meetings. We will discuss informal support in Chapter 4 and Chapter 5.

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[2] Read the "Equality Act 2010 Technical Guidance on Further and Higher Education" for an understanding of the responsibilities of the Higher Education sector toward disabled students (Equality and Human Rights Commission, 2014).

3. Universal design

Universal design is a type of “support” that is put in place before the institution even knows which disabled students will be joining them in the coming year. Accessibility needs to be considered in an anticipatory fashion, including in the creation of the physical and digital environment, in teaching, policies and in staff training, to name a few areas. For instance, regardless of whether there is a wheelchair user currently at the university, new buildings and refurbishments must be wheelchair accessible (EHRC, 2014). Similarly, regardless of whether or not the lecturer knows that there is a blind or partially sighted student in the audience, it is good practice for them to describe what is on their slides when presenting. Universal design is the least visible and most forgotten form of support. We will touch more on such adjustments in Chapter 3 and Chapter 6.

Key outcome variables

Whether students had the above types of support can be challenging to measure directly. In this report we treat three survey answers as key outcome variables: whether students reported receiving the support they required, whether they reported a sense of belonging and whether they reported that the PhD had negatively impacted their physical health. See Figure 1.

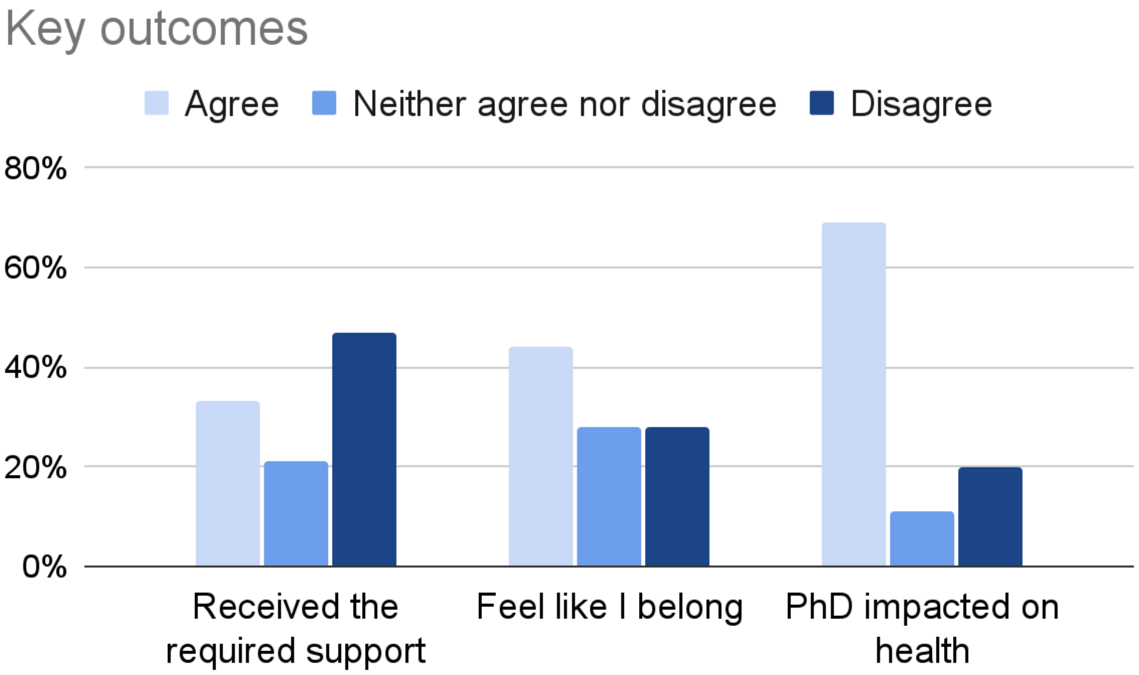

Figure 1. Key outcomes

The biggest factors associated with the likelihood of receiving the required support can be seen in Figure 2.

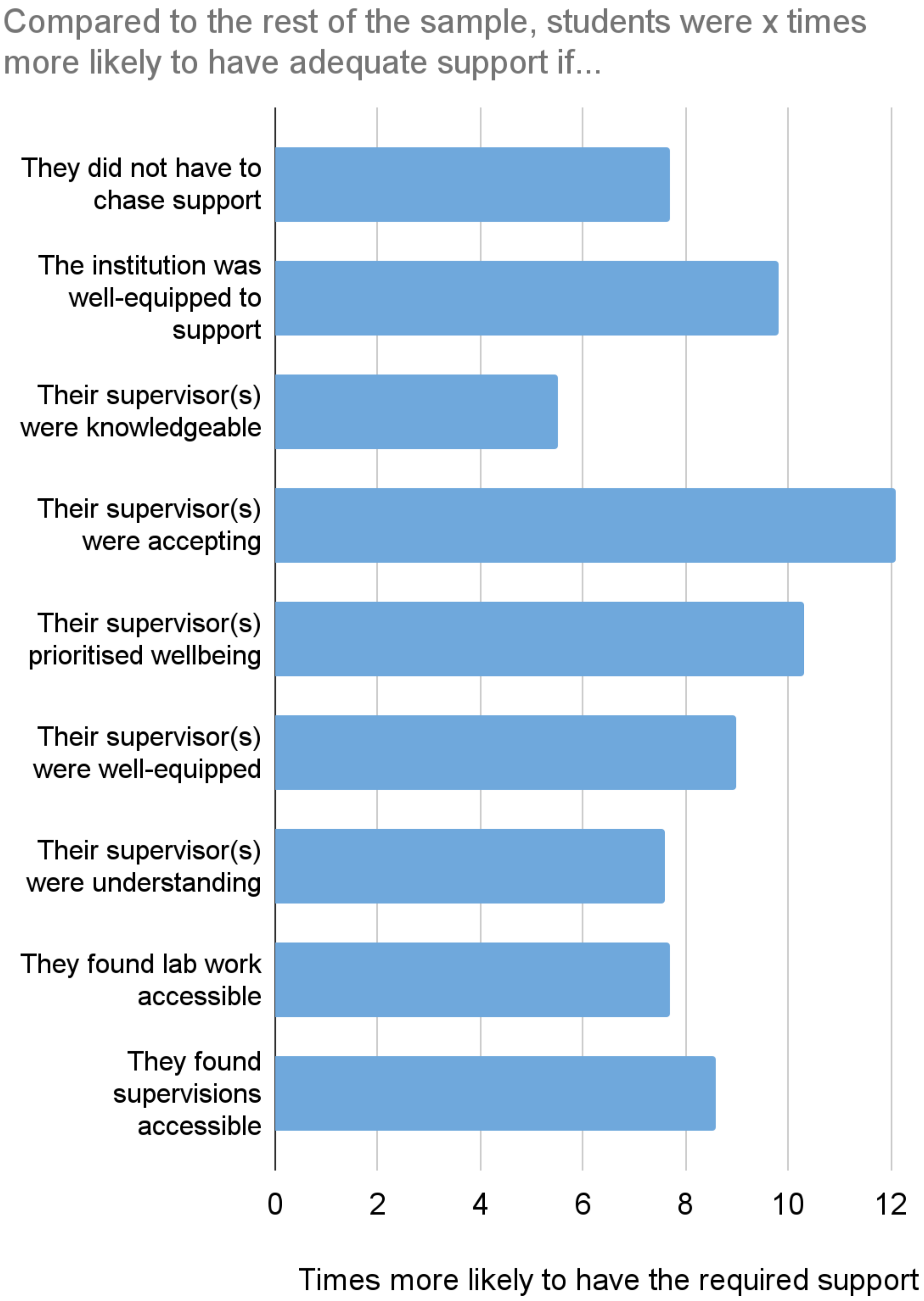

Figure 2. The biggest predictors of adequate support

1. Approving individualised support

Clarifying which bodies are responsible and filling gaps in support

Students who felt it was clear where they should get their disability support as a PhD student were 2.8 times more likely to have received the support they needed, compared to students who felt it was not clear.

A list of individualised adjustments is not automatically created when a disabled student joins an institution. Students must first contact the right staff members with the right information. While most universities have specific departments and staff dedicated to disability support, their existence does not automatically mean that all students have knowledge of where to get support. In our survey, 43% of respondents disagreed that it was clear from whom they should get their disability support (43% agreed and 15% neither agreed nor disagreed[3]). One survey participant writes:

> *“I am lucky in that my PhD naturally allows for remote working, and that my supervisor is happy to meet online instead of in-person on any weeks that I request it (without me having to disclose mental health as a reason).[...] However, if this system wasn't already in place within his group, I have absolutely no idea how I would go about requesting this support or who I should disclose my conditions to”*

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[3] Possible answers were “strongly agree”, “agree”, “neither agree nor disagree”, “disagree”, “strongly disagree” and “not applicable”. For clarity we have removed the “not applicable” responses and combined “strongly agree” and “agree”, as well as “disagree” and “strongly disagree”.

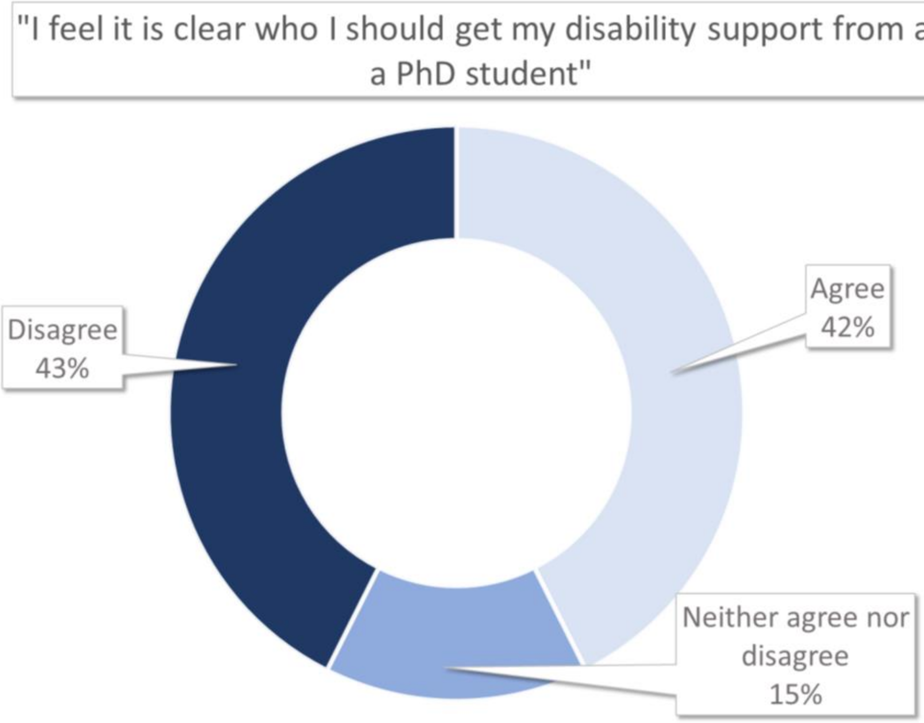

Figure 3. Where to get support

Almost all of our participants (99%) had declared their disability to their institution[4] and thus should have been signposted to the correct body for support. Unfortunately, because PhD students are sometimes thought of as having a status in between that of a student and that of a member of staff, and because of the complicated mix of bodies responsible, staff members are often uncertain about who is supposed to provide disability support to PhD students. This lack of clarity regarding how doctoral students can apply for support and what support is available has been detailed in previous research, and is especially an issue for STEM students (Careers Research and Advisory Centre, 2020; Disabled Students Commission, 2021). One survey participant writes:

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[4] Note that our research suffers from the same bias as the rest of the literature on disabled students, in that the vast majority of our respondents have declared at least one of their disabilities to their research organisation, thus failing to capture the experience of those who are undeclared. The research especially fails to capture the experiences of those with conditions which regularly disrupt work yet are less likely to be recognised as disabilities such as migraines, hay fever, menopause-related symptoms or dysmenorrhea (severe period pain).

> *"Make the support more obvious! I did not get anything until this year, my LAST YEAR of PhD, simply because I had no idea where to go and thought all the adjustments would only work with undergraduates when there is actually some support specific to PhDs."*

In this chapter we first consider which bodies are responsible for approving support and then look at how we can allocate responsibility for support that none of these bodies are currently taking responsibility for.

Who is responsible for approving formal individualised support?

There are a number of bodies responsible for approving individualised support for PhD students:

- PhD students are eligible for Disabled Students' Allowance (DSA) if they are home students and should be signposted to apply for this. This also applies to UKRI funded international students (see Appendix A).
- Disability Services will generally be the body within a university that is responsible for approving formal individualised support, whether funding is internal or comes from DSA.
- If the student is employed at the research organisation then Occupational Health or Human Resources usually have a responsibility to approve support and the doctoral student could be eligible for the government's Access to Work (AtW) scheme.
- Some types of individualised formal support are not centralised; for instance approving sick leave or extensions is usually the responsibility of the academic department, doctoral training programme or funder.

Below we consider each responsible body in turn.

DSA funders

Disabled Students Allowance (DSA) is government-funded financial support which covers study-related costs incurred due to disability. It is available to disabled students at all levels of study. On paper, the funding is provided on the basis of individual needs, which are ascertained via an assessment, however there is usually an evidencing process before this to prove one's disability. Support can be provided for specialist equipment, e.g., a dictaphone or lightweight laptop, note-takers, specialist study support, or for instance travel costs incurred due to disability. DSA can be paid directly to the student or to their support provider.

Currently only 24% of doctoral students with a declared disability are in receipt of DSA (Pugh, 2023, p.16). PhD students are generally less aware of DSA than taught students: Johnson et al. (2019, p.21) found that 38% of the disabled PGR students they surveyed had never heard of DSA.

There are a lot of misconceptions among staff and students about PhD students' DSA eligibility[5]. Several students in our focus group had been told by their doctoral training programme or university staff they were not eligible for DSA either because they were PhD students or specifically because they were Research Council funded. The truth is that all disabled home students are eligible for DSA (and UKRI funded international students, see Appendix A); the difference is where they should make their application: while most students make their applications to Student Finance England (SFE), Student Finance Wales (SFW), the Student Awards Agency Scotland (SAAS), or Student Finance Northern Ireland (SFNI), if a student is funded by a Research Council, they should make the DSA application to that council, via their institution.

DSA from Research Councils differs from DSA provided by the more common funding bodies in that:

- All services and equipment, including any potential needs assessment, are the responsibility of the university/research organisation to organise.
- The university/research organisation is reimbursed by the Research Council only after the equipment or services have been procured/paid for (other DSA funders pay up front costs rather than reimburse) (UKRI, 2021).
- UKRI will not compensate the university for tools or services purchased before or after the funded period of the studentship (UKRI, 2021), meaning that the university is not compensated for anticipatory steps in the weeks leading up to the student beginning their studies, nor for support provided after the end of the studentship.

It should be emphasised that any disabled student has the same right under the Equality Act to not be disadvantaged during their degree, whether they are eligible for UKRI DSA, other forms of DSA or no DSA.

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[5] The confusion could be in part due to poor phrasing in the rules put forward by funding bodies such as the Student Loans Company. SLC guidance states:
"*Under regulation 159(4), a PG student is not eligible for DSA if they: a) are, in connection with the course [...] eligible to apply for an allowance, bursary or award of similar description made by a Research Council*" (Student Finance England for Practitioners, 2022, p.31.). What this means is that if the PG student is eligible for DSA from a Research Council then they must not at the same time get DSA from the SLC. However, given the phrasing, it is easy to mistakenly believe that PG students who are Research Council funded are not eligible for DSA at all.

Disability Services

Disabled PhD students are covered by the Equality Act 2010 in the same way as disabled taught students. As such, their institution is liable to fund any reasonable adjustments not covered by the DSA or the Access to Work budgets.

Most universities have a department named Disability Services (DS) or similar which coordinates and approves this support. The majority of our survey respondents (88%) had declared their disability to DS[6] and 72% of participants received support of some kind from Disability Services.

Disability Services plays an administrative role as well as resourcing funding for any support not funded by DSA or AtW. The administrative role of DS includes signposting and supporting DSA applications, providing internal needs assessments, advising students on support and creating support plans, coordinating with support providers, informing staff members in different departments of the plan (with the consent of the student), and advocating for these adjustments. As one survey participant notes, the student's disability advisor plays an invaluable administrative role:

> *"I then changed college and ended up with an extremely competent [Disability Services] person, who has helped with my student support plan, keeping my admin updated with new diagnoses and new adjustments, getting reassessed for DSA equipment after I lost access to my adapted office setup in the pandemic and general signposting me towards who I need to talk to."*

Our survey participants reported receiving equipment such as recording software, adjustments to the physical environment such as auxiliary aids including induction loops, specialist support such as counselling and support with travel such as taxis, organised via their DS department.

Staff services

Half the students in our sample did some teaching and were thus employed in some capacity. As such, they had a right to disability support as employees. Access to Work is a government-funded grant to help disabled people access or

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[6] The data probably overestimates the declaration rate specifically to Disability Services considering that the survey was sent out in part via Disability Services.

stay in work. Employed PhD students are eligible to apply for Access to Work in order for support to enable them to fulfil the commitments of their role. This support can include travel costs, British Sign Language (BSL) interpreters, lip readers, or note-takers, a support worker or job coach to assist them in their role, or adaptations to a vehicle in order to help them get to work (Department of Work and Pensions, 2021). Worryingly only 3% of PhD students received Access to Work.

Surprisingly, we found that whether a student taught or not did not change the likelihood of them being in contact with university services usually reserved for staff. Compared to support from DS, the kind of support students received from Occupational Health (OH) was more geared toward the needs of academic staff, including workplace assessments, laboratory safety advice, laboratory adjustments, physiotherapy and signposting to Access to Work. However, some doctoral students experienced a sense of OH trying to shield others from them rather than providing them with support:

> *"[I]t felt like the process was there to exclude me from activities if they deemed that necessary. They did not know much about my conditions and thought they would stop me from being able to participate in any capacity, so I had to downplay them and seek support in the form of accommodations elsewhere."*
>
> *"My OH assessment was an upsetting process. In the end their guidance was for me to go through the access to work process (which by that point I was too burnt out to face). The [appointment] was more to do with whether I am a risk to others than how to support me at work."*

Only 12% of disabled doctoral students who taught received support from OH, and even fewer from HR. This may reflect a lack of disability support for staff in general. Students and staff often express a sense that disability is seen as less acceptable and disability support is less developed the higher in the academic hierarchy they get. In 2021/22 only 6% of academic staff in HE declared a disability (HESA, 2023a, Table 5) despite 22% of the working-age population being classed as disabled (Department of Work and Pensions, 2023) indicating that disabled people are either pushed out of academia or pushed not to declare their disability.

Decentralised services

29% of respondents to our survey reported receiving some form of disability support from administrative/technical staff outside of student/staff disability services. Most of the support from decentralised services such as academic departments, Doctoral Training Partnerships and colleges is either informal or in the form of universal design for learning as will be discussed in chapters 3-7. However these bodies also sometimes approve formal individualised support not funded by DSA, OH or DS, such as ergonomic equipment or extensions.

Table 1. Experience of disability support from different staff members/services

	Percentage who declared their disability to this staff member / service.	From 1-5 how accommodating and knowledgeable did those who declared to the service/staff member find them	Percentage of declared who received support	Percentage of supported who found support somewhat or very helpful	Percentage of supported who found support very helpful
Disability services	88%	3.5	82%	71%	24%
Supervisor(s)	87%	3.4	88%	79%	39%
Mentors/ advisory staff	33%	3.3	69%	72%	35%
Admin/ technical staff	34%	3.4	85%	73%	25%
Counselling services	30%	3.4	80%	67%	24%
Assessment staff	22%	3.2	54%	68%	23%
Student services	22%	2.9	63%	52%	20%
Educators	21%	3.4	75%	77%	30%
Admissions staff	20%	2.9	74%	83%	31%

Occupational health	16%	3.1	69%	70%	40%
HR	8%	2.6*	50%*	75%*	13%*
SU / peer support	5%	2.9*	56%*	100%*	20%*

**These figures should be interpreted with caution due to the small sample size*

Falling through the cracks in support approval

Compared to the support for taught students, the system of bodies responsible for approving support for PhD students is less established. Our research showed many examples of students falling through the cracks, as each staff member insisted that someone else was responsible, or simply did not know what support to offer. One focus group participant describes this:

> *"What happens a lot is you get told, 'Oh, you need to go to this person to say this', and you will go to this person and they'll be like, 'Oh no. That's the university's job, you need to go tell them it's their job.' So you get kind of stuck in this infinite loop of going around people and trying to explain what everybody else is saying or where everybody else is at before you can get a solution."*

Having looked at the bodies responsible for supporting disabled PhD students, let us look at how we can allocate responsibility for support that none of these bodies are currently taking responsibility for. We find the following problem areas:

1. One area of support which is covered by DSA for undergraduate students is not covered by UKRI DSA (ergonomic equipment and furniture).
2. Some support is supposed to be covered by UKRI DSA but is not approved due to process issues.
3. Some support could be approved by either staff or student disability services and the lack of clarity around responsibility is leading to neither service approving the support.
4. Some bodies lack the experience of PhD students' needs and processes to approve appropriate support.

Support not covered by DSA – the work environment

The lack of a designated support approver was especially clear in regards to the accessibility of the physical and sensory working environment. As we will discuss in Chapter 6, the environment is the aspect of their degree that the greatest proportion of PhD students in our research found inaccessible. UKRI DSA does not cover the cost for ergonomic equipment and furniture for the office or lab where the student does their research (UKRI, 2021). In practice this leads to an inequality of DSA provision as, for instance, SFE DSA does cover ergonomic equipment and furniture (Student Finance England for Practitioners, 2023).

The lack of UKRI DSA coverage for these adjustments is an issue on its own. However, given that it is the responsibility of the university to fund all reasonable study adjustments not funded by DSA or AtW,[7] it is unclear why DS, OH and the student's academic department do not step in to provide adapted laboratory and office equipment. Only two survey respondents reported such support from their DS department. Unfortunately, our survey results indicate that DS will offer less support if the student does not receive DSA funding:

- Of those who declared to Disability Services and did receive DSA, 97% received some support from Disability Services; 77% of those who received support found it helpful.
- Of those who declared to Disability Services but did not receive DSA, only 78% received some support from DS; only 67% of those who received support found it helpful.

This indicates that rather than compensating for the lack of support from DSA (as is their obligation), university services are leaving PhD students without the needed support. While the doctoral training programmes or academic departments can step in to cover this failure from centralised services, in practice decentralised support is often harder to access for disabled students due to staff members in these departments being less educated about specific disabilities, disabled students rights, and the processes that enable support. Students found DS more accommodating and knowledgeable on average (3.5 on a scale from 1-5) than other administrative staff (3.4) or mentors (3.3). For staff, Occupational Health would normally be the body responsible for workplace assessments, however as we have seen, only 12% of employed disabled PhD students in our survey received support from them.

Thus, in practice, as we shall see in Chapter 6, adjustments to PhD students' work area are often not provided to those who need it.

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[7] Considering that our survey showed that 71% of home students received support from Disability Services and yet only 41% of home students received DSA, ignorance around PhD students' DSA eligibility leads to a missed funding opportunity on the part of universities.

UKRI process issues

Another way in which PhD students may fall through the cracks in support relates to support funded by UKRI. Several students indicated that DS lacked familiarity with UKRI funding specifically and that this limited their ability to support the students effectively with this administration, one survey participant explains:

> *“Unfortunately the university is not used to arranging disability support that relies on [Medical Research Council] funding (in which the MRC reimburses the university for my accommodations at the end of each term, rather than where SFE DSA would directly pay for all the accommodations). This has led to months-long delays in getting my support workers set up through an external agency, which has impacted my progression during my first term. It has also affected my ability to use the subsidised taxi service because I cannot use the SFE DSA taxi provision and instead rely on the university's taxi account, which has frequent technical problems”.*

In theory the retroactive funding from Research Councils should not be a problem, it may even benefit those universities that have an in-house assessment process, as internal sign-off is faster and delays can thus be reduced. However, in practice our survey results indicate that DS offers less support if students are UKRI funded:

- Of those who declared their disability to Disability Services and were not UKRI funded, 85% received some support from DS; 77% of those who received support found it helpful.
- Of those who declared their disability to Disability Services and were UKRI funded only 79% received some support from Disability services; only 66% of those who received support found it helpful.

One factor behind this outcome may be that despite their increased responsibility for funding disabled student support since 2016/17, many universities lack ring-fenced central funding for support, instead needing to find funds from the individual departments if an external funder will not cover the cost upfront. The lack of ring-fencing complicates the process not just for those ineligible for DSA but also for students whose DSA is paid in arrears.

Another problem highlighted by both staff and students was that UKRI DSA did not cover support before or after the grant period, meaning that the university were not reimbursed for anticipatory individualised adjustments bought before October 1st on the first year of the grant, nor adjustments during write up or extension periods, if these were not included in the grant period (UKRI, 2021, p.8). Staff gave several examples of where UKRI DSA funding covered only parts of the student's time on the program. This is especially important as disabled students are likely to take longer to complete their program for disability related reasons. This means that for instance viva support is often not covered by UKRI DSA, with the costs instead falling on the university.

Further examples of what was perceived as inflexibility on the part of UKRI are covered in Chapter 7. Staff members at the universities and doctoral training programmes who were interviewed for this research highlighted that this system risks making staff view disabled students as a financial liability rather than an asset.

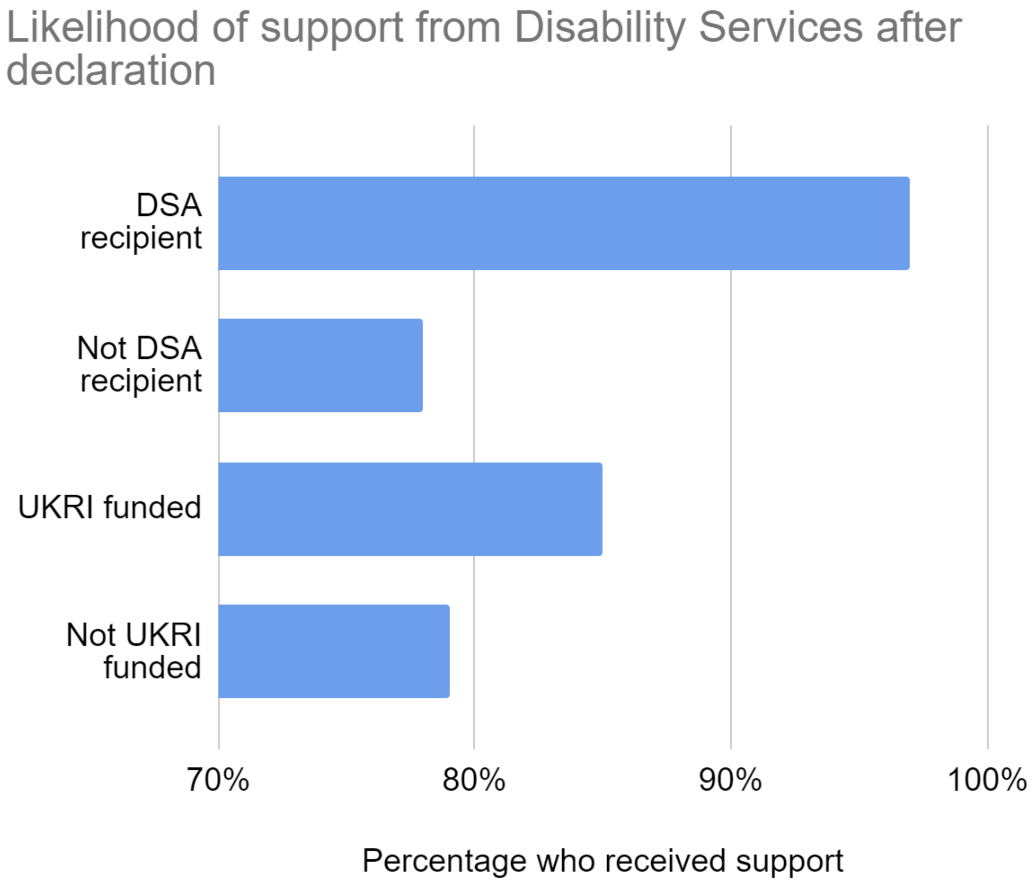

Figure 4. Difference in university support depending on funding source

Staff or student support

A third way in which disabled doctoral students fall through the cracks relates to a lack of clarity regarding whether they should receive student or staff support - and where funding should come from if they go the staff route, again due to lack of ring-fenced funds. This issue was illustrated by one of the survey respondents:

> *"Occupational health initially said they couldn't help me, as I am not employed, however after 3 months of back and forth, they agreed to send a member of staff to do an assessment of my workplace. This advisor was able to recommend an ergonomic chair, and measured me for this, but was unable to recommend anything to help adjust the microscope. I had to spend time doing my own research and searching out other disabled PhD students / postdocs online to ask for suggestions. Once I found an adjustable eyepiece that I believed would help, my occupational health advisor was happy to recommend that this be purchased for me. The occupational health advisor then passed on the details of the chair and microscope eyepiece to my supervisor and my dept HR, recommending that these be purchased for me. However, HR were then repeatedly asking me how to pay for these items, and I had to spend a significant amount of time chasing occupational health, [Disability Services] (which don't seem to interact with each other at all), and my MRC programme, to find where this money could come from. This meant that 9 months passed between having my assessment by occupational health and the items actually being ordered, during which I was in significant pain and really struggling to do my lab work. In addition, my occupational health advisor said that if I was employed, the university would have paid for private physiotherapy for my pain caused by the inappropriately positioned microscope, however because I am a PhD student I don't count as an employee, so I waited nearly a year for an NHS appointment."*

The lack of clarity regarding whether a student should engage with the employee provision or student provision of support was echoed by staff members interviewed for the report, reflecting a lack of institutional awareness of appropriate funding streams and processes. Staff members gave several examples where the provision of support was reliant on the student uncovering and navigating a bureaucratic workstream in parallel to their doctoral work and other responsibilities.

This could partly be solved through more centralised funding processes as well as communication around this. One survey participant writes:

> *“There should be one clear method for paying for any reasonable adjustments recommended by occupational health or the [Disability Services department], and all HR staff should be trained to know this pathway and the payment method.”*

Lack of familiarity with the needs of research students

In addition to a lack of clarity regarding which body was responsible for approving support, many participants felt that DS, the most obvious candidate, were currently less equipped to help PhD students compared to taught students. When asked what support they received from their DS department, approximately one in ten respondents unpromptedly mentioned that DS either were confused about research degrees or had no relevant support to offer PhD students:

> *“Disability services staff were very kind and wanted to help, but just had no experience supporting PhD students, especially those working in labs. I went to them because long hours working at an inappropriately positioned microscope was exacerbating my chronic pain and making it very difficult to work, and initially all they could offer me was "extra time in exams, and permission to record lectures". Both of these accommodations are useless because as a PhD student I don't have lectures or exams. It felt like they had no idea how to support anyone that wasn't doing an undergraduate degree. After a few months, they lent me an ergonomic mouse, which has been some help.”*

The same issue was raised in our focus groups:

> *“I think quite a big issue is that there's no real, like, centralised help you can access as a doctoral student [...] the advice they give is based around teaching access. And, you know, we're the ones that are supposed to be doing the teaching. So it's not, like, it's just not applicable in a lot of ways.”*

The lack of familiarity with the particular circumstances of PhD students is likely related to the fact that PhD students made up only 4% of new students in 2021/22 (HESA, 2023b, Figure 3). One departmental administrator interviewed for this report described that disabled research students with complex disabilities may appear as rarely as every five to ten years, and emphasised that the department then requires advice and input. Further complicating the needs of PhD students, their activities can be quite varied: A PhD student may have a taught period to start with (undertaking skills development sessions as well as subject related sessions), followed by a period undertaking research, followed in some cases by fieldwork or placements away from research organisation.

Previous research supports the finding that there is a lack of understanding of adjustments relevant to postgraduate students and scientists (Careers Research and Advisory Centre, 2020; Johnson et al, 2019) with inappropriate adjustments sometimes being provided instead (Johnson et al, 2019). The kind of support our survey participants reported receiving via DS is similar to that offered to undergraduate and postgraduate taught students. Only 2 out of 142 students who responded to the question in our survey about support from DS mentioned some form of PhD-specific support being provided by their DS.

Under the current circumstances, only 23% of students found the support they received from Disability Services "very helpful". This is problematic as the purpose of reasonable adjustments is to completely remove the significant disadvantage that disabled students find themselves at. The Equality and Human Rights Commission (EHRC) has made it clear that an adjustment that only partially removes the barrier, or is only somewhat helpful, is unlikely to be a sufficient reasonable adjustment (Equality and Human Rights Commission, 2014).[8] Thus, on EHRC terms, arguably a majority of PhD students are lacking the support they are entitled to.

In the final question of our survey we asked respondents what changes they wished that their university would make to become more accessible to disabled

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[8] *"Where there is an adjustment that the education provider could reasonably put in place and which would remove or reduce the substantial disadvantage, it is not sufficient for the education provider to take some lesser step that would not provide education or access to a benefit, facility or service in an accessible a [sic] manner".* (Equality and Human Rights Commission, 2014, p.106)

doctoral students. One of the most common themes in their answers was to ensure that there was support tailored to PhD students. The lack of specialised knowledge among DS is especially worrying as DS tend to be the most knowledgeable body: Of all the staff and bodies which students declared their disability to, DS were indicated as the most knowledgeable and accommodating, with students rating them on average 3.5 on a 5 point scale. Given the importance of DS it is crucial those that approve support are upskilled to have an understanding of PhD students' needs, rights, and the system of support available to them. One survey participant writes:

> *"All workers at the [Disability Services department] should be trained on the needs of PhD students and lab based students, as currently they only know what to offer to undergrads."*

The issue of lack of familiarity with the needs of PhD students also extends beyond DS, to external needs assessors. Doctoral training programme staff members who contributed to this report argued that the DSA study needs assessment process is generic and built on the same methodology as the taught student assessments. This may be a contributing factor to the finding that a greater proportion of postgraduate students (39%) found the DSA application process difficult compared to students overall (31%) (Johnson et al, 2019, p31). The 'needs assessor' is likely most adapted to a relatively static course structure and may assume that reasonable adjustments for PhD students will simply be building on those that are recommended for taught study. Reasonable Adjustments from prior study were thought to be somewhat relevant for year one in some cases but not often aligned with the research environment.

Conclusions

It is important for a smooth transition into their studies that disabled PhD students have individualised support in place as early as possible. The application for support is a high stakes process, as accessing appropriate support and adjustments for study is necessary for disabled students to be able to access their education on equal terms to their non-disabled counterparts. Not having adjustments in place prior to the start of a student's doctorate means that the student is at a disadvantage in their studies. Students who did not have the support they needed were also 1.5 times more likely to say that their studies had negatively impacted on their physical health.

To ensure support is approved in time, students must know where to apply for support, and must think that making an application is going to be worth the time and energy investment. As we have seen in this chapter, in addition to students being pushed from one body to the other, there are a number of issues with the current support system that disincentivise applications:

- Support is spread over different bodies, resulting in a greater administrative burden for the student (to be discussed further in Chapter 2).
- It is unclear to many students what support they can get from which bodies.
- There are gaps in support provision with key adjustments being omitted.

43% of our sample had held back from discussing their disability at some point, because they did not think that the adjustments or support on offer were going to be effective/make their experience much more equitable to the experience of a non-disabled student. 38% had held back because they thought the support that existed was for students enrolled in taught degrees, and thus not helpful for them (see Table 2). Several focus group participants expressed that factors such as these resulted in not applying for support:

> *"I'm like, I've got enough to do right now. Like, I'm trying to settle into a PhD and stuff like that. And I really can't be bothered to spend hours filling out forms for stuff that I may or may or may not even get. And if I do get it, will it be useful? Maybe, but maybe not. And it's just like, yeah, a lot of work for low reward, in my past experience. I'm like, 'why would I do that again?'"*

Previous research has found that doctoral students have limited faith in the benefits of going through the application process for formal support (Careers Research and Advisory Centre, 2020). This was echoed by doctoral training programme staff interviewed for this project. They observed that the current system often leaves students in limbo, confused about what route to follow and stressed by the processes and systems as a whole which adds problems rather than providing resolution.

A single point of contact

While it is important to have a holistic approach to disability support, with staff members across departments and services taking responsibility (as we shall see in Chapters 3, 4, 5, 6 and 7) the confusion around responsibility is currently leading some disabled students not to receive the support they need. It is important to reduce the number of processes that students need to go through in order to receive support. A system where the same student needs to go through DSA for some support, DS for some support, OH for some support, their academic department for some support and Access to Work for some support, discourages applications.

While their support provision is not perfect, taught students do have a single body to turn to which is intended to communicate with other bodies on their behalf and help arrange their support: Disability Services. There are a few reasons why a properly funded and resourced DS may be most suitable for providing formal individualised support also to doctoral students:

- Decentralised support is often harder to access for disabled students due to staff members being less educated about specific disabilities, disabled students rights, and the processes that enable support. Despite the difficulties with PhD-specific support, students found DS more accommodating and knowledgeable on average (3.5 on a scale from 1-5) than other administrative staff (3.4), other student services (2.9).
- Despite OH being more specialised for the needs of staff, DS were found more accommodating and knowledgeable than OH (3.5 versus 3.1).
- It was raised in the focus groups that DS, unlike OH, are more informed about the complexities of DSA (several students considered the Access to Work application a comparatively easy process).
- Only 12% of disabled students who teach currently receive support from OH, showing how underdeveloped this service is compared to DS.

- If support was centralised via DS, DS would still be able to utilise the expertise of OH, for instance, to carry out workplace assessments.

Recommendations

1. The bodies responsible for approving and funding disability support for PhD students within and outside the research organisation should improve their communication and establish clear remits so that all administrators are on the same page regarding which bodies are responsible for what. This clarity should be reflected in staff and student facing guidance. For instance, SFE and similar funding bodies should clarify that those funded by Research Councils are eligible to receive DSA from their Research Councils.

2. DSA funding bodies should ensure that the DSA application process is adapted to the specific and varied needs of doctoral students and that study needs assessors are trained in this topic.

3. DS staff should receive development sessions and guidance on the funding application process for PhD students and PhD students' needs to ensure that they are able to provide support tailored to this population.

4. UKRI should change their DSA guidance to acknowledge and incorporate the legal obligation to provide disabled students with all reasonable adjustments to fully remove the barriers placing disabled students at a significant disadvantage.
    a. UKRI should consider funding ergonomic equipment and furniture for the space in which PhD students conduct their research, in line with other DSA funders (see Chapter 6).
    b. UKRI should consider the benefit of funding disability support upfront, rather than after the institution has already procured it.
    c. UKRI should ensure that there is a process in place for obtaining DSA covering anticipatory adjustment put in place before the start of a students' grant period, adjustments needed during extension periods, as well as adjustments needed after the grant period, such as during any unfunded writing up periods.

5. UKRI should change their terms and conditions to *"provide further information [...] on the need for anticipatory reasonable adjustments as well as the provision of DSAs*" (Pugh, 2023, p.17) in keeping with the recommendation of the 2023 Assessment of UKRI terms and conditions of training grants from an EDI perspective, currently under review.
    a. UKRI should "*ensure that grant holders are aware of the need to ensure that reasonable adjustments cover the breadth of a doctoral student's research for example, to the research environment, within their department, during field work and while on work placemen*t" (Pugh, 2023, p.17) in keeping with the recommendation of the 2022 Assessment of UKRI terms and conditions of training grants from an EDI perspective, currently under review.
    b. UKRI should change their terms and conditions to inform research organisations of the obligation to consider the needs of disabled students in their health and safety assessments, in keeping with the recommendation of the 2023 assessment of UKRI terms and conditions of training grants from an EDI perspective, currently under review (Pugh, 2023).

6. DS should be the dedicated body for disabled PhD students within the research organisation, including for those who are employed.
    a. All communication should go via DS to reduce the administrative burden on the student. Workplace assessments for PhD students should be arranged via DS.
    b. DS should be better connected with specialised bodies such as OH, academic departments, Doctoral Training Partnerships or other doctoral training programmes and should work closely with them to take advantage of their expertise when it comes to PhD students.
    c. DS should refer employed students to Access to Work only for those services which DS cannot provide such as physiotherapy.

7. Research organisations and funding bodies should systematically inform all PhD students that they should engage with DS for formal individualised disability support, as well as providing information on who to turn to for common types of support which DS cannot provide such as extensions of their programme.

8. Research organisations should investigate why DS is less likely to provide support to doctoral students who are UKRI funded or who do not receive DSA, keeping in mind that these students have the same right to accessibility as other students.

9. Research organisations should ensure that DS has access to ring-fenced central funding for disability related individualised adjustments, allowing the institution to pay upfront for the support of those PhD students whose funds are reimbursed later (as per UKRI guidance) or who do not receive DSA (such as most international students, see Chapter 6).

10. Research organisations should investigate why so few PhD students are receiving workplace assessments, whether this is due to poor connections between DS and OH for instance.
    a. Occupational Health should offer a workplace assessment as standard for any new disabled PhD student, including those who are neurodivergent (see Chapter 6).
    b. Any risk assessment to ensure the safety of the disabled student and their co-workers should be carried out with compassion and happen in conjunction with an assessment for support, always keeping in mind the obligation to make reasonable adjustments.

11. Funders and research organisations should especially prioritise the international student population (see Appendix A for details)
    a. Funders and research organisations should clarify in their information to PhD students that international disabled students have a right to the same support for their disability related study needs as home students.
    b. Funders such as UKRI should collect data regarding the proportion of home fee eligible and international fee eligible doctoral students that are disabled, both for applicants and for students accepted onto doctoral courses. Funders should investigate the possibility that their grants are not going to disabled international students to the same extent as disabled home students and implement measures to ensure that disabled international students are not disadvantaged.
    c. Funders such as UKRI which provide DSA for international students in principle, should investigate the possibility that disabled

international students awarded UKRI funding are not aware of and receiving DSA to the same extent as disabled home students, and funders and research organisations should implement measures to ensure that international disabled students do receive DSA support for disability-related study needs.

   d. DSA funders which currently do not offer DSA to international students, should consider following in the footsteps of UKRI and offering DSA to international students to ensure that they receive the same level of support for their disability-related study needs.
   e. Research organisations should review why Disability Services does not currently provide equitable support to those students who are not in receipt of DSA (see Chapter 1).

12. UKRI should evaluate whether research organisations are meeting the terms and conditions as regards disabled students through evaluating statistics regarding the disabled student experience within the research organisation. This could be done through the Annual Disabled Student Survey (Disabled Students UK, 2023), a comparison recommended by the Disabled Students Commission (2023).

2. Reducing the administrative burden

Easing the route to support

Those who had found the administrative process of setting up support quick and easy were 4.5 times more likely to state that they had the support that they needed compared to students who had not found it quick and easy.

When we asked our survey recipients what their institutions, funders and research centres should do to become more accessible to disabled students, the single most popular answer was to make changes which reduce the administrative burden on disabled students.

The administrative burden on disabled students in Higher Education is well evidenced. Coughlan and Lister (2018) documented the challenges caused by the way disabled students are required to complete forms, navigate information, communicate and go through needs assessments[9]. One of our focus group participants described this:

> *"I've only recently received support, and I'm almost a year into my PhD now. So like, I feel like, in a way they make the process really difficult. Like, you have to provide evidence and my first evidence got rejected, which can be really like disheartening. And then you've got to get another doctor's note. And obviously, that takes a while. And then yeah, like I almost gave up at one point, but then I just kept going, and I don't have a lot of energy as it is, and the stress that it causes can also make my condition worse."*

In addition to the practical work required to gain support, the administrative process also often requires 'emotional labour' (Wilton, 2008). The disclosure of

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[9] The burden is also covered in Chapter 2 of *Arriving at Thriving* (Higher Education Commission & Policy Connect, 2020) and Chapter 4 of *Going Back is Not a Choice* (Disabled Students UK, 2022).

one's needs requires vulnerability, and yet it is not unusual for the application to be rejected. One focus group participant comments:

> *"[T]he processes [...] also tend to really rely on like, laying your soul bare, like this whole emotional burden of sort of having to prove that you are in sufficiently dire need for them to be worthwhile caring about, is really draining. And a lot of people just get to the point [...] where they go through all of that, without any certainty that I would even actually get any support, let alone whether that support would be adequate or appropriate, or what I need. I just can't be bothered. And I will just sort of struggle along. And it's really bleak. But yeah, the processes are always... they're never built from a place of compassion."*

In the previous chapter we saw how issues that especially affect doctoral students add to this burden: support is spread across too many bodies, with unclear structures of responsibility. 45% of our survey respondents found the administration related to their studies very or somewhat inaccessible. The experience is shared across disability types, and compounded for those who have other disability support to manage, fatigue or executive dysfunction (which makes organisation difficult). We asked our survey participants whether they had found the administrative work involved specifically in gaining support easy and quick. 48% disagreed with only 30% agreeing.

Staff interviewed within the doctoral training programmes and universities noted the high burden on students to navigate and pursue mechanisms for funding support, arguing that the processes are often highly impersonal and more anxiety provoking and emotionally taxing than they need to be.

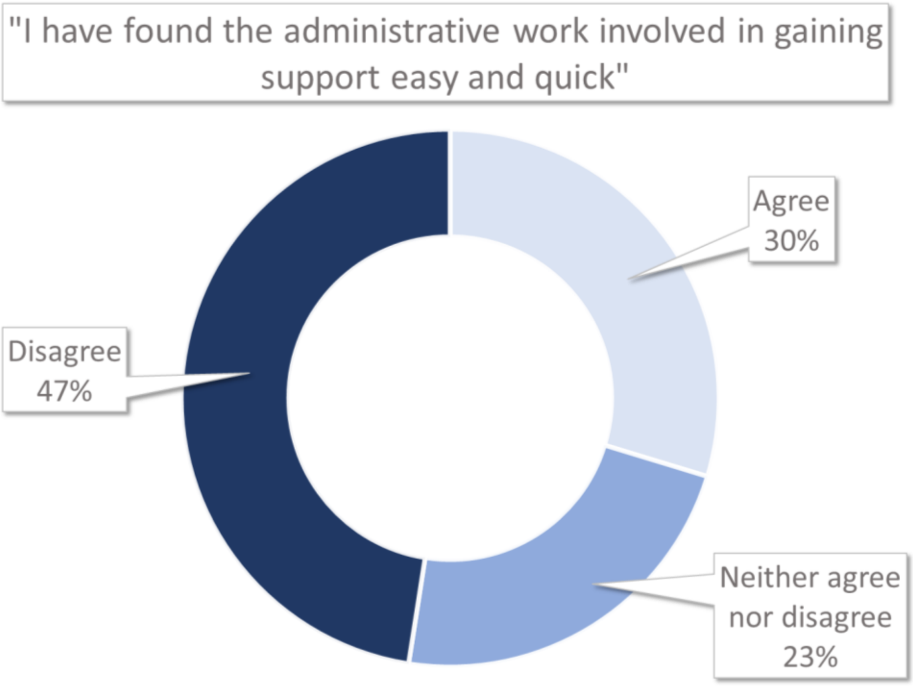

Figure 5. Ease of admin

Factors increasing the administrative burden

In addition to the lack of clarity around who is supposed to fund and approve support addressed in Chapter 1, students highlighted the following four barriers[10]:

1. Lack of information about what support is available
2. Unnecessary evidence requirements
3. A disproportionate communication burden and unclear processes
4. Underfunding of Disability Services

Lack of information about what support is available

When students do not receive information upfront about what support it may be possible for them to receive, it places the burden on the student to research possible adjustments and disincentivises support applications. This was a common issue raised by survey participants:

> *“I don't even really know what is available to me at the moment as I haven't been able to meet with disability services.”*

Staff interviewed for this report similarly highlighted the importance of informing students about possible ‘reasonable adjustments’. Several staff members argued that students need clear information to be able to make informed decisions, but also for adjustments to be normalised. One staff member argued that sharing the definition of a ‘Reasonable Adjustment’ was an absolute minimum; but it would be even more helpful to outline a number of potential Reasonable Adjustments based on the adjustments of previous PhD students. This is especially important for PhD students as the adjustments they need are likely to differ from adjustments needed by taught students.

Some survey participants directly related lack of information to the evidence requirements:

> *“Disability services have largely been very helpful, however they would not even discuss what could be available until I presented evidence of a*

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[10] Even once initial support had been agreed there were barriers such as lack of implementation, lack of follow up and a lack of a culture of support. We will address these in Chapter 3.

> *diagnosis, which I found intimidating as I was unsure if I wanted to disclose initially."*

Unnecessary evidence requirements

Different administrative bodies will impose different evidence requirements and while the majority of participants found the evidencing process straightforward (54%) some struggled (29%). One survey respondent commented:

> *"I had an interview with a student disability support worker at the start of the year. They got me forms for allowances and told me how to fill them in, but I never completed or submitted them because they were too complicated and required a lot of data gathering."*

Sometimes the evidence requirements are clearly unnecessary. A focus group participant made a tongue-in-cheek comment on the absurdity of needing to renew the evidence for their specific learning difficulty, a lifelong condition:

> *"I had DSA when I was an undergrad. I don't have it now. Because, well, partly, I would have to get re-diagnosed. Because you know, in the four years since my diagnosis, my brain may have completely changed its orientation to become undyslexic."*

Across many sectors, including Higher Education, the most commonly declared disabilities are neurodiversity, mental health difficulties and chronic health conditions. Given the known pressures on NHS and other health and diagnostic services there is a feasibility issue with insisting on evidence before making any adjustments. The onus on providing evidence leads to delays of support that is necessary in order for disabled students to have an equitable experience. Staff within universities and doctoral training programmes who were interviewed for this report noted an increase in neurodiversity and mental health disabilities in the last few years and several reported students withdrawing in the face of lengthy diagnostic waiting times and unwillingness to make adjustments without proof.

Survey participants who found the process of providing evidence straightforward were 3.4 times more likely to have the support they needed compared to those who did not find the process straightforward. Several survey participants commented on the need to improve practices around evidencing:

> *"Offer more help to students who suspect a disability or a long standing mental health condition."*
>
> *"The biggest change would be to believe and accept students' disabilities even if they don't have a formal diagnosis or documentation. This would involve adjusting the process for requesting accommodations and making it more accessible to those who do not yet have formal documentation. I struggled severely for the first 2 years of my degree due to health issues and lack of accommodations, but I did not have the required medical diagnosis documentation to be able to submit the online form and begin the accommodations process."*
>
> *"Until I filled in this questionnaire, it never occurred to me that I could complain about the lack of support [my university] offered. I'd told them I was on a waiting list of ASD assessment, but there was no support available without a diagnosis, and the waiting list was 18 months long, so it's been a bit of a surf-through-hell-on-a-chocolate-board really."*

Requiring evidence of medical diagnoses rather than investigating the needs of the student is out of step with the 2010 Equality Act and risks putting the Higher Education Provider in a difficult legal position. This was highlighted by the Natasha Abrahart ruling that her university has failed to put reasonable adjustments in place in part because they were waiting on a medical evidence despite the fact that Natasha's disability was already apparent to staff[11].

A disproportionate communication burden and unclear processes

As has been documented many times for taught students, being the one to go between different staff members and bodies, offering solutions and explaining the process of support to staff, can cause a lot of strain on the student. This may be exacerbated by the confusion regarding responsibility for PhD student support. One focus group participant comments:

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[11] See Abrahart v. University of Bristol (2022, p.28), *"the University's staff could see for themselves that Natasha had a mental impairment which had a substantial and long-term adverse effect on her ability to carry out an otherwise normal task within her course from October 2017".*

> *"I've also experienced difficulties with lab work. Because I feel like I've had to be the person to do all the arrangements to make it accessible. So I've had to chase people and come up with sort of ways for the labs to be accessible to me. Only through emailing loads of people, am I now able to do some lab work, and I feel like it's just a big barrier, because obviously, like, not everyone can fight and send so many emails. Whereas other students can just go in the labs, for me, I've had to do, like, a lot of sort of fighting for it."*

Another focus group participant highlighted the need for better communication practices to reduce this burden on the student:

> *"I think one of the massive issues as well is that--and I don't know, it might be different in different universities, but it tends to be dealt with here that you're kind of managing multiple different organisations and people, and none of them actually communicate with each other despite the fact that they all tend to be like, 'Oh, you need to ask this person to do this, and then we'll do that.' And I feel like it needs to be dealt with more in a multi-discipline meeting kind of way almost, at least initially. Because what you end up doing is you'll get a phone call from say, DSA say, saying 'Your university hasn't filled in the form correctly, you need to approach them and tell them'. And actually you ended up going in between all these different people when they could be communicating with each other and that would actually take some of the burden off of you. [...] Say, like, [...] the university set up a central, say like, almost like an online profile where everyone, say like, your DSA providers could view messages on, or a DSA worker, and, and your disability support worker in university [...]. Everyone could be involved and see what people needed to do, almost like a discord page. Without it being all down to the disabled person to kind of go between everybody and try to manage everybody."*

As detailed in Chapter 1, part of the problem is a lack of clarity even among staff regarding who is responsible. However in other cases the process is simply not clarified to students. Several focus group participants commented on the need for greater clarity around both what support is available and how the support application processes work:

> *"I find it incredibly hard, and actually quite sort of degrading, because I was having to reach out over and over again and then being told, [...] "I'm*

> *not the right person". So, like an overview system, an overview of what's available. And a sense that you're sort of being supported in that process continuing on, because everyone knows who's responsible for what."*
>
> "[it would be good to have] *a sense that there is a bit of a timeline of what we expect. So whether or not the requirements for evidence stay the same. I understand that for different things they want different information. There can still be like, a menu of options of like, these are the things that can be available to you as a student who needs support. This is all of the stuff we can offer. And a sense that like, here are the steps that are going to take place, and then we can say okay, we're stuck at step two, and now that means that I need to go and email someone else. Or actually, step two means that I need to wait for them to come back to me. Some clear outline of like, what the process actually is at the offset. Because I had no idea."*

Several survey participants made similar points on the need for clarity:

> *"It would also be more helpful to see specific detail on how PhD students can access support on the website".*
>
> *"Give new joining PhD students a pack containing leaflets on resources, proper protocols, complaints, training, what to expect, who to ask for help, etc, etc."*

Underfunding of Disability Services

In keeping with previous research (Disabled Students UK, 2022), many survey participants reported issues with DS consistent with an underfunded and overburdened department: delays, paperwork getting lost or needs being recorded incorrectly, staff not responding to emails, long wait-times and having to constantly chase in order to receive support. When asked what support they received from DS survey participants wrote:

> *"None. I was told I was eligible to access lots of things, but they recorded information incorrectly (they thought I had a laptop and I don't) and all the software I was awarded required a laptop. They just told me to buy a laptop but I didn't have the money, so I've had no support at all."*

> *"Once I got registered (took several months of me chasing my college [Disability Services] person, despite having submitted my evidence early) I only got the physical adjustments I needed to my working space in place ready for my first day because I contacted my doctoral programme directly. Otherwise, I would have been without the adjustments I needed for the first month of my studies. My college [Disability Services] person was utterly useless. I was eligible for mentoring and specialist equipment through DSA, which, again, took forever and only really happened when my [Disability Services] person left and was replaced by someone vaguely competent."*
>
> *"[T]he process has stalled and it's been 3 years now and I don't have the energy to fight anymore."*

18% of participants who declared a disability to DS received no support from them. Borkin and NADP (2023) surveyed 103 HE disability services staff members, finding that the average disability advisor is currently responsible for 583 disabled students. The latest guidance (HEFCE, 1999) recommended a ratio of one disability advisor to 200 disabled students. This ratio leads many disability staff members feeling tired and overwhelmed with 30% stating that they do not feel supported by the higher education provider that they worked for (Borkin, 2023) and 34% stating that attending disability relevant training did not fit into their current workload.

When staff members are put in the position of gatekeepers and provided with insufficient resources to provide the support students need, it erodes staff morale. Borkin (2023) found that 15% of disability services staff are in receipt of Access to Work or similar, indicating that disabled people are overrepresented in this group. Staff exhaustion due to process and funding failure can easily lead to burnout and a situation where they are having to choose between their own health and the needs of the student. This is especially important to consider as a decade of decline in Higher Education working conditions is already eroding staff morale (University and College Union, 2022).

Several participants explicitly noted that funding of DS was an important part of the solution. One focus group participant commented that *"[b]etter funding for disability services feels integral to me. It feels like the first thing."* Several survey participants echoed this:

“Fund the disability services so they are no longer so horrendously overworked that it takes months for them to reply to their emails.“

“Employ more people in the disability offices so students don't have to wait for months after they start to get the reasonable adjustments they need and are entitled to from day 1.”

Conclusions

Having looked at four causes of the admin burden, let us consider its consequences. Those who had found the administrative process of setting up support quick and easy were 4.5 times more likely to state that they had the support that they needed. As detailed in Appendix C, the administrative burden was so impactful as to influence institution choice:

> *"I decided to stay at the same university so I wouldn't have to go through the process of disclosing my disability again, and have to rearrange support."*

Those of our survey respondents who had not found the administrative process of setting up support quick and easy were 1.3 times more likely to say that their degree had negatively affected their physical health. Coughlan and Lister (2018) found that the most common issues disabled students faced in relation to the administrative burden were related to their health and their studies: increased stress level, the worsening of their conditions, losing studying time, and problems arising when support was not arranged in time. Several of our focus group participants similarly noted the effects that the emotional and cognitive burden had on their time as well as on their conditions. As we shall see in Chapter 4, many disabled students already have mental health difficulties and the burden can exacerbate these, alongside physical health conditions (Hazell, 2022). In addition, this barrier exacerbates the sense that many disabled researchers already have that they do not belong in academia.

The fact that the administrative processes were so burdensome also affected students' willingness to continue or even start a support application process. 29% of our sample had held back from discussing their disability at some point because they did not want to go through the administrative process required for support (Table 2). One focus group participant recalls considering making a DSA application:

> *"I looked at DSA, but just the length of time that it would have taken to get any funding through [...it] just felt completely pointless [...] Also, you know, after shielding for like so many months, I was already completely burnt out and mentally drained anyway, I just didn't have any extra energy. So I ended up [not] going for it and just sort of going, "it's fine, I can stomach this for a bit".*

At this point the administrative burden is one of the best evidenced barriers to accessibility in Higher Education and yet it is often ignored. There was a perception among several focus group participants that the support application processes are not being simplified because bodies are attempting to limit the support they fund. One focus group participant comments:

> *"I feel like it is definitely like a lot of energy to have to like, arrange all this stuff. But also, I feel like on their part they do kind of make it in a way where it is kind of difficult to get it because I feel like they probably don't... they want to limit the amount of students, they're giving, like, funding to. That's the sort of impression I got. But then once I got accepted, from there the people I met with were very helpful. But just trying to get to that point where I was accepted was a bit difficult, and it definitely could have been made a lot easier, I think."*

To sustainably reduce the administrative burden, it is important to adequately incentivise this reduction. For instance, within Arriving at Thriving (2020) the Higher Education Commission recommends that the Office for Students monitor "*the extent to which HEPs monitor and reduce the administrative burden on their disabled students*" as a key indicator of a Higher Education Provider's support for disabled students (Higher Education Commission & Policy Connect, 2020, p.8). For PhD students, this type of regulatory role could also be played by UKRI and other funders, which have the power to influence research organisations through setting the terms and conditions for their funding.

Recommendations

1. DS should provide clear and widely spread information (which students can access before declaring a disability), about what support may be available, and what the process of acquiring support looks like. As the student begins the application process DS should provide more detailed guidance so that every step required is clear to the student as well as whoever is responsible for each step.

2. UKRI should provide information and guidance for prospective applicants and those in receipt of a UKRI studentship regarding reasonable adjustments and DSA, as recommended by the Assessment of UKRI terms and conditions of Training Grants from an EDI Perspective, currently under review. (Pugh, 2023).

3. Research organisations should adequately fund and resource DS so that they are able to reduce admin times to reasonable targets, and improve the proportion of students who go from disability declaration to implemented support.

4. DS and DSA funders should provide support based on an assessment of need rather than medical diagnosis, in keeping with the Equality Act 2010.

5. DS and DSA funding bodies should implement better communication processes. Rather than communicating via the student, there should be an online system accessed by DS and funding bodies which allows them to communicate about the stage of the application, and what has been agreed.

6. DS should take a more active role in facilitating the application process, communicating with other bodies involved and problem solving any steps where the process halts (see Chapter 3).

7. UKRI should include in their terms and conditions measurable conditions that grant holders should:
    a. Inform students about support available and how to go through the support application processes.
    b. Adequately fund their DS and ensure a reasonable average time period from declaration to support implementation.
    c. "*only ask for evidence of disability where it is necessary to do so*" (Pugh, 2023, p.17) in keeping with the recommendation of the 2023 Assessment of UKRI terms and conditions of training grants from an EDI perspective, currently under review.
    d. "*make reasonable adjustments, as soon as they are made aware of a person's disability or could reasonably be expected to know that a person is disabled*" in keeping with the recommendation of the 2023 Assessment of UKRI terms and conditions of training grants from an EDI perspective, currently under review (Pugh, 2023, p.17).

    Note that Disabled Students UK is already measuring HE providers on such criteria as part of their Access Insights project, a potentially valuable resource for UKRI.

8. UKRI should investigate where they may be able to reduce the administrative burden on disabled students through removing barriers in their own processes, such as delays in responding to staff questions regarding accessibility (see Chapter 3 and Chapter 7).

3. Decentralised support

Enabling a holistic approach to disability

Students who did not have to repeatedly explain their access needs were 2.5 times more likely to feel they belonged at the institution compared to students who did have to do so.

Students who did not have to intervene in order to have their agreed support put in place were 2.2 times more likely to feel they belonged compared to students who did have to intervene.

The responsibilities of decentralised bodies

Once adjustments have been agreed within Disability Services, Occupational Health or a similar support approver, a list of adjustments is then sent to a number of educational and administrative staff members within the student’s academic department, research group, Doctoral Training Partnership or college, with the student’s consents. These staff members are then expected to step in to implement agreed support.

In addition to implementation, these decentralised bodies are often responsible for:

- Applying universal design principles to the physical environment (see Chapter 6), digital environment, assessments or processes such milestone assessments.
- Providing individualised adjustments before the students has gone through the support application process, e.g. for the doctoral application process.
- Signposting the student to centralised support.
- Providing pastoral support and ensuring the interpersonal environment is supportive (see Chapter 4).

- Approving sick leave or extensions (see Chapter 7)[12].

Decentralised support is commonplace. 76% of respondents had received some form of disability support from their supervisor(s) (addressed in depth in Chapter 5), 29% had received support from technical or administrative staff outside of student or staff disability services, 23% had received support from a mentor or advisor, 16% had received support from an educator, 17% had received support from admissions staff and 11% had received support from assessment staff.

In this chapter we will first address challenges in the implementation of already approved support, to then look more widely at how decentralised bodies can be aided with the different forms of disability support they provide.

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[12] Decentralised bodies are sometimes also forced to step in to support students in ways that (as we have suggested in Chapter 1) should ideally be organised by centralised processes, such as providing ergonomic workplace tools, creating Personal Emergency Evacuation Plans (PEEP) funding support when there is no centralised funding, and communicating a student's support needs with other organisations, for instance when the student is on a placement.

Implementation of approved support

Our survey responses showed that a significant proportion of respondents experienced challenges in having agreed support implemented. Only 37% of students whose university, institute or research centre had agreed to provide adjustments, felt that these adjustments were quickly implemented without further intervention from the student (43% disagreed). Survey participants explain:

> *“The [disability] service facilitated me getting these adjustments but could not enforce them onto the academic staff who make the ultimate decisions on these requests.”*
>
> *“[administrative staff] passed the job around, avoided all responsibility. They suggested I should 'intercalate' because they had failed to get equipment in place.”*
>
> *“[Disability Services] made me a "support plan" which has never been referenced by anyone. if they even knew that I had a plan or that plans existed in the first place.”*

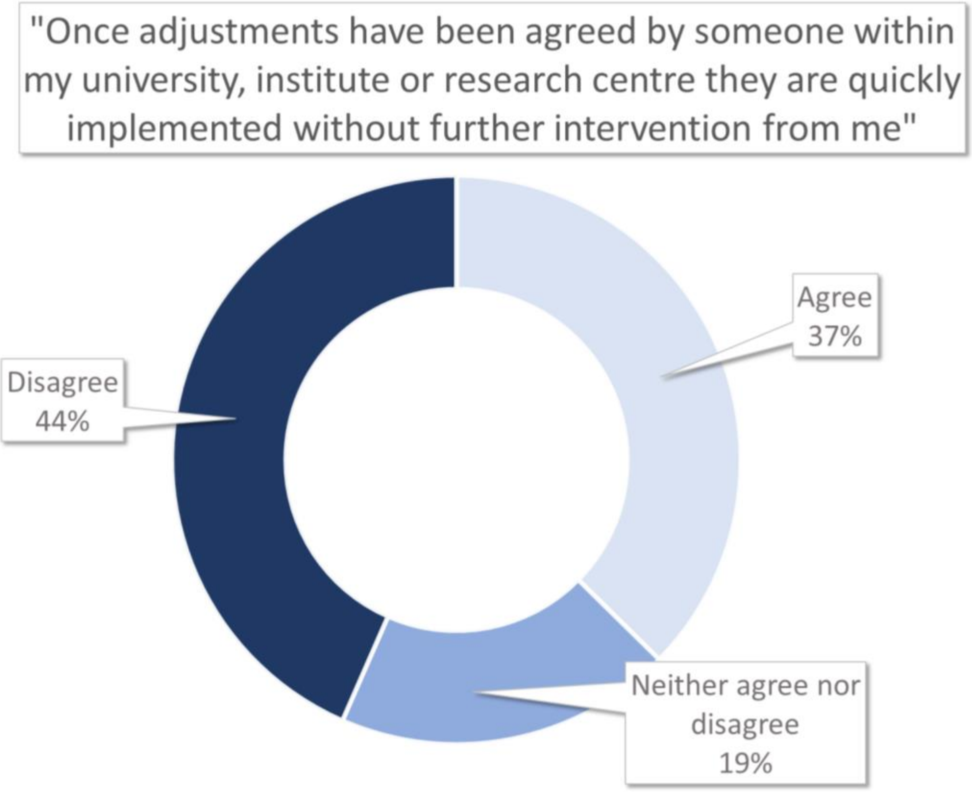

Figure 6. The need to chase support

Implementation failure has been widely reported in previous literature (Disabled Students UK, 2022; Higher Education Commission and Policy Connect, 2020) and is likely one factor explaining why 29% of our survey participants who had received support from Disability Services found it unhelpful. Students reported that support had been agreed in theory and yet in practice the support was never actually implemented.

Whether agreed support is implemented by decentralised bodies depends on individual staff members involved and whether they are knowledgeable and accommodating. One survey respondent's comment shows just how many staff members a doctoral student may have to navigate, and how variable their level of knowledge and helpfulness is:

> *"The lab managers and greenhouse staff are amazing. One person is super knowledgeable (she's disabled herself) the rest have no clue, but if you explain what you need, they will try their damndest to get something set up for you. The logistics managers are more of a mixed bag, very set in their ways and I sometimes have to argue the toss with them because they don't understand my access needs properly and don't have the active empathy and curiosity to find out (e.g. I had to make it clear (and get backed up by a PI) that I don't care if the air temperature reading in the greenhouse is 21 [degrees celsius], the irradiance temperature reading under the grow lights is 27 [degrees celsius], so I'm still going to faint if I stand there for too long) this is administrative labour I could do without. And this guy has nothing on the admin people. The admin people consistently forget or ignore my communication needs despite reminders and often make me do their job for them. They do not understand the difference between them enabling me (getting my input where it matters, but essentially them doing the work) and me doing their job, and often think they are doing a good job making things accessible by putting all the work of identifying the problem, thinking about possible solutions, running them past people and putting together documentation for that on me. That way disabled people are very involved in their adjustments plan, right?"*

Five barriers to implementation

Our research found five main barriers behind the failure to implement agreed support:

1. **Lack of resources and training within decentralised bodies**

Out of students who needed support, only 38% of respondents agreed that their institution was well-equipped to support them in all aspects of their PhD, including regarding taught material, placements, teaching, and lab work (41% of respondents disagreed). Many survey respondents wrote about a need for staff training. One survey participant described their experience with administrative staff thusly:

> *"It seems they want to help but it wasn't until very recently when they were approached on this. The admin simply haven't thought of supporting neurodivergent students in the same way as other disabilities/learning differences."*

2. **Lack of structures of responsibility within each decentralised body**

Just as there was a lack of clarity around the distribution of responsibility between different bodies (Chapter 1) there can be a lack of clarity around responsibility within decentralised bodies. One of the focus group participants recounted an experience which highlighted the consequence of this lack of clarity:

> *"I literally just needed a stamp to send the DSA form, and it took three weeks just to find out who could stamp and sign a form."*

Staff members interviewed for this report agreed that uncertainty about who has key responsibility for disability support is an issue. Doctoral training programme staff members highlighted that although the proportion of PGR students with a disclosed disability has increased substantially in recent years, from 7,225 in 2017/18 to 11,625 in 2021/22 (HESA, 2023b), disability support had not necessarily been resourced accordingly, with a lack of staff or a lack of clarity for staff as to who should be dedicated to these important tasks.

3. The list of adjustments not being communicated between responsible bodies

Our online survey asked participants to state if they agreed or disagreed with the following statement: “Despite having already explained my access needs, I find I then need to re-explain them in new settings, such as for placements or lab work.” Of those whose access needs had been relevant in two different settings, 78% agreed that they had to re-explain their access needs (8% disagreed). In theory, the aim of the list of adjustments put together by DS is to avoid such duplication, to reduce the administrative burden discussed in Chapter 2. However, if more than three out of four students are having to re-explain their needs, the list of adjustments is not being communicated as intended. When asked what support they were provided by the administrative staff they had disclosed their disability to, one survey respondent said:

> *“Almost none - I had to ask for things and was questioned as to why I needed them before them being granted after persuading them”.*

Students needing to once again persuade staff of the need for adjustments which have already been agreed is problematic. Several of the staff members interviewed from doctoral training programmes and wider universities confirmed that there were issues with receiving information and support plans. In these conversations there were regularly examples of university disability contacts at the department or faculty level having little engagement with or knowledge of doctoral training programme staff and structures. As a result, information was not passed on or arrived with a delay, such that anticipatory adjustments could not be made. This was a particular difficulty for Doctoral Training Partnerships which were considered separate from the institution and as such were not included on the default list of staff to inform. Even when asked, university staff sometimes hesitated to share information with Doctoral Training Programme staff.

This poor communication likely added to the delay caused by the lack of clarity around responsibility (Chapter 1) and the administrative burden on students (Chapter 2).

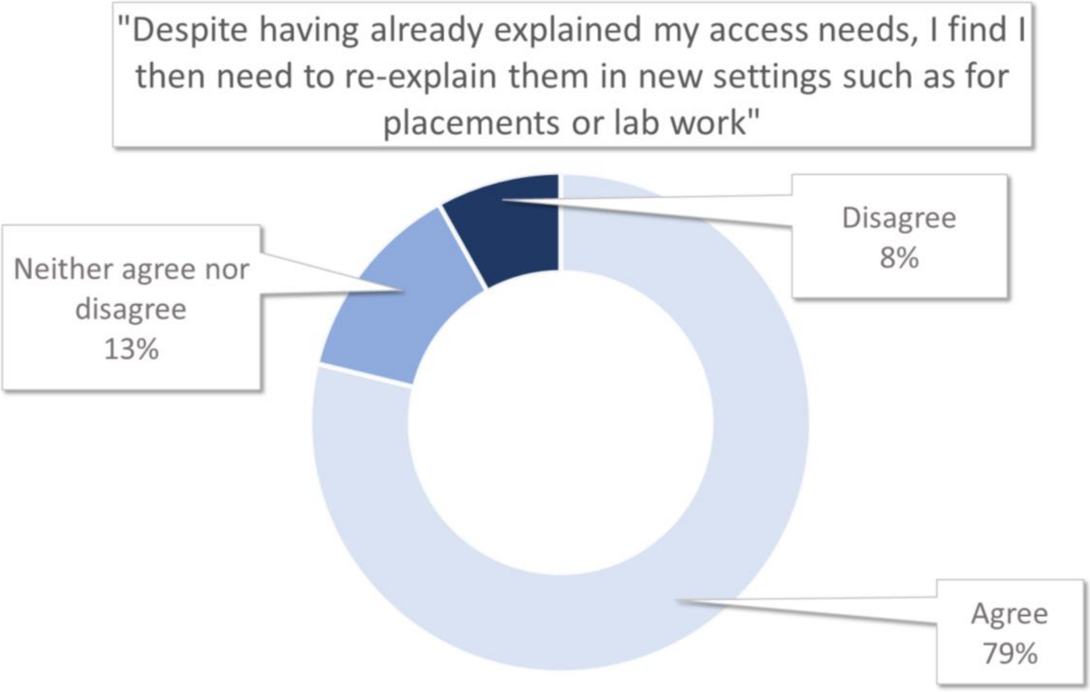

Figure 7. The need to re-explain needs

4. A culture of optionality

Students' testimonies showed that they sometimes had to re-explain themselves despite the fact that their agreed adjustments had clearly been communicated. In some cases the lack of implementation was due to staff simply ignoring the list of adjustments:

> *"They have my Learning Support Plan but do not provide, or ensure my courses provide, anything on it even when I request directly."*

Students often note that some staff members seem to see the implementation of agreed adjustments as optional. When decentralised staff refused agreed adjustments in this manner, this was sometimes a matter of ignorance, a sign that staff failed to realise the legal requirements around accessibility, sometimes a matter of attitudes (further discussed in Chapter 4), and sometimes a matter of agreed adjustments not being communicated with sufficient authority. These three issues were confirmed by disability advisors surveyed by Borkin (2023).

5. Lack of follow up from DS

While DS will sometimes step in and explain the legal responsibilities to other staff members if the student calls on them, in practice they often lack the resources or authority to enforce the implementation of agreed support. One survey participant writes:

> *"[Disability Services provided] no help in the department where all services claimed it was not their responsibility to help".*

Without support from DS the burden is much more likely to fall on the disabled student to once again advocate for themselves.

Consequences of implementation failure

Our research shows that despite disabled PhD students providing information regarding their access needs to their research organisation, despite the significant administrative and emotional burden that they faced to have adjustments approved, and despite a list of agreed adjustments being sent to the decentralised bodies responsible for implementation, decentralised staff regularly fail to implement agreed adjustments. This is due to ineffective systems of responsibility, communication, training and follow up which in practice put the research organisation and doctoral training programmes at risk of breaching their Equality Act duties[13].

As we saw in Chapter 2, the emotional labour required by students in going up against barriers time and time again in order to have agreed support implemented can be detrimental to their academic work, and compounds the likelihood of experiencing the mental health difficulties common for doctoral students (Woolston, 2021). Implementation failure also seems to have a particular effect on their sense of belonging. The need to re-explain themselves can signal to disabled students that they are not welcome: students who did not have to intervene in order to have their agreed support put in place were 2.2 times more likely to feel they belonged at the institution. Students who did not

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[13] *"The duty to make reasonable adjustment is far broader than is often appreciated; the outcomes required are not merely about ameliorating disadvantage, or providing some level of access to disabled students, but rather as far as is reasonably practicable providing access to the resources, experiences and benefits of study which approximates to that of non-disabled students."* (Disabled Student Sector Leadership Group, 2017, p.21)

have to repeatedly explain their access needs were 2.5 times more likely to feel they belonged.

Supporting decentralised bodies

Both when it comes to implementation of agreed individualised adjustments and when it comes to ensuring their environments and processes are accessible through universal design, it is crucial that decentralised bodies such as academic departments and Doctoral Training Partnerships have the right support.

While DS can and should step in to provide advice on the implementation of individual adjustments, they currently do not usually have capacity to support the adoption of universal design. It is therefore important that academic departments and doctoral training programmes have support from other teams dedicated to working on accessibility in a more universal and anticipatory fashion, creating guidance, training and being a supportive resource for decentralised bodies. Borkin (2023) found that only 9% of disability advisors felt that the Higher Education Provider they worked at had adopted and embedded the principles of Universal Design for Learning (universal design as it applies to teaching and learning methods).

Some institutions already have such teams for specific areas of accessibility; for example, a “digital accessibility team” which works on digital accessibility for individualised adjustments, institution wide universal design, as well as supporting decentralised bodies. Other areas where such teams may exist include Estates, Health and Safety, and Professional Development. Unfortunately no equivalent accessibility teams exist to offer best practice guidance and training on universal design as it regards PhD student specific topics such as milestone assessments and vivas. A disability advisory board convened by UKRI to support research organisations would be a useful resource.

Support from UKRI and the Research Councils

While UKRI and the Research Councils do answer questions about accessibility issues that arise, this process was criticised by the university and doctoral training programme staff we interviewed.

Many staff members brought up the retrograde nature of Research Council regulations in contrast to the much more progressive and inclusive wider university regulations, policies and procedures that provide more flexibility and, as one contributor observed: “*create an environment where childcare, disability* *and religious observance requirements should be accommodated without discomfort or [procedural] difficulty*". The 2023 Assessment of UKRI terms and conditions of Training Grants from an EDI perspective notes that UKRI terms and conditions for training grants currently do not so much as mention the duty to make reasonable adjustments (Pugh, 2023).

Research Council responses to questions about disability support were often described as being perfunctory and it was noted that, although the individual staff members are often supportive they regularly provide an excerpt of policy or procedure as their response to a complex DSA query, which felt dehumanising .. The Research Councils provide generic email inboxes which doctoral training programme and university staff are expected to use even for very complex and sensitive situations. Some interviewees characterised a call centre approach which felt like a depersonalised experience when a more human response was necessary. One staff member described the need for frequent and escalating contact with a Research Council with responses tending to quote regulations rather than solutions. It was acknowledged that the response from the Research Council was usually positive once it had been escalated, however the escalation added a bureaucratic burden that would benefit from a change in practice. It was also observed that UKRI is not harmonised or consistent and the same responses to the same question aren't guaranteed across councils.

The lack of a timely response was also mentioned by many of the doctoral training programme staff members who contributed insights to this project. Staff expressed hope that there could be more dialogue between Research Councils and doctoral training programmes. They noted more collaborative discussion within the universities and with the doctoral training programme which could easily be extended to include the Research Council teams.

The support provided by Research Councils does not extend to universal design but is focused only on individual students. As a result, the decentralised staff interviewed for this research reported a general lack of understanding for things such as the PEEP process, good accessibility practice in interviews, or the process of applying reasonable adjustments during milestone assessments.

The doctoral training programme staff we interviewed felt there was a need for better guidance and awareness-raising regarding accessibility processes in areas such as assessment and admissions. They articulated the need for guidance from experts convened by UKRI on milestone assessments as well as training and development expectations for supervisors and other key staff.

These conversations highlighted that it would be beneficial for UKRI resources to be developed that put forward good practice guidance when it comes to universal design, as well as listing examples of individualised adjustments that could be carried out by doctoral training programmes. The issues raised in Appendix B forms a starting point for which topics such guidance should address. An advisory board convened by UKRI or the Research Councils could complement central university support for decentralised departments with support focused especially on PhD specific processes such as supervision, milestone assessments and vivas.

Conclusion

In this chapter we have seen that disability support that has been agreed often fails to be implemented and we have investigated the causes and consequences of this. We have seen that decentralised bodies need further support, not just with implementation but also with universal design, and we investigated the responsibility of both the research organisation and the funder in this matter. Before moving on to recommendations to solve these issues it is worth highlighting that the current situation is not inevitable. One focus group participant highlighted contrasting experiences demonstrating that the process of acquiring disability support for a PhD student is currently more complicated than it needs to be:

> *"So during my master's there was literally everyone copied into the same email, and I just said 'I consent to sharing all my information. All of you, between you, have all my documents; I filled in the form. I don't have the mental headspace to do this, and to do what I'm here to do'. And that went absolutely fine. And when I went to do my PhD, I literally just needed a stamp to send the DSA form, and it took three weeks just to find out who could stamp and sign a form. Whereas when I told them I was pregnant, it was the same day, all my health and safety stuff and occupational health stuff was done. So like, the capacity is there for people to do what they're doing. They just don't see it as much of a problem. Whereas realistically, there are definitely more students with disabilities than there are pregnant PhD students."*

This example demonstrates that some of the barriers we have laid out here exist as a result of disability not being prioritised. If support can be implemented for pregnancy then there is no reason it cannot be implemented for disability. Both are protected characteristics under the Equality Act. As such there is great potential for improvements if the right steps are taken.

Recommendations

1. Decentralised bodies such as academic departments and Doctoral Training Partnerships, which are responsible for the experience of disabled PhD students, should:
    a. Create clear structures of responsibility which are communicated to students and staff alike.
    b. Fund a role with lead responsibility for universal design who is also a contact person as regards individualised adjustments for other staff members in the body as well as DS and Research Councils
    c. Investigate whether a lack of resources or knowledge is preventing administrative and educating staff from dedicating the required time to disability support, and work to address any resource gaps.

2. Research organisations should allocate the needed resources and authority for Disability services to take a more proactive approach after agreeing support, including:
    a. Ensuring implementation has occurred before signing off responsibility when an individual student's support is first set up.
    b. Conducting regular check-ins with the student after the initial implementation to ensure continued implementation and update support plans as the student's needs or settings change.

3. Research organisations should ensure that DS and disability contacts within academic departments are aware of PhD specific contacts and structures such that all relevant information about a PhD student's needs reaches the staff members responsible for supporting them.

4. In order to be able to support doctoral training programme staff to consider accessibility in an anticipatory fashion (as well as implement agreed support), UKRI should:
    a. Create and resource a project team to develop guidance and training resources for doctoral training programme staff. This

    guidance and training should cover good accessibility practice and the importance of swift implementation of reasonable adjustments. The project should be co-created with disabled doctoral students and staff. The UKRI EDI team should then ensure this guidance and training is embedded. In order to ensure that this training is effective it needs to be delivered in tandem with the attitudinal training and campaigns recommended in Chapter 4.
    b. Create and resource an expert group which can offer good practice advice for doctoral training programme staff that have questions about accessibility and disability inclusion, including UKRI DSA. This group should especially assist with specialised knowledge in areas which research institutions are less likely to have knowledge of such as the accessibility of supervision and vivas[14].

5. Research organisations should create a central team which supports and resources academic departments and colleges to implement universal design as well as agreed individualised support by:
    a. Developing guidance and providing frequent development opportunities for administrative and educating staff (including supervisors). This guidance and training should cover good accessibility practice and the importance of swift implementation of reasonable adjustments. In order to ensure that this is effective it needs to be delivered in tandem with the attitudinal training and campaigns recommended in Chapter 4.
    b. Providing support for staff in the academic department or colleges that have questions.
    c. Assisting with specialised knowledge in areas such as the accessibility of the built environment and digital accessibility.

6. UKRI should include in their terms and conditions measurable conditions that grant holders should:
    a. Implement support that has been agreed.
    b. Enforce adequate structures of responsibility in decentralised bodies.

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[14] See Chown, N., Beardon, L., Martin, N. and Ellis, S. (2015) Examining intellectual prowess, not social difference: removing barriers from the doctoral viva for autistic candidates: Journal of Inclusive Practice in Further and Higher Education 6 (1) 22-38.

c. Enforce adequate training, support and communication around disability with decentralised bodies

Note that Disabled Students UK is already measuring HE providers on such criteria as part of their Access Insights project, a potentially valuable resource for UKRI.

4. Belonging

Somewhere to turn and a culture of support

Those who felt they had somewhere to turn with disability issues were 3.7 times more likely to feel they belonged than those who did not feel they had somewhere to turn with these issues.

Those who had somewhere to turn when they felt anxious or down about their work were 3.1 times more likely to feel that they belonged compared to those who did not feel they had somewhere to turn at those times.

44% of our survey participants agreed that they felt they belonged at their institution (27% disagreed). Belonging has been found to correlate with wellbeing, academic achievement and retention (Freeman et al., 2007; Pedler et al., 2021; Pittman & Richmond, 2008). The percentage of our survey participants who felt they belonged was reduced for those who were multiply marginalised: only 35% of racially marginalised participants felt a sense of belonging.[15] However, the biggest predictive factors of belonging were not identity groups, but support. Our survey found that whether a student had a sense of belonging (Ahn & Davis, 2019), was closely connected to four factors (Figure 8) controlled in large part by their doctoral training programmes or academic department:

1. The implementation of agreed support (see Chapter 3).
2. Having somewhere to turn with access issues needing resolution.
3. Having somewhere to turn when troubled about the work.
4. Their supervisor(s) (see Chapter 5).

As should be clear from this list, decentralised staff members make up a large part of a PhD student's interpersonal environment and as such have a great influence on the student's sense of belonging within the institution. We have

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[15] Belonging also varied by disability, only 38% of those with mobility difficulties felt they belonged, perhaps reflecting the inaccessibility of the physical environment for this group (see Chapter 6).

addressed the implementation of agreed support in the previous chapter. The supervisor-supervisee relationship is unique in importance and will be the subject of Chapter 5. In this chapter we will focus on having somewhere to turn and the importance of an institution-wide culture of support.

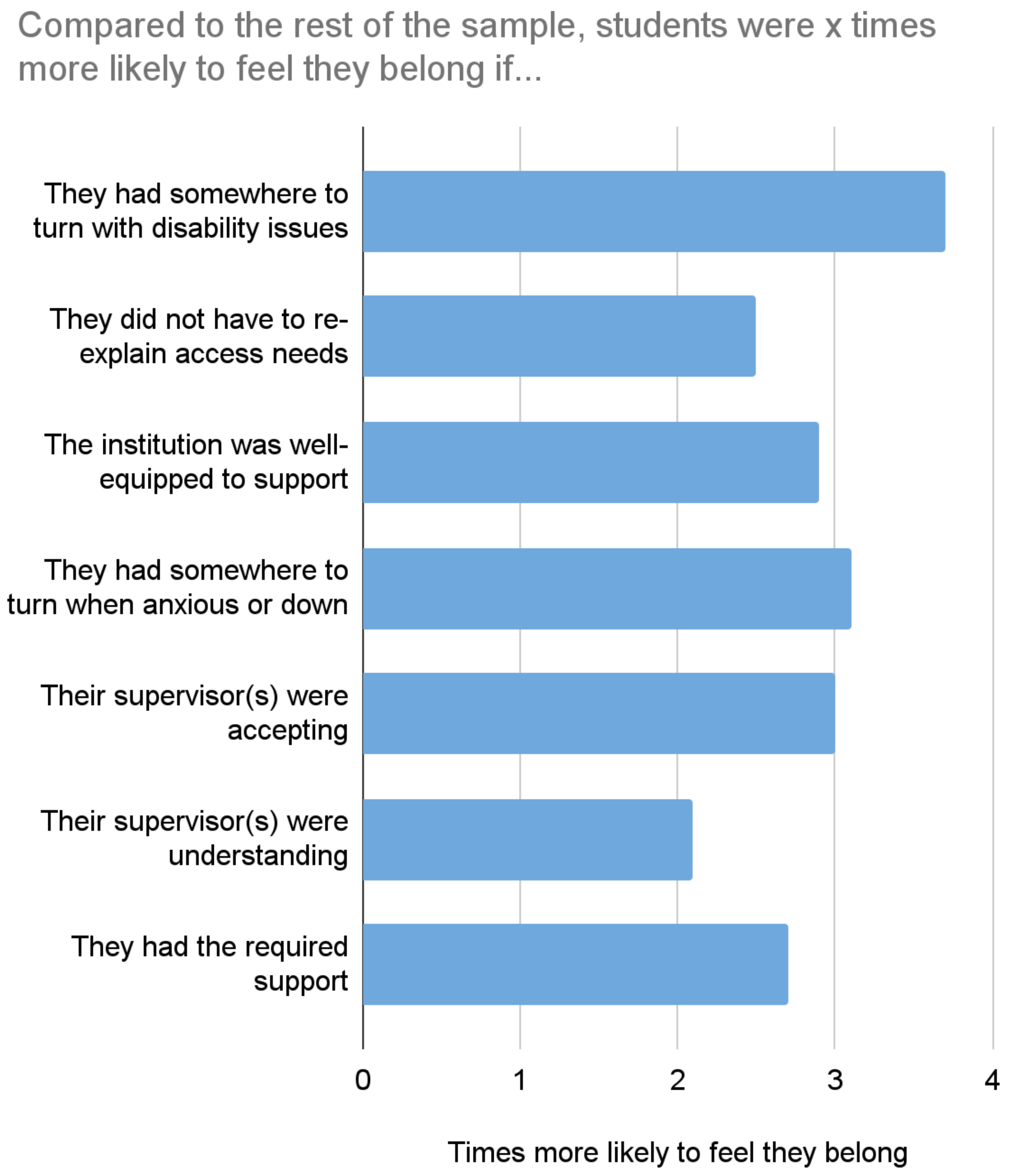

Figure 8: Predictors of belonging

What students answered to certain questions predicted whether they felt they belonged at their institution. This figure shows the seven factors with greatest predictive power.

Resolving access issues

Often access barriers appear after the initial meeting with Disability Services. This could be either due to failure to implement support as discussed above or the appearance of an access need that was unknown when the student started their degree. For instance, a student may have a change in activities or work location (such as starting fieldwork), or experience a change in access needs due to a progressive or intermittent disability. Because access issues appear over time, it is crucial that new issues are recognised and students have somewhere to turn for support with resolution.

The availability of effective support, especially during times of struggle, is essential for the progression and well-being of disabled PhD students. However, only 29% agreed that at times when they had been struggling, someone at the university, institute or research centre had recognised this and offered effective support (58% disagreed). Half of our survey respondents (49%) said they felt that they had somewhere to turn in the event of a disability or accessibility issue (28% disagreed).

Even if students had somewhere to turn in theory, attitudes toward disability meant that many censored themselves: Of those who had experienced access issues, 55% stated that they had held back from raising them, thus hindering resolution. Some of the most common reason for not discussing their disability with a staff member were (Table 2):

- “I don’t want others to see me as difficult, incompetent or like I’m trying to get an advantage over other students”. 58% of students selected this statement as a reason behind not discussing their disability at some point.
- “I am afraid I would be treated worse or that it would affect my academic prospects”. 45% of students selected this statement as a reason behind not discussing their disability at some point.
- “I feel embarrassed to be needing adjustments/I feel I should be able to undertake my studies without adjustments or support”. 38% of students selected this statement as a reason behind not discussing their disability at some point.
- “I don’t think the particular staff member I considered speaking with about my disability would understand or believe me”. 28% of students selected this statement as a reason behind not discussing their disability at some point.

It is clear from these statistics that the attitude towards disability that the student has themselves, as well as the attitudes they face at their institutions, play a role in whether they feel comfortable raising issues. According to our data, people with disabilities associated with a greater degree of stigma - autism and mental illness - are especially likely to hold back from raising issues.

Unfortunately the fear that the student could be treated worse as a result of their disability is not entirely unfounded. 18% of respondents felt that their supervisor shows a lack of understanding when their disability affects their performance or attendance. 11% had faced a disciplinary action resulting from their disability. One survey participant explained their non-disclosure:

> *"I'm also afraid to talk to too many people about the full extent of my disabilities because I don't want to get kicked off the PhD or mastered out."*

Relatedly our survey found a lack of awareness of formal options for raising issues. Only 24% survey respondents were aware of how to go about making a formal complaint about disability accessibility. All universities have formal complaint systems in place, however it is rarely advertised that students are able to complain about the failure to provide positive support. In addition, previous research shows that the faith in complaints processes is low among PhD students in general. One-sixth (18%) of PhD students believe they can raise incidences of bullying and harassment without fear of negative personal consequences and one-quarter (26%) believe complaints regarding bullying would be acted on (Cornell, 2020, p.10).

Whether a student had somewhere to turn not only impacted whether the student received the support they needed but also their sense of belonging: Those who felt they had somewhere to turn with disability issues were 3.7 times more likely to feel they belonged.

Table 2. “If you have ever held back from sharing/discussing one of your disabilities with a staff member/body within your university, institute or research centre, please could you indicate all the reasons why”?	**Percentage**
I don’t want others to see me as difficult, incompetent or like I’m trying to get an advantage over other students	58%
I am afraid I would be treated worse or that it would affect my academic prospects	45%
I don’t think the adjustments or support that staff members or university bodies can offer are going to make my experience much more equitable to the experience of a non-disabled student	43%
The support that exists is for undergraduate students or students enrolled in other taught degrees and is not helpful for me.	38%
I feel embarrassed to be needing adjustments/I feel I should be able to undertake my studies without adjustments or support	38%
I don’t want to go through the administrative process of applying for support	29%
I don’t think the particular staff member I considered speaking with about my disability would understand or believe me	28%
I don’t know who I would raise it with	17%
I mentioned my disability in my application but there was no follow up on this	16%
The university asked if I have a disability, but I didn’t think my condition counted	13%
Not applicable, I have never held back from sharing/discussing my disability with a staff member/university body	13%
I don’t think I have the evidence they need	13%
My university, institute or research centre has not asked me if I have a disability	9%
My university does not employ any staff whose role is to help disabled PhD students	7%
Other (please specify)	7%
I didn’t have a disability/didn’t know I had a disability until recently	5%

Mental health, the culture of overwork, and having somewhere to turn

Only 9% of our participants had a mental health condition as their only disability, however half of our participants (48%) reported having a mental health condition as one of their disabilities, indicating the increased vulnerability that students with other disabilities have to develop mental health problems. Mental health problems are also common among PhD students in general. Anxiety and depression are so prevalent in the population that it could be considered "the norm", with PhD students being twice as likely as professional workers to show signs of anxiety (Woolston, 2021). Compared with working professionals, PhD students are more likely to meet the criteria for clinical levels of depression and anxiety and to have more severe symptoms. 41% of PhD students report that most of their PhD colleagues have mental health problems (Hazell et al., 2021).

Existing research highlights how research culture promotes inequities and encourages feelings of exclusion though "*a high workload, an ever-increasing pace and an unequal distribution of credit to members contributing to research and innovation*" (Sotiropoulou, 2022, p.14, Wellcome Trust, 2020; Royal Society, 2018; Tazzyman et al, 2021). The normalisation of overwork is compounded for those with disabilities in part due to much of the work taking longer for those with disabilities, and in part due to the additional administrative work required from disabled students (McVitty & Kernohan, 2020). A number of reports (Royal Society, 2018; Tazzyman et al, 2021, Wellcome Trust, 2020;) have argued that research culture is contributing to poor mental health and making the UK HE sector an unsustainable and uninviting environment.

67% of our survey respondents stated that conducting their doctoral studies had impacted on their physical health and 86% stated that their degree had negatively impacted on their mental health and wellbeing,

Given the increased risk wellbeing challenges pose for disabled students, it is essential that disabled PhD students have someone at their institution to whom they can turn. Our survey indicated mixed results when we asked respondents whether there was someone at their institution to whom they could turn when they are feeling anxious or down about their work. 45% of the total respondents agreed that this was the case for them while 34% disagreed. Which of these groups they belonged to had an impact on their experience. Those who had somewhere to turn were 3.1 times more likely to feel that they belonged.

A culture of support

Belonging was as predictive of physical health as students having the support they required was predictive of physical health

Many factors influence whether agreed support is implemented, access issues resolved and students feel they have somewhere to turn, however one of the most important factors is arguably the existence of a culture of kindness[16] and support within the academic departments, labs, research centres and other decentralised bodies responsible for disabled students' support.

Cultural barriers to support

Cultural issues were raised by the staff contributors to this report from doctoral training programmes and universities. Throughout the conversations and in work beyond this report, it is evident that PhD study is increasingly being perceived as something that is endured rather than enjoyed, that is stressful rather than satisfying and is viewed as something to be "survived" rather than something that "sustains".[17]

Several interviewees raised examples of supervisors or senior figures who refused adjustments by insisting on an existing or fixed meeting time for someone with a fluctuating condition. One doctoral training programme staff member encountered significant reluctance to provide interview questions in advance. This was in spite of the host university publicising advanced interview questions as inclusive staff recruitment practice. Resistance toward providing reasonable adjustments often arises from an "we've always done it this way" approach. Challenges can especially arise when the staff member in question has a fixed mindset or pattern of work arising from their own lived experience,

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[16] For more on kindness see the Office of the Independent Adjudicator, (2022) and Thurman (2021)

[17] In 2014 the Guardian published an opinion piece on, "How to Stay Sane During a PhD…" where it was suggested that, *"There are many factors that drive PhD students into unhappiness: from ill-defined topics and incomplete data sets to supervisors who do not seem to care about their students, or provide feedback that is so vague or unconstructive that it kills all motivation and creativity. Financial difficulties and self-absorbed colleagues don't help, either. And finally there is the over-arching question of whether all that time and effort will ever "pay off"* (von Weitershausen, 2014).

neurodiversity, disability or other responsibilities, which limits flexibility. There can also be a perception among staff that if they survived the current inaccessible status quo then it should not be made easier for someone else, as if the struggle itself has value. Interviewees commented that some staff hold the view that academic or career success can only be attained by working long hours, and that if students are required or encouraged to work fewer hours this will disadvantage them in a highly competitive environment, framing their reluctance to support standardised or limited working hours as being in the student's best interest..

Creating a culture of support

When we asked survey participants what changes they wish their university, institute or centre would make to become more accessible to disabled doctoral students going forward, a large proportion mentioned improving staff attitudes, whether this was encouraging staff to prioritise accessibility instead of gatekeeping support, take different disabilities into consideration instead of stereotyping, listen to disabled people and generally just be considerate. In particular, many students asked staff not to take a penalising approach:

> *"Please don't penalise me if I do not seem to answer your question, I might have just heard the question wrongly. Sometimes I might need you to repeat your question or comment more than once since I really could not catch what was being said the first or second time"*

> *"After covid, my supervisor asked me to confirm how many days a week I would be coming back to the office. I said none. She said she would be 'disappointed in me' if I didn't come back. She had clearly forgotten that I have a physically disability. I responded to her saying I was disappointed in her for insensitivity towards my disability. She scrambled and said coming back into the office wasn't applicable to me and that we would have a proper conversation about it. She never mentioned it again. Overall, a really unfriendly department to students with physical disabilities. Would not recommend."*

> *"Not making students feel guilty for being off and not forcing them to come back before they're ready (I.e saying they'll have to take an interruption and their stipend will stop)."*

To improve staff attitudes many students recommended training or informing staff regarding disability:

> *"More education for members of staff regarding disabilities, sometimes I am unsure which staff members I can mention it to without stigma."*
>
> *"Better training to staff on [fluctuational] disorders (aka not making comments on 'what's wrong with you now[?]' when you are using your walking stick one day when you weren't the day before). Training on (hidden and visible) disabilities for all staff. What to say and what not to say. Give a basic understanding to everyone of what the issues are [that] we face."*
>
> *"Training for staff about different conditions and how to help/ access the help."*

Some staff members feel that they are being asked to give disabled students unfair "special treatment". To address this it is important to educate staff about the difference between competence standards and accessibility barriers. The duty to make accessibility adjustment does not apply to competence standards - standards which determine whether a person has a level of competence needed for their course. As an example, showing a certain level of knowledge about law may be a competence standard for a law degree, however completing an exam within a fixed period of time is unlikely to be a competence standard for the same degree (EHRC, 2014).

Staff members interviewed for this report lifted examples of good practice for improving research culture. In particular an innovative project at the University of East Anglia (UEA) was highlighted which focused on improving the mental health of PGR students. The Higher Education Funding Council for England (HEFCE) funded 'Courage project' was a two year impactful co-produced initiative which focused on PGR community building, embedding mental health into everyday practices, as well as training supervisors in mental health friendly supervision and signposting. A number of PGR students were employed as part of the project (UEASU, n.d.).

Two other peer-led initiatives were conducted in a University of Cambridge doctoral training programme. The programme benefited from two "Wellbeing advocates"; students who had been trained as "Mental Health First Aiders". These were complemented with peer research groups including 12-14 members across the doctoral training programme year groups. The peer research groups met weekly or fortnightly with both post-doc and academic input providing connection and a sense of shared endeavour.

Supervisors interviewed for this project wanted to benefit from appropriate training, especially with regard to supporting students with mental health difficulties, including students in crisis. Several observed that Principal Investigators[18] do not, in their opinion, naturally have a skillset around supporting student mental health challenges, which often arise from harassment, personal crisis or family crises, relationship breakdowns, life changes and other unforeseen circumstances. Several interviewees noted that there was an increasing number of students emerging with significant mental health difficulties, often in crisis, and in these situations the Mental Health First Aid (MHFA) training they were provided with was insufficient. One interviewee argued that a two hour training session from their University Counselling team was much more relevant and beneficial, as the training allowed them to connect with people in the service and thus signpost students more effectively.

There was concern among staff that without training their colleagues often try to assist students on their own based on what they think will be best, almost as if involving others was a sign of failure. It is important that students are signposted to the support services as a matter of course, as these are equipped to provide professional support for mental health problems.

Staff that work with disabled students who experience mental health struggles should also themselves be signposted to counselling and other support (often available through an Employee Assistance Programme). Sometimes academic and administrative staff who interact with doctoral students are on the frontline of student disclosures about suicidal ideation, self-harming, or encounters with symptoms of psychosis or emotional outbursts. This can in turn affect the mental health of staff and it is important that supervisors are aware that they can and should also seek support.

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[18] A Principal Investigator or PI 'is the individual responsible for the preparation, conduct, and administration of a research grant, cooperative agreement, training or public service project, contract, or other sponsored project.' (University of Massachusetts Amherst, n.d.).

While training is important we must not forget that staff also needs to have the time and resources to dedicate to support and accessibility. When staff members are provided with insufficient resources to provide the support students need, and their own needs are not appropriately addressed, it can put them in a situation where they are having to choose between their own health and the needs of the students.

Conclusion

In this chapter we have observed a number of factors which predict a PhD students' sense of belonging at their institution, including having somewhere to turn with accessibility issues and when feeling down. We have seen that student and staff attitudes toward disability prevent important discussions about support and that research culture is negatively affecting the mental health of the vast majority of disabled students. We have also seen that improving the culture within academic departments and doctoral training programmes can significantly impact how staff and students with disabilities are supported.

When a culture of inclusivity and support exists within the academic departments it is more likely that support such as sick leave will be granted and anticipatory steps will be taken to ensure that the environment is accessible to all. As we have also seen, it creates a sense of belonging.

When students lack a sense of belonging they suffer: survey respondents who lacked a sense of belonging were 56% more likely to say that their studies had negatively impacted their physical health. In this sense belonging was as important for health as whether students had the support they required[19]. The lack of belonging also leads to negative consequences for their departments, including a less diverse academic community.[20] Clement and colleagues (2020) note that positive experiences with faculty are important not only for the general academic development of life sciences students, but can be essential in ensuring the "retention and success" of those from historically underrepresented groups.

Recommendations

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[19] Students who did not have the support they required were 54% more likely to say that their PhD studies had negatively impacted their physical health.

[20] In some ways, the lack of diversity is self-perpetuating with lack of representation deterring PhD students from further engagement in academia. Only 12% of respondents said there were openly disabled academics in their field that they could look up to. Students who agreed to this question were 73% more likely to agree that they had a sense of belonging. The representation of non-academic disabled staff members is also important. Several respondents reported getting better support specifically from staff members with disabilities.

1. DS should make the same disability advisor available for the student during their time at the institution, where possible, and signal that this staff member is available to talk if any issues occur. Where this is not possible, records should be kept and shared that minimise the need for students to invest time during meetings providing contextual information that has previously been provided.

2. Research organisations and UKRI should inform students of the formal routes for raising disability issues, including making formal complaints about a failure to provide reasonable adjustments. They should ensure that these processes are accessible to disabled students.

3. Research organisations and UKRI should review their policies with the aim of actively combatting the overwork culture currently prevalent in PhD studies.

4. Each research organisation, academic department and doctoral training partnership should clearly signpost their pastoral support.

5. UKRI and research organisations should organise and fund disabled-led campaigns and training aimed at improving understanding and attitudes toward disability and accessibility among both staff and students and promote a culture of inclusivity and support. All staff members should be informed about the importance of reasonable adjustments, how they can signpost students to support, and where they themselves can get support with implementation (see Chapter 3). Supervisors should receive additional training (see Chapter 5).

6. UKRI should include in their terms and conditions measurable conditions that grant holders should:
    a. Invest in a culture that is conducive to the mental health of all students.
    b. Train staff specifically on the importance of disability support.
    c. Ensure decentralised staff have enough time, support and resources to be able to provide the support disabled students need.
    d. Invest in reducing bullying and harassment against disabled students.

Note that Disabled Students UK is already measuring HE providers on such criteria as part of their Access Insights project, a potentially valuable resource for UKRI.

7. Research organisations should investigate whether resource issues underlie poor staff attitudes. Are staff access needs being addressed? Do struggling staff members have access to counselling? Do staff members have the time and resources they need to provide a qualitative and compassionate service for students?

5. Crucial Relationships

Supporting Supervisors

Of all staff members and bodies that students in our survey had contact with, the relationships that had the biggest impact on disabled PhD students' experience, both in terms of their likelihood to have the required support and their sense of belonging, were the relationships with their supervisors. PhD students who found their supervisors' support "very helpful" were 4.7 times more likely to have the support they needed compared to those who found supervisors' support unhelpful. This is greater than the impact of support from Disability Services.

Supervision relationships are key and as such it is fortunate that they are the most positively rated relationships in our survey. 87% of survey respondents disclosed their disability to their supervisors, almost as many as those who disclosed to Disability Services. Of students who disclosed their disability to their supervisors, the percentage who actually received some sort of support from their supervisors was 88% (a higher proportion than those who receive help from any other body or staff member within the institution). 39% percent stated that the support they received was "very helpful". Again this is higher than for any other body. Appendix C shows that there is reason to think that the supervisors' attitude to disability is considered more important than many other factors when choosing an institution. One focus group participant comments:

> *"I spoke to a lot of universities, and there was a lot of universities that were interested in my study, but I ended up going for a university that actually didn't have a better reputation, or wasn't as good, purely because the supervisor was so pro-active and disability positive. And that has made the world of difference for me."*

The strengths and weaknesses of supervisors relative to DS is best summarised with this quote from the survey:

> *"My supervisor is typically willing to accommodate what I need/ask for (extensions, work from home, sick days, etc.), though he isn't very*

> *knowledgeable of how the process works or of how to work with students with disabilities (eg choosing accessible meeting locations, etc.).”*

In this chapter we will address these two aspects of the relationship in turn: being accommodating and being knowledgeable.

Supervisors are generally accommodating

PhD students whose supervisors were accepting and supportive of their disability were 12.1 times more likely to have the support they needed and 3.0 times more likely to have a sense of belonging than those who did not feel their supervisors were accepting and supportive.

PhD students whose supervisors were flexible, accommodating and valued their well-being were 10.3 times more likely to have the support they needed and 2.3 times more likely to have a sense of belonging than those who did not feel their supervisors were flexible, accommodating and valued their well-being.

When good support was reported in our focus group discussions, this was often contingent on the attitudes of supervisors. 66% of survey respondents agreed that they felt that their supervisors were accepting and supportive when it comes to their disability, only 16% disagreed. One survey participant wrote:

> *"My current supervisors are lovely, understanding and helpful. They help me manage my time and my research, give me feedback that I can use, help me break down tasks, make sure I don't break myself down while working and support me in balancing my research with teaching opportunities."*

When we asked students what form of disability support they received from their supervisors, some named concrete things like arranging equipment for the laboratory, making assessment accommodations, or making sure meetings are accessible. However, many also responded to the question with observations about softer skills, such as supervisors being encouraging of their development and supporting them in advocating for their needs:

> *"Support in moving office for a quieter environment and asking [the] department for a single occupancy office (which they said they couldn't provide). Encouraging and positive about me working in a way to suit me e.g. working from home when needed."*

Unlike support through DS, support through the supervisors is very much built on a human relationship, with all the pros and cons associated with this: support often depends on the interpersonal skills and attitudes of the supervisor. Because it is a less formal system, there is a great scope for discretionary kindness. This was also highlighted in the focus groups:

> *“So it's been really nice coming into this PhD and having a supervisor that understands and is really like, sure if you know, there's been a lot of university strikes recently, so I've been doing a lot of working from home more than normal. And she'll be like, ‘I just want to check in and make sure you're not suffering from loneliness’ like, ‘Are you getting everything done? Is your workspace okay?’ She's really good at checking in. And that's kind of, you know, really helps so far.”*

One focus group participant mentioned how this support made up for some of the cracks in other parts of the support system:

> *“Even though the DSA process is extremely laborious and difficult to manage, the fact that my supervisor’s extremely supportive emotionally has been the biggest thing. And as [other focus group participant] says, it is really key to how it works. If she hadn’t have been on board with the fact that things should be more straightforward, or should be better for me during the process, then it would have made it much harder.”*

However, the single most mentioned form of support from supervisors was flexibility, whether this was flexibility with attendance, location of work, timelines, or assessment results:

> *“They have also been willing to let me work remotely and set my own schedule, which is incredibly helpful for accessibility for me.”*

Out of all the survey respondents, 74% overall agreed that they felt that their supervisors were flexible, accommodating, and valued their wellbeing (Only 15% disagreed). Over half of the survey respondents (55%) agreed that their supervisors were understanding when their disability impacted their attendance or performance (18% disagreed). A survey participant describes this:

> *"My supervisors are very understanding and empathetic when it comes to the struggles I've been having with my PhD, and try to offer support when I am able to suggest ways they could help. They try to accommodate regular meetings, they are flexible when I struggle to submit work to them on time or attend a meeting on time, and they have helped guide me through processes like securing a leave of absence."*

This understanding was impactful. PhD students whose supervisors were understanding when their disability impacted their attendance or performance were 7.6 times more likely to have the support they needed. The sense that the supervisors were understanding was more common among those with stereotypical disabilities such as mobility difficulties (71%) and neurological conditions (90%) compared to invisible disabilities, especially neurodivergence such as autism (49%) or specific learning differences (47%).

While the supervisors' attitudes and awareness toward different disabilities clearly make a difference, developing their interpersonal skills[21] is equally important. Some students do not yet have a diagnosis, or cannot disclose a disability for other reasons such as immigration rules. It is important then that supervisors act with compassion whether they are able to identify the student as disabled or not, as illustrated by this survey respondent:

> *"Pre-diagnosis my supervisor identified that I was struggling to remember procedural information and was making lots of mistakes when performing routine tasks in the lab. Although these issues were clearly evident, I feel like they were ascribed to character flaws and thus the responsibility to overcome these issues was placed solely on me. Post-diagnosis my supervisor has been very open to putting measures in place to help me complete my studies (e.g. discussions about support for thesis/viva preparation), however, because my issues went undiagnosed for the majority of my PhD, I failed to develop practical skills/knowledge at the*

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[21] Sometimes the social skills required can be quite nuanced. One survey participant writes: *"In my supervisor's case it was largely a matter of understanding/bearing in mind that I have difficulties, which he seems to be doing to just the right degree. That is: I explicitly did not ask… for any accommodations of him, but just wanted him to know what was going on if ever my work wasn't up to scratch, etc. He senses that one can sometimes offer help where it's not useful, so he very tactfully left implicit an offer of more help if I want it, and made clear that he supports me."*

same rate as my peers and on occasion was ridiculed publicly for this. I began to develop extreme anxiety about being in the lab setting and this severely hindered my progress through my PhD."

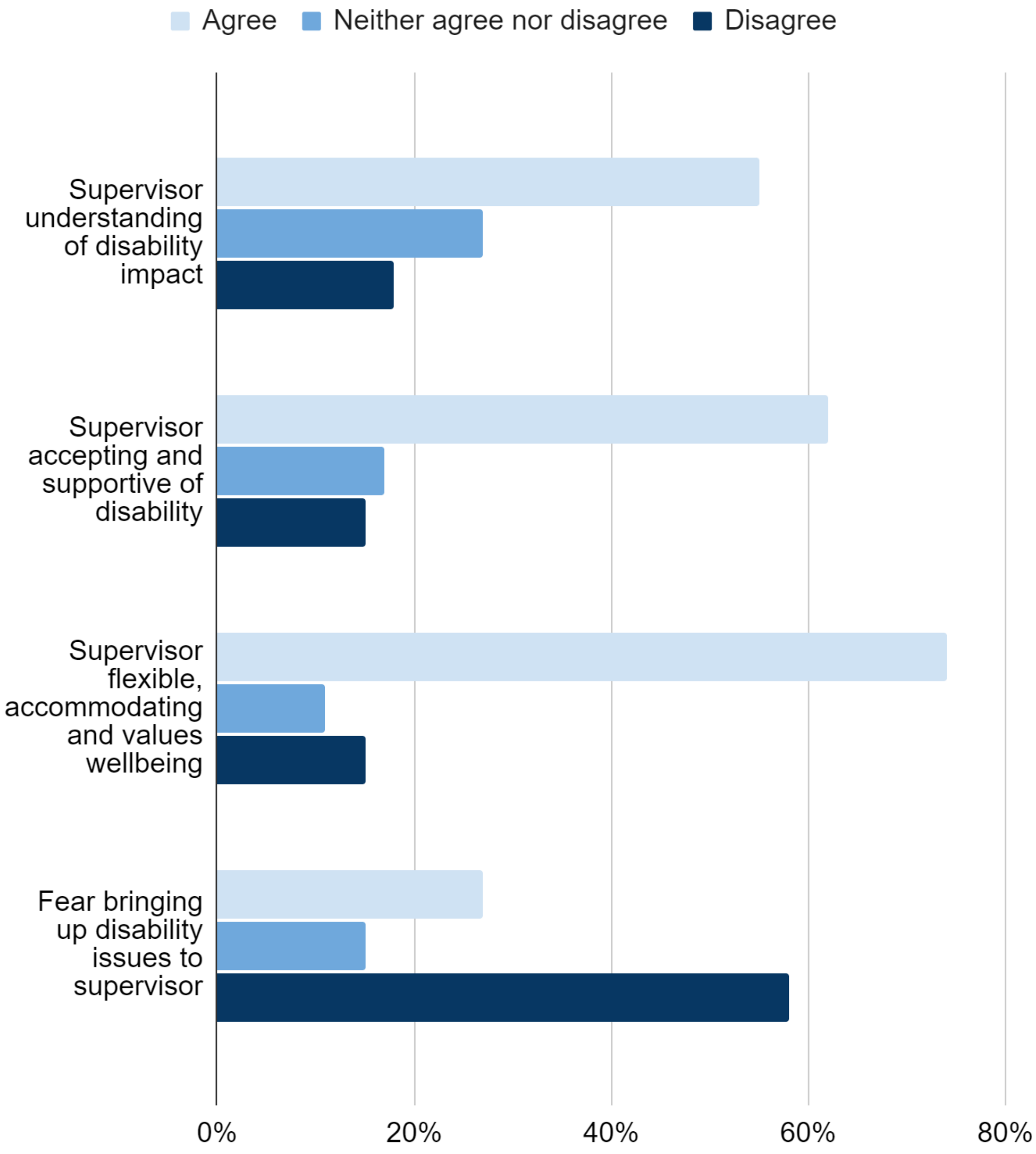

Figure 9. Supervisors accommodating

Precarity – The negative side to individual discretion

While it is fair to say that the biggest strength of supervisors (relative to other support staff) is their willingness to make accommodations, and their biggest weakness is their lack of disability knowledge, we also have to highlight the existence of outliers in this regard, as they have such an impact on the sense of support and belonging of PhD students. 16% of respondents disagreed that their supervisors were accepting and supportive and 15% disagreed their supervisors were flexible, accommodating, and valued their wellbeing. Of students who disagreed with either of these statements only 4% stated that they had the support they required.

Our survey asked if respondents feared that they would face negative consequences from their supervisors if they brought up access and/or disability issues. Despite the majority of respondents answering that this was not a concern, just over a quarter (27%) did state that they feared negative consequences. Some feared being treated as less competent:

> *"It is clear they care but (2 months in) I don't yet feel comfortable opening up with them about how difficult my disabilities can be to manage, in case they try to limit me to 'less strenuous' experiments etc. As they work from home a lot as well (have young children), they don't necessarily see how much I might struggle in the lab - I have always managed to get the work done and do work quite flexibly but not sure how long I can keep the pace going."*

Others feared their access needs not being taken seriously. Some attitudes of supervisors, such as stating that their supervisee "should be more resilient", were noted as being detrimental to progress, and "missing the point", reflecting a lack of understanding of the issues faced by disabled PhD students. As we saw in Chapter 4, when the supervisor does not understand their obligations under the law or has a fixed mindset this also leaves room for a failure to accommodate. One survey participant writes:

> *"[My supervisor] was very dismissive until I applied for my student support plan. I applied due to a comment that made me realise she did not understand the seriousness of my disability."*

Still, others may fear bullying or victimisation for raising issues. Without enough checks on supervisors, the disabled student becomes an easy target for bullying, as described by several survey participants:

> *“My previous supervisor kicked me out of his lab for becoming too disabled (degenerative condition worsened by negligence) after I came back from long-term sick leave, so that was pretty terrible. He also outright refused a reasonable adjustment in rescheduling a meeting and then said it wasn't discriminatory, so he failed on both the knowledge and the accommodation.”*

> *“Leaving my PhD because I have been told I am not meeting milestones though other times I am told I am exceeding expectations - this depends on my [supervisor’s] mood. Have been discriminatory and told me I don't rank well against my peers - who are not disabled. Have yelled at me in private for related matters.”*

> *“I was verbally assaulted and discriminated against by my supervisor because of my disclosure. He told me I was so mentally unwell I have to leave [my university] and need to be assessed by medical professionals before I can ever be allowed back in his lab. My supervisor is a doctor.”*

Interviews with staff revealed that some supervisors perceived their own doctoral study as an overbearing, demanding, and unhappy time. They experienced an environment of ‘presenteeism’ during their time as PhD students, working excessively long hours in a hierarchical and hostile environment. Unfortunately, some supervisors perpetuate this culture, perceiving these practices as normal, despite the existence of more contemporary examples of better practice that included understanding, inclusive and effective supervisory relationships.

It should be stated that while only a minority currently experienced severe issues with their supervisor, the precarity of the situation, the sense of dependence on the grace of a single individual, affects all disabled PhD students. As two focus group participants put it:

> *“Even for those who are fortunate and have had those kind of understanding supervisors, it's very uncomfortable to be in a position*

> *where you know that your access to your work and education and so on is essentially reliant on the fact that, and the fact that they happen to be someone who, you know, cares and wants to support you. And then sort of living with the fact that you realise like, that could change because the structure isn't there. It's purely reliant on good fortune, it puts one in a really kind of unstable, insecure position."*
>
> *"Your PhD supervisor relationship is something that can like, make or break the ultimate success of the PhD. Particularly as a disabled student, because they can act as a barrier to actually being able to enforce accessibility. If, say, they are resistant to any sort of change or that sort of thing."*

A functioning disability service and better training for supervisors can make up for some of these issues. However, there is also a need for safeguards, especially as disability services often do not take a proactive role and the student often lacks the rights of an employee. The lack of oversight here is an issue and it seems there is little recourse when things go wrong. One survey participant writes:

> *"[The disability coordinator] did not listen to my needs but instead counselled with my supervisors, to see what would suit them best. I am leaving my programme due to mismanagement and continued harassment".*

A focus group participant who had decided to leave her degree said:

> *"[The supervisor] is pretty much the whole reason I left. [...] like, I have no say in how my brain functions. Please just meet me halfway. Like, if I have to work in this environment, can you adapt for me? Sent him as many resources as I could, which was a lot of emotional labour, especially when there are so many pages on the internet focused on the deficits rather than anything. So after all of that, and putting in the work, it was still, it was awful. It was when I had a break from doing it that I looked back, and it was borderline traumatic [...] And we tried to go through, like the departmental mediation and all of that. But he essentially said he'd been a successful researcher this far, so he didn't see the need to change. So, yeah, just decided I wasn't going to sacrifice my mental health [...] I thought the love*

> *of the work could override it, but some things are just not worth it. Like, it’s just not worth it.”*

Another focus group participant similarly highlighted a lack of support when they were struggling with their supervisor:

> *“[My old university] were really crap about mental health support whilst my first supervisory situation was going to hell. There was a ‘facade’ of student support service, but no actual service that I could access and talk to someone in the counselling department, and the admin team were disorganised, and generally chaotic. It was massively destabilising. I'm a lot happier having moved to [my new university], and with a really wonderful supervisory team.”*

One focus group member was able to get someone to intervene but it damaged their relationship with the supervisor:

> *“Like, the difficult thing is, if you do have a problem or you know an issue, you're basically having to like, complain about your boss, which is basically like, your supervisor is your boss in the PhD context, but you're not recognised as staff. So you don't have the support of HR, you don't have the support of the union if you need to, like, do anything like that. And you basically just have to kind of find the person in your department that’s going to be sympathetic. And to intervene, I basically had to, like, get somebody else in my school to come and do some disability 101 with my supervisor, because she was just being so useless. And saying like “I think everyone should just be more resilient”. Like, basic stuff. Yeah, I think, yeah, like I say, really links to this point of not being staff, because we would have a lot more support there. And that really like damaged the supervisory relationship, like it took a bit of time for us to rebuild our working relationship because I basically had to go and like shamed or embarrassed her by like getting someone else to come tell her how things should be.”*

On knowledge and resources

PhD students whose supervisors were knowledgeable about services available to support disabled students within the institution were 5.5 times more likely to have the support they needed compared to those who did not feel their supervisors were knowledgeable.

If the human(e) approach of most supervisors is their strength, disability knowledge is generally their weakness. While supervisors may have the desire to support their disabled supervisees, without adequate understanding there will be a limit to how much support they can offer. Unfortunately only 27% of survey participants agreed that their supervisor was knowledgeable about support available, while 44% of the respondents disagreed. One survey respondent writes:

> *"[...] my supervisor is very accommodating and wants me to work in a way that is most efficient for me. But in terms of his knowledge of the services, he lacks even the most basic information on who I should access to get support, so I had to find this information out for myself."*

One focus group participant asserted that they knew what support to ask for because they had been in work before. If they had not had previous experience of support in the workplace they would not have been able to identify what they needed on their own. Several other participants mentioned having to teach their supervisor about accessibility, adding to their administrative burden. One survey respondent writes:

> *"[my supervisor is] good at anticipating potential physical problems in the lab, but may not involve me in finding workarounds and so sometimes their suggestions are not appropriate. As a new-ish PI, they are well meaning and try their best but aren't as knowledgeable about systemic supports or how to access them. In this respect, I have been teaching them to some extent."*

A focus group participant came to the conclusion that there needed to be: "*[..] some sort of universal training for supervisors so that labour isn't put on* *students if their supervisor is not trained up. Because that can be like, very dependent on individual supervisors."*

Several focus group participants highlighted that when there is no one but the student to educate the supervisor, it also creates difficulties because of the power imbalance. It is hard for a student to convey the obligatory nature of accessibility. Thus, several participants suggested the involvement of third parties through training or other forms of instruction:

> *"I would also like for there to be a clear process where a PhD candidate's supervisor is trained by the university to meet the accessibility needs of their student. My supervisor has good intentions but I get the impression doesn't have clear guidelines on how to help me, other than signposting me to disability services."*
>
> *"Supervisors should be trained in how to approach the limitations of disabled students and learn how to support them the best way possible."*
>
> *"Every supervisor (existing and new) should do mandatory training on neurodivergent and disabled in academia - and how to be inclusive, knowing resources to direct their students, etc."*
>
> *"I would like it if my institute offered training courses for my supervisors on working with someone with my disability (ADHD) and others. I would like for them to be mandatory for those who supervise disabled students, as I don't believe my supervisors would attend them otherwise".*
>
> *"Mandatory supervisor training for supporting neurodiverse individuals."*

Unfortunately supervisor training and development on these topics is rarely prioritised by universities and is not mandated by UKRI funders. One of our survey group participants recalls:

> *"My lead supervisor asked the university to fund training from the support providers that had been working with me so that she could understand and work with me in the most accessible way. The university said no because they already pay for support provision so she didn't need to".*

One focus group member raised a good practice example which went some way to addressing this: A number of supervisors of disabled students had created a group with the aim of sharing advice and good practice between themselves. The participant felt that this was a good step but noted that it was an opt-in system and not widely advertised.

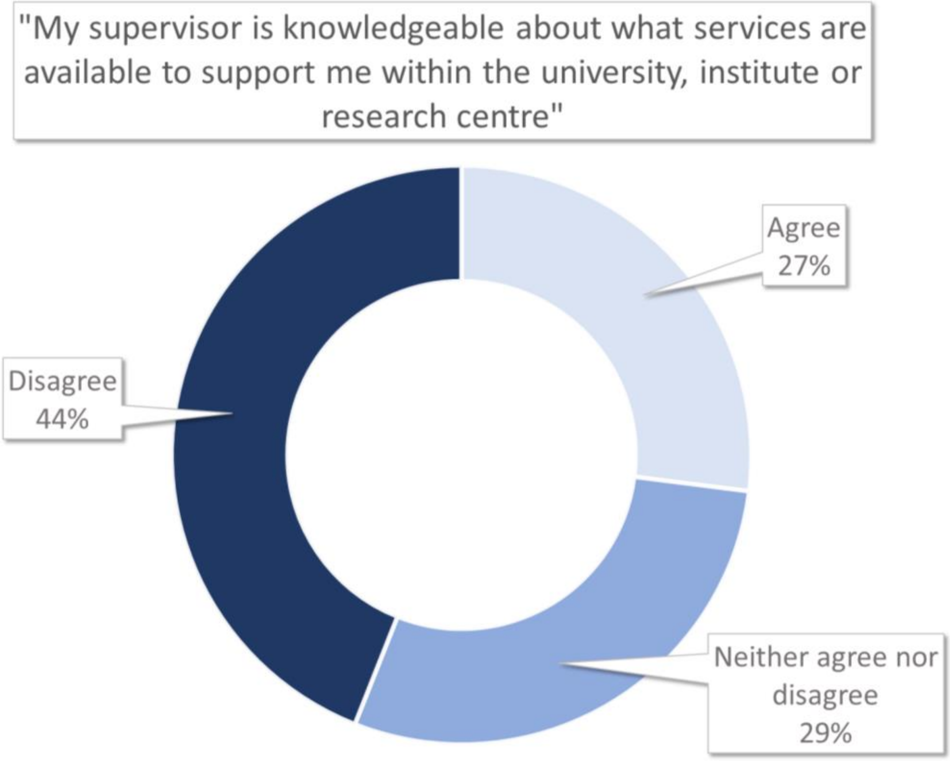

Figure 10. Supervisor knowledge

Supporting the independent work of neurodivergent PhD students

PhD students whose supervision and feedback were accessible were 8.6 times more likely to have the support they needed and 2.4 times more likely to have a sense of belonging compared to those whose supervision and feedback were not accessible.

While supervision and feedback were generally considered accessible (77% felt they were very or somewhat accessible) a significant minority of students with autism (29%), specific learning differences (28%) and mental health disabilities (29%) disagreed. We can find various good practice examples for these populations to be extracted from the data.

When we asked students what form of support they received from their supervisor, several survey and focus group participants spoke of ways that meetings were made accessible, such as note taking support being offered. This can be particularly helpful to neurodivergent students such as those with dyslexia, dyspraxia, ADHD, or autism. It could enable the student to freely discuss and engage with the supervisor, without the distraction of ensuring everything is noted, thus allowing them to get the most out of meetings. Meeting adjustments could also include permission to record supervisory meetings, or a supervisor creating bullet points of the discussion and action plan/next steps for the student (Farrar and Young, 2007; University of Worcester, 2018).

Some students also struggle with research planning due to their disabilities, as well as the uncertainty and isolation inherent to doctoral study (Farrar and Young, 2007). In particular many of our survey participants with specific learning differences found the writing process inaccessible (40%):

> *"Also supervision has been an absolute disaster in my case. My supervisor seems to be even more chaotic than I am and that is saying something. Unless I actively try to get hold of him, we can go months without contact, and it's the worst thing for me because I really need someone to be there at least somewhat holding me responsible for doing things I am supposed*

> *to do. Which my supervisor absolutely isn't, instead he is so excited about science that every time we talk I somehow end up with even more ideas on the list of what would be a really interesting thing to do next (but somehow none of those is giving him a draft of a chapter by a set deadline or anything like that). [To be honest] I feel there was someone who'd be like a line manager directly above, to whom I'm responsible. I didn't have that and as the result it's been an absolute chaos these past 7 years."*

While independent working is a core part of a PhD, supervisors can assist in ameliorating challenges arising from these elements of research study. For example, supervisors can help to create structure for the student by setting short-term goals, giving regular feedback, and creating an interim or long-term research map or plan (Farrar and Young, 2007). One focus group participant comments:

> *"From what I can tell there seems to be a period at the beginning of a PhD in particular where the supervisory team want to emphasise that this is your work; you need to be independent and resilient. And they tend to do this with everyone. However, I think this is particularly harmful when disabled students can have such a difficult transition anyway. I find mutually agreeing work targets in between supervisions is super helpful, and still leaves the student with autonomy and independence."*

One survey respondent requests *"More obligation for supervisors to actually assess work / progress and give feedback."*

However, equally, it was suggested in the focus groups that someone other than the supervisor may be best suited to help when a student needs more structure, partly due to acknowledging the workload of their supervisors, partly due to the lack of expertise that many supervisors have when it comes to disability, and partly to avoid the many roles of the supervisor getting mixed up:

> *"I find holding myself to account challenging and my supervisors are often busy so I can be left to my own devices. I would benefit from having a regular chat with somebody who I'm not a "subordinate" of to check in on how I'm doing."*

Other students requested study skills support in the section of the survey which asked how they wish their institution would improve:

> *"Before I realised I had ADHD, I chose to do a PhD because I wanted to strengthen areas I felt were my professional weaknesses: project planning, project management, time management, reviewing the literature,*

> *scientific writing, etc. I have since realised that those weaknesses are (at least in part) ADHD-related, and the PhD progress does not actually train you to do them any better, it just puts you in a sink-or-swim situation where they are essential to making good progress. So the main change I would make would be far more intensive support in these areas. Perhaps a dedicated project management coach for ADHD students could be a good accommodation."*

> *"I can't speak for all but I really [wish] there was more of a conversation about dyslexia and how to approach the writing process when a person has a mind that struggles with [this] sort of information processing. Seminars or short lectures on it could be helpful and then also introduce mentors in these areas to support students through their thesis."*

Some students were already receiving this sort of support from other staff. 33% of students had disclosed their disability to a mentor and while most of the support from mentors was emotional or advocacy related, some also received support in structuring their work:

> *"Weekly mentor meetings to help with planning activities and answering emails."*

> *"Useful advice on how to improve my workflow."*

> *"Guidance and advice in terms of administrative things and help in navigating and planning my PhD progression."*

A focus group participant recalls:

> *"[D]uring my master's I had a mentor and having access to someone like that, someone--a third party who you have a call with them once a week, and they're like, "Right what have you got to get done?" And you list out everything they've got to get done. And like, well, in my experience with mine, what we do is we set fake deadlines. So say like, I said, I have something due on the 23rd. If I had my mentor still she'd be like, "Okay, I want you to tell me—" or, "I want you to get it done by the 21st, and send me some evidence of that." And I used to find that so helpful during my masters. It's the only reason that my master's got done, essentially, was because I had access to that mentor. But someone like that, who's kind of*

> *separate but yeah, knows about that sort of stuff. And that was through DSA that I had that. But full access to something like that'd be really useful, kind of in conjunction to the supervisory support with structuring."*

Another focus group participant also had a mentor, and when asked whether this was helpful they said:

> *"The mentoring has been. And knowing that there's sort of a separate group I can go to. I have a feeling that if my supervisor was kind of responsible, or could help me with structuring, I don't think they would have enough time or capacity for that. And I think it would end up taking away from, sort of, bits that they are or can help me with. So like, planning research or like, sort of like technical help. It's already kind of quite hard to find time with them a lot of time. So it's like, it would, I think it would stress me out more if they were also responsible for the sort of writing procedures, somewhat."*

Study skills support without medical evidence

We know that many students are undeclared or undiagnosed. As such it is crucial that some level of study skills support is accessible to all students.

During lockdown and enforced remote learning in earlier periods of the pandemic there was a wider awareness of students and employees emerging with hitherto unidentified neurodivergent profiles. In some cases this has led to a focus on providing support for all students beyond those with a diagnosis. The University of Oxford has been trialling a web based modular screening and assessment system providing graduate and some PhD students the opportunity to reflect on their learning styles. The personal report output that results includes study skills and wellbeing profiling insights for themselves and their study strategies.

The majority of students, including those who are neurotypical, have reported that they have found the tool very helpful as an approach for reflecting on their current practices and how they might adapt these or seek adjustments in relation to any neurodivergent traits identified. For students who are self-reflective and active in their continual development it's a good solution; albeit perhaps less so for students who may need more prompting.

Unfortunately, as many services still insist on diagnosis or other medical evidence, those students who do find that the tool, together with their own lived experience, indicates that they might be neurodivergent face the standard challenge of being unable to get a student support plan without a diagnosis, which can take years.

Conclusion – Supporting supervisors

PhD students whose supervisors were well equipped to support them were 9.0 times more likely to have the support they needed and 2.4 times more likely to have a sense of belonging compared to those who did not feel their supervisor was well equipped.

Academic supervisors generally have their students' best interest at heart and wish to support them, however they do not always have the resources to do so. When asked if supervisors were well equipped to support them, a higher number of our survey participants disagreed with this (38%) than those who agreed (31%).

Supervisors must have adequate time, knowledge, and help to support their supervisees. Reflecting the unique importance of the supervisor-supervisee relationship, when we asked survey participants what changes they wish their university, institute, or centre would make to become more accessible to disabled doctoral students going forward, a large proportion mentioned supervisors. One participant writes:

> *“PhD students often have to rely on their supervisors being empathetic towards our conditions rather than there being structured solutions.”*

The challenge we face is to put support and checks in place without lessening the greatest strength of the supervisor-supervisee relationship: the fact that it is very much a human rather than a bureaucratic arrangement. Below we suggest a number of changes to support supervisors in roles that they are currently unreasonably being expected to take on by themselves, including disability support administrator, advocate, pastoral support, study skills tutor, and provider of accessible supervision and assessment. The recommendations are based on our survey responses and focus group discussions.

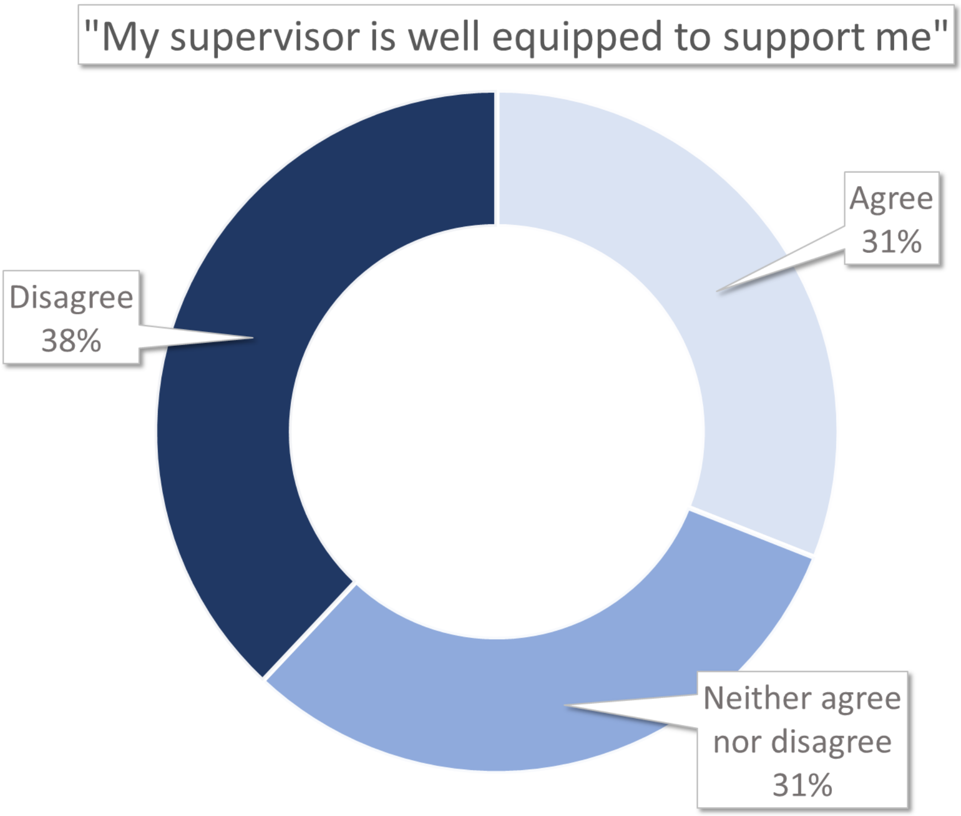

Figure 11. Supervisor equipped

Support for all supervisors

As a first step we suggest that all supervisors, whether they know their supervisees are disabled or not, receive information about how to signpost students to DS if they have a (suspected) disability, and how to start the discussion about their access needs while the student is waiting for DS to set up a list of adjustments. Ensuring students have access to Disability Services is key.

As discussed in Chapters 3 and 4, survey respondents asked that supervisors be given training regarding:

- Practical information about support available to the supervisor and student, including which university services and external services are involved and their roles and responsibilities.
- Attitudes toward disability and the rights of disabled students.

A survey respondent writes:

> *"I would love for supervisors to be given disability ally training."*

> *"Ensure supervisors have proper understanding of the disability of their student and the ways it might impact their work."*

As noted in Chapter 4, several of the supervisors interviewed for this report expressed a wish to develop their skills and capabilities to appropriately support students. The widespread view was that training should include: general mental health awareness and appropriate response to mental health crises for students and colleagues, safeguarding, disability confidence and neurodiversity training, reasonable adjustments in the research space and to admissions or recruitment interviews, assessment milestones, and the viva. Active bystander harassment training, suicide prevention workshops, and areas such as managing difficult conversations were also widely requested. The majority view was that this training should be delivered in person and attended by all new supervisors with a three year refresher.

A UK Council for Graduate Education report (2022) commissioned by UKRI details the outcome of a series of focus groups which were commissioned in order to ascertain how UKRI could best support research supervision. The findings support the creation of a statement of expectations from UKRI for doctoral study. It was suggested that such a statement should assert that supervisors should be aware of potential mental health and wellbeing issues that could arise during students' doctoral study. Appropriate training was noted as essential for this. Also proposed to be included in this statement was an expectation of adequate support of supervisors, by ensuring sufficient time and resources to enable them to in turn support their doctoral students. Additionally, it was noted that clear guidelines on bullying and harassment should be provided, as well as guidance for students on how to access confidential advice or raise a complaint on matters of this nature. This suggests that there is a growing awareness at the upper institutional level of the particular challenges faced by PhD students generally, and demonstrates motivation towards engendering a positive culture in order to best support both students and supervisors.

Further research is going to be conducted on best practice for supervision from the autumn 2023. The four year, £4.6million project (named "Research SuperVision Project" (RSVP)) is led by the University of York and will develop professional development resources for supervisors (UK Council for Graduate

Education, 2022). There is an excellent opportunity to embed accessibility and disability inclusion into these resources.

Support for supervisors of disabled PhD students

Once a support plan has started taking form, we suggest that supervisors are invited to a meeting with the student and their disability advisor to solicit their help in being an advocate for their student within the department, and to aid in ensuring support is implemented. Focus group participants spoke about the benefits of the supervisors being brought into the accessibility process in this way, without the student having to train them themself:

> *"The idea [of] there being a third person, so that sort of a special postgraduate person, or even just someone who can actually sit down with you and your supervisor, as well, kind of changes the power dynamics situation of it, because you're not the person who's doing all the work."*

By creating buy-in from the supervisor in this way, they can be educated about the student's rights in a positive environment where their help is solicited, building on their compassion rather than pushing an attitude of legal compliance which may cause an over-reliance on bureaucracy. To reduce workload of supervisors, it is important that DS take the lead on administration. The supervisor should assist the disability advisor in their administrative role, and the disability advisor should assist the supervisor in providing accessible supervision.

While the disability advisor should continue to be the student's main point of contact for all disability administration, neurodivergent students, including those with mental disabilities, should also be offered a study skills mentor who is specialised in their disability. This can help to ensure that responsibility for study skills support does not fall solely on supervisors. All supervisors of neurodivergent students should however either be offered training on how to incorporate accessibility into their supervision or, if the student has agreed to a study skills mentor, a meeting with the student and their mentor to learn more about how they can adapt their supervision to the individual student. One focus group participant commented:

> *“One of the things that I suggested was having a third party, either arrange for someone to do it. To either sit down and discuss what it means for someone to have ADHD, autism, and problems they have. So just to discuss broadly, like, everyone, to kind of define these things, but kind of how it impacts my day to day life. And how we can work through that together, to still kind of reaching the goals you want to. In my head will be a third person facilitating us meeting in the middle. So we'll be educating each other on how the expectations we can reasonably have from one another, and how to help each other to get there. Yeah, and instead, someone suggested just doing like one of those generic, watch a video, fill out a questionnaire thing, which was shut down as a tickbox exercise that you just pick it up with all the health and safety ones you do. And again, if there was someone who was trained in, like, from the Disability Support Services at a university, trained in postgrad support, that could be something like that help facilitate as well. Because although it would be a few hours, you know, everyone--even people with the same diagnosis or set of problems can present so differently and need different support, but it also, I think, it shows you're willing to respect each other […]. And I think it kind of helps keep that relationship where it should be, rather than you trying to educate them, or something like that.”*

Throughout this process it is important that disclosure is discussed with the student so that neither the disability advisor nor the study skills mentor discloses anything to the supervisor which the student is uncomfortable with. One focus group participant commented:

> *“I didn't disclose a lot of things at the beginning of my PhD, and I did once I felt more comfortable, further down the line. And that was something that I wouldn't have wanted my supervisors to see initially, as part of my application, or as part of the beginning of the process, or for them to have that oversight. I think, I wouldn't have found that--I wouldn't have been comfortable with that. And I don't know how to kind of have that weeding out happen, but to have someone be there as the sort of in between, and also a someone where you can disclose as much as you want to that person, and then they know to disclose some certain amount to your supervisor. And to have them as a proxy who also helps with the admin would be amazing.”*

Workload management and safeguards

To manage the workload of supervisors, the work that they put into accessibility and advocacy needs to be recognised by managers so that it does not come at the cost of the supervisors' own health and wellbeing. It is important that academic departments and doctoral training programmes are set up in such a way that supervisors have somewhere to turn for support. We also encourage doctoral training programmes to utilise supervisory teams rather than a single supervisor for each student, with mechanisms to ensure that all co-supervisors or academic mentors do periodically interact with students, and all supervisors are aware of disclosed disabilities and support plans (with the student's consent). This will not only provide supervisors with support but offer a potential safeguard. Having a number of people to turn to increases the chances of the student finding at least one ally to support them in gaining the needed adjustments. One focus group participant stated:

> *"I have a supervisory team, so I don't just have one supervisor. And one is self-proclaimed, like, a disability-disabled student ally. And I think that has made a massive difference. And I know for a fact--she's left the university now, but she's still my lead supervisor. And the difference I've seen just in having her as a supervisor within the institution, when she's able […] to speak up as well on my behalf. And the difference now […] is massive.*

Finally, universities should improve safeguards protecting students from unsuitable supervisors. Safeguards should include improved signposting to the complaints process, proactive check-ins by the disability services, improved routes for disability advisors to hold a supervisor to account when they are not upholding the values of the institution, and constructive ways for PhD students to raise improvement points without jeopardising their academic future.

Recommendations

1. Research organisations should provide all supervisors with obligatory training on the importance of reasonable adjustments, how supervisors can signpost students to disability support, where they themselves can get support with implementation. In addition all supervisors should be offered training in safeguarding and mental health. This training may

include SafeTALK and ASIST[22] as suicide prevention training, Trauma Informed Management (TRIM)[23] which enables delegates to manage difficult situations with pre-awareness as well as Mental Health First Aid[24].

2. After a list of adjustments has been drawn up, DS should offer all disabled PhD students a meeting with their supervisors and disability advisors, to enable disability advisors to brief the supervisors on the support implementation process.

3. DS should offer all neurodivergent students, including those with mental illnesses, a study skills mentor who is specialised in their disability.

4. Research organisations should offer all supervisors of neurodivergent students (including those with mental illness) additional guidance: either training on how to incorporate accessibility into their supervision or, if the student has agreed to a study skills mentor, a meeting with the student and their mentor to learn more about how they can adapt their supervision to the individual student.

5. Research organisations should review the routes to constructively addressing issues in the supervisory relationship with the aim of putting in place safeguards to protect students from unsuitable supervisors, including:
    a. Improved signposting to, and accessibility of, the complaints process.
    b. Proactive check-ins with the student by the Disability Services.
    c. Improved routes for disability advisors to hold a supervisor to account if they are not upholding the values of the institution.
    d. Effective mediation processes when a student raises issues.

6. UKRI should produce best practice guidance for supervision of disabled students, including how supervisors can best be supported by their departments and Research Councils. UKRI should investigate the benefit of supervisory teams and networks where supervisors of disabled students can share best practice.

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[22] Details via https://www.livingworks.net/asist

[23] Details via https://www.growth-pod.co.uk/ or via hello@growth-pod.co.uk

[24] Details via https://mhfaengland.org/

7. UKRI should include in their terms and conditions measurable conditions that grant holders should:
    a. Provide adequate disability training and support to supervisors.
    b. Have adequate safeguards in place to protect disabled students from unsuitable supervisors.

   Note that Disabled Students UK is already measuring HE providers on such criteria as part of their Access Insights project, a potentially valuable resource for UKRI.

8. The RSVP project should include recommendations 1,4,5,6,7 above in their development of resources for research supervision.

6. A Space to Work

Making the physical and sensory environment accessible

Students who felt the physical or sensory environment on campus was accessible were 2.7 times more likely to feel they had the support they needed compared to those who felt it was not accessible.

Students whose workspace was accessible were 2.5 times more likely to feel they had the support needed compared to students whose workplace was not accessible.

The physical/sensory environment on campus was the aspect of the PhD experience that was found inaccessible by the largest number of survey participants (51%), closely followed by the workspace the student had been offered (45%). This is reflected in previous research: the Postgraduate Research Experience Survey found that disabled PGR students were less likely to be satisfied with the working space/resources (56%), compared to their non-disabled peers (68%) (Neves, 2022).

The inaccessibility of the physical environment could explain why our survey found that students with mobility difficulties were the group least likely to feel that they belonged at their institution. As highlighted in Appendix C, the accessibility of the work environment was one of the biggest factors considered by disabled students when choosing their subject. When we asked survey participants what they wished that their institute or centre would change to become more accessible, the physical and sensory environment was one of the aspects highlighted most often: 32% of participants raised this.

Table 3. Aspects of PhD found inaccessible by greatest to smallest proportion of students

Physical/sensory environment on campus	51%
Workspaces offered to you	45%
Administration	45%
Viva process	41%
Placements	41%
Additional training	33%
The writing process	31%
Lab work	31%
Teaching and learning methods	26%
Supervision and feedback	23%
Physical libraries/learning resources	24%
The digital environment	22%
Digital learning resources	14%

Physical environment

Of these comments, 12 mentioned physical inaccessibility. This was an issue for students with a variety of disabilities but especially those who have mobility difficulties, 70% of whom answered that they found the physical or sensory environment inaccessible. Students asked for things like buildings to have wheelchair access and automatic doors, lifts to be fixed within reasonable time frames when they are out of service, more disability accessible bathrooms, and more ergonomic furniture and equipment (for instance labs having height-adjustable benches, electronic pipettes and broad enough spaces for wheelchairs). One survey participant writes:

> *"My institute is a secure building due to the nature of the research and location relative to the hospital, however this means all of the doors are quite inaccessible to me as they are all heavy and require handles to open and close - I struggle with these when using my mobility aids and due to weakness in my hands and arms. Having power assisted doors would*

> *make a big difference for myself and other disabled students going forward."*

Sensory environment

24 comments on the other hand mentioned sensory issues with their workspaces, noise being the most common. It is currently common practice for labs and offices to have an "open plan" layout using hot desking, a set-up widely considered inaccessible (BBC, n.d.; British Standards Institution, 2022, p.43; Musser, 2023). There is evidence that open plan offices are bad for the health and wellbeing of workers in general, an effect which could be exacerbated for disabled workers (Colenberg et al., 2020). This was especially an issue for autistic students, 78% of whom found the physical or sensory environment inaccessible. One survey participant commented:

> *"I have spent 3/4 years of my PhD working from lab benches in quiet areas of the lab, cafe's of campus, or from home because I find it physically impossible to get work done with the level of over-stimulation and stress that the open-plan office causes me."*

Several focus group participants agreed, with one pointing out that this isn't just an issue for neurodivergent students:

> *"But one thing I will say is, hot desking is the worst thing in the world for multiple people with disabilities. Like, as a visually impaired person, when I'd come in and [...] it used to be like, hot desking, I couldn't see if someone was set up at the office. Like, if they're not sat directly at their desk, if they were sat, say, talking to somebody else, I couldn't see which desks were being used, which weren't. And it was so incredibly awkward to be like, 'Is someone using this?' and they'd be like, 'Yeah, yeah. Do you want me to move?' 'No, no, I just--there a desk free?' Like, it just feels you can't just walk in and kind of get on."*

Reasons behind the inaccessibility of the physical and sensory environment

The proportion of PhD students who found the physical and sensory environment inaccessible is greater than the proportion among taught students (Disabled Students UK, 2022). We can find four possible reasons why STEM PhD students would particularly struggle with the physical environment:

1. **The physical environment for staff is not being considered in an anticipatory fashion by departments**

To some extent, the physical environment has to be made accessible in an anticipatory fashion, e.g. before the department knows whether any of their staff or doctoral students will be wheelchair users, doors should be made wheelchair accessible when they are updated. In a similar way, before it is known whether the department or centre will have any neurodivergent students, the accessibility of open plan offices should be considered when the office layout is being planned/redesigned. In many cases it takes far greater resources to redesign the physical space based on one individual's need rather than considering accessibility through universal design. While accessibility is being considered in an anticipatory fashion to a greater extent these days, when designing taught student spaces, staff and PhD students tell us that it is still not being considered to the same degree when designing research spaces. This is an area of current focus in STEM research and in industry, with publications such as Chemistry World featuring good practice (Atkinson, 2023). One of our focus group participants commented:

> *"From a wet lab perspective, there's already usually things in place in the teaching labs to accommodate teaching students, but they aren't always in place in research labs. So there's not like a height adjustable bench. Or you know, the doors aren't wide enough for whatever reason. Other things haven't been put in place. So then you can reach a crossroad where "do we do our work in the teaching lab or do we, who's going to pay for the money to have the extra support come in to deal with the lab set up?" That's another thing."*

2. **Ergonomic furniture is not being provided by DSA**

As discussed in Chapter 1, ergonomic furniture currently falls through the cracks between DSA and institutional support for PhD students. While taught students can get DSA funding for ergonomic equipment for their workplace at home, UKRI funded PhD students cannot get DSA funding for ergonomic equipment for their workplace - the lab.

3. **Institutions are not stepping in to fill the gap**

Institutions are not stepping in to fill this funding gap centrally through Disability Services or Occupational Health as we saw in Chapter 1, and decentralised support is often slow and burdensome as we saw in Chapter 3, due to staff in academic departments having limited knowledge or processes for accessibility. One focus group participant comments:

> *"I feel like I've had to be the person to do all the arrangements to make it accessible. So I've had to chase people and come up with sort of ways for the labs to be accessible to me. Only through emailing loads of people, am I now able to do some lab work, and I feel like it's just a big barrier, because obviously, like not everyone can fight and send so many emails, whereas other students can just go in the labs. For me, I've had to do like a lot of sort of fighting for it".*

A sensorily accessible workspace

There is a legal responsibility to make the physical and sensory environment accessible under the Equality Act and Article 9 in the UN Convention on the Rights of Persons with Disabilities (Women and Equalities Committee, 2017). Guides such as the recently published British Standard Institution's (BSI) PAS 6463 "Neurodiversity and the built environment – Guide" (2022) and the BS 8300:2018 Design of an accessible and inclusive built environment (British Standards Institution, 2018) can help research organisations meet these obligations. However, the accessibility of the environment is a complex issue and requires specialist consultation. To limit our scope we will focus here specifically on how institutions can use universal design to make workspaces sensorily accessible to neurodivergent students. This is an area of accessibility that is only starting to be highlighted in Higher Education, with projects such as the Research England funded "Supporting neurodivergent research culture" at Bristol University (University of Bristol, 2022).

Of the 24 students who requested improved sensory accessibility in their environment, some called for a dark or quiet place to rest:

> *"To have quiet, dark, accessible rest rooms on campus".*

One focus group mentioned this already being implemented in their institution:

> *"Yeah, so on this one, I'm quite lucky. At [my university] we have a disability or disabled students room. Which is a small room within our student's union that has been sort of specifically made into—it's got sort of fidget toys, kind of octopuses, sort of like, weighted blankets. It's really--it's a lovely space. But that was as a result of--we have a student led disability campaign group called Access [name of university]. And we as a group are kind of what kind of got that made and kind of retain that space."*

More common among the accessibility recommendations however was for students to have a quiet space to work, whether this was among others or isolated. Of the 24 students who requested improved sensory accessibility in our survey, 10 students specifically requested a work space where they were isolated, e.g., could not see or be seen by others:

> *"Make it possible for disabled students to get a desk space / office space in an empty room rather than the compulsory shared-office arrangement. There are days when I'm unable to focus or function because of the presence of other people in proximity to my desk. I do understand the value of shared offices. But in practice, I get the small talk I need with all my colleagues in labs and I wish every day I could have a room for myself when I can rest/stim/think without being constantly observed or heard."*

Four survey respondents specified the need for a dedicated space:

> *"I hope we can have a personal space to modify the environment to fit our habits."*

To ensure that adjustments are effective it is important that they are planned ahead of time rather than finding emergency solutions. In particular several participants mentioned space limitations that need to be considered. One focus group member recalls:

> *"There's physically no space in the building I was in. The only thing they offered to do was give me access to the first aid room on the condition that the people who used it to give themselves insulin shots or, you know, pump milk for their babies knock and ask me to leave whenever they needed to come in. It isn't really a space you can work in; it's not a workspace. It's a first aid room."*

Survey respondents also pointed out that solutions must not unfairly isolate the disabled student. The risk of isolation is especially a consideration when it comes to working from home. While many PhD students do wish to work from home (96% of PhD students in Disabled Students UK's survey for *Going Back is Not a Choice,* 2022) stated that they would benefit from the continued option of accessing teaching from home after the pandemic), and this should be an option when possible[25], it is also important that access to teaching from home or away from campus is not offered in lieu of making the physical and sensory environment accessible.

It is worth noting that universal design is not always enough. Students may need ergonomic equipment, assistance with fieldwork, or certain manual tasks. For instance, a student with a latex allergy may not be able to use a particular piece of lab equipment, and if the costs prohibit buying a new piece of equipment, it may instead be necessary to pay someone to assist the student in carrying out specific tasks. Nonetheless, universal design lays the groundwork and reduces the number of individualised adjustments needed.

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[25] Staff security and accessibility must always be taken into consideration as regards online access. In addition, if the teaching is delivered within an underdeveloped digital infrastructure, absent lecture capture, or without full access to teaching materials, then it may not be a sufficient reasonable adjustment.

Conclusion

In this chapter we have touched briefly on the complex topic of physical and sensory accessibility of the environment. We have seen that this was the aspect of the PhD considered inaccessible by the greatest number of students, and have suggested some reasons why this might be. Finally, we have considered how our survey participants would like to see their workspaces become more accessible through universal design.

Recommendations

1. Research organisations should investigate why the physical and sensory accessibility of staff and doctoral student spaces through universal design is not being considered in an anticipatory fashion by academic departments, for instance, if this situation would be helped by the recommendations in Chapter 3.

2. Research organisations should update the standard work spaces to reflect the latest knowledge around worker wellbeing, using isolated cubicles as the standard workspace, with associated social spaces and quiet rest spaces.

3. Research organisations should ensure that DS has access to ring-fenced central funding for disability related individual adjustments, including ergonomic equipment, thus allowing the institution to pay upfront for the support of those PhD students whose funds are reimbursed later (as per UKRI guidance) or who do not receive DSA (such as most international students) (see Chapter 1).

4. Occupational Health should offer a workplace assessment as standard for any new disabled PhD students.
    a. Universities should investigate why so few PhD students are receiving workplace assessments, for instance, whether this is due to poor connections between DS and OH (see Chapter 1).

5. UKRI should consider funding ergonomic equipment and furniture for the space in which PhD students conduct their research, in line with other DSA funders (see Chapter 1).

6. UKRI should include in their terms and conditions measurable conditions that grant holders should consider accessibility in an anticipatory fashion. Note that Disabled Students UK is already measuring HE providers on this criterion as part of their Access Insights project, a potentially valuable resource for UKRI.

7. UKRI should produce best practice guidance for universal design and reasonable adjustments of the physical and sensory environment in workspaces and labs.

7. Pace and Funding

Giving disabled students permission to slow down

Students who felt that their funder was flexible, accommodating, and valued their wellbeing were 1.5 times less likely to say that undertaking the PhD had negatively impacted on their physical health compared to students who did not feel that way about their funder.

When it comes to their pace of work, we know three things about disabled students. Firstly we know that disabled people on average take longer to complete tasks. This is why 25% extra time in exams and two week extensions to written work are among the most common disability adjustments on taught courses. Appendix C shows that several of our survey respondents had avoided applying to certain institutions or subjects due to assumed stress levels. Secondly, we know that many disabled people have less time - they may have an energy limiting condition or have to spend more time on disability related administration. This is why many disabled students study part time.[26] Finally, we know that many disabled doctoral students are in a financially difficult position. Disability comes with increased costs (Scope UK, n.d.) and the doctoral stipends can be difficult to live on[27], as our survey respondents illustrate:

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[26] In 2021/22 16% of part time research students declared a disability while only 14% of full time students did (HESA 2023b, Figure 5). 28% of disabled doctoral students take 5 years or more to finish their degree, compared to 20% of non-disabled doctoral students (Lopes & Wakeling, 2022, p.39)

[27] Doctoral stipends are tax free, with the UKRI rate recently increased to £18,622 as of the academic year 2023/24 (UKRI, 2023d). It is widely reported that doctoral students face serious challenges in surviving on the stipend (Woolston, 2022) and disabled students are more likely to be from a lower socioeconomic background (Burchardt, 2000). In 2020 Cornell found that as the average PhD student works 47 hours a week their stipend averaged out as less than minimum wage (Cornell, 2020). The 2023 assessment of UKRI terms and conditions of training grants from an EDI perspective

> *"The level of funding provided with the stipend is not adequate to address the general cost of living with an anxiety disorder/disability - due to my condition I cannot supplement my income with extra work as easily as a typical student."*

As highlighted by the recent UKRI call for input, it is difficult for PGR students to get benefits such as Universal Credit (UKRI, 2023e). 53% of our participants report being concerned about how they are going to meet their financial commitments. During the cost of living crisis the National Union of Students (NUS) has reported disabled students being among those most likely to use food banks and cut down on food, heating and sanitary products (NUS, 2022). One student comments:

> *"I wish I could afford catered accommodation so that I didn't have to choose between showering or eating (energy wise). I wish I could afford accommodation that isn't mouldy, but I don't have the energy to work on top of doing my PhD."*

Given these three factors affecting disabled students: taking longer to complete study tasks, having less time and being in a financially difficult position - we were concerned to see that funders often have policies which make it impossible for disabled students to get extensions, take sick leave or reduce their work hours without a loss of funds.

Adjustments which are conditional upon a reduction in funds are not going to be accessible to most disabled students. The result is that in practice disabled doctoral students are put at a significant disadvantage compared to non-disabled students. Without financially viable options for slowing down against the ticking clock of researcher timeframes they are much more likely to burn out before finishing their degree (Forrester, 2021).

In this chapter we consider survey respondents' experiences around sick leave, extensions and part time studies and their recommendations for change. We consider cultural and policy factors behind the current situation and we suggest

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concludes that the level of stipends is likely to especially impact PGR students with disabilities.

how funders can provide options for disabled students to work at a pace that is healthy for them.

Policies around pace

Sick leave

A 2022 University and College Union (UCU) survey found that 19% of PGR students were not entitled to paid sick leave at all, while others were entitled to only a few weeks (Kirby-Reynolds & Munro, 2022)[28]. When we asked students to write about how they felt their funding body supports and is adaptive to disabled PhD students one in ten wrote of limited or non-existent sick leave:

> *"We have no sick pay or extensions for illness. I'm not well at the moment and really should be off, but can't afford to not receive my stipend. We brought it up at a cost of living meeting recently, and it seemed like it was the first time that anyone has ever mentioned it (I've asked for it to be brought up by our rep several times over the past few years)"*

When asked how their institution or research centre could become more accessible going forward, survey respondents raised this as an area of improvement:

> *"Funding available to allow for time out of programme (due to disability) without having our funding (stipend) stopped. This means we are unable to rest / recover as we cannot afford to have time out of the programme."*

> *"Changes to sick leave […] every year I have used my annual leave to mitigate the impact of my illness."*

> *"Not making students feel guilty for being off and not forcing them to come back before they're ready ([i.e] saying they'll have to take an interruption and their stipend will stop)."*

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[28] See a description and overview of disability leave via University and College Union (2016)

Restrictive sick leave was not universal. One survey respondent mentioned the policy for her studentship changing for the better:

> *"[M]y studentship was changed a couple of years back so that it can pay a stipend for up to four months of sickness absence. Now, that isn't great, but it is so much better than previous, that I think it deserves some praise!! I think the tendency before that was to struggle on, just doing enough not to need to tell the funder that you were ill, but now there is some acknowledgement that people do get sick, and that disabled students get sick a little more."*

The doctoral training staff we interviewed highlighted that the lack of financial support for sick leave resulted in disabled students being seen as potential liabilities. When some disabled students inevitably required leave in excess of the allocated time, staff either had to find funds within the research organisation or doctoral training programme, which was rare, or the student had to drop out.

Staff members were hopeful about the possibility of policy change however. They observed that changes had been made to sick leave policies for students affected by Covid-19 and felt that this set a great precedent which could be transferred to disability-related leave. UKRI guidance, for instance, allows 28 weeks of sick leave for Covid-19 related illness and states that the student should not be put under an undue burden of proof. The 2023 assessment of UKRI terms and conditions of training grants from an EDI perspective suggests that a similar length of leave should be provided to all disabled students. The assessment further recommended that UKRI should "*make clear that a medical certificate is not required for 7 days or less and to consider if a medical certificate is appropriate for people with known long term health conditions*" (Pugh, 2023, p.30), in order to reduce the administrative burden on sick students. This recommendation is currently under review by UKRI. Other funders could similarly learn from this good practice during the pandemic.

Phased returns and part-time studies

As mentioned in Chapters 1 and 3, university and doctoral training staff interviewed frequently referenced the restrictive nature of regulatory rigidity from the Research Councils, in contrast to university regulations. A key issue reported was inflexibility in phased returns to work. UKRI currently requires that students work at a minimum of 50% of full-time equivalent (FTE)[29] and states that a phased return should happen over a period of 4 weeks. In some cases staff members report this going against medical advice and results in part time students being unable to do a phased return. One staff member recalled fighting for flexibility for a student to go below 50% as part of a phased return, however this was ultimately judged as not "feasible" by the Research Council. Conversely, it is often the case that universities have flexibility on modes of study possible, with students being able to switch from full to part-time studies as a reasonable adjustment.

The 2023 assessment of UKRI terms and conditions of training grants from an EDI perspective asks that UKRI consider why students cannot study at a pace slower than 50% FTE and why the phased return period must be 4 weeks: "*Outlining the rationale will help grant holders to make decisions where students request a variation for exceptional or other circumstances. Being clear as to whether there is an opportunity to study at less than 50% FTE over the course of a studentship may enable students to better balance their work and personal commitments and circumstances alongside of their study*" (Pugh, 2023, p.22).

The assessment encourages UKRI to have more flexibility in their phased returns, allowing such returns for part time students as well, emphasising that the responsibility for this plan must not put an unreasonable burden on the student. It also highlights the need to provide disability support during absences and phased returns. These recommendations are currently under review. If UKRI takes the lead in making these changes, other funders will surely follow suit.

Degree length and extensions

When asked how they felt their funding body supports and is adaptive to disabled PhD students, several survey participants wrote of being expected to conduct some part of their degree without funding and/or extension being denied.

For most students financial support is currently set at 3-4 years, including training and in some cases compulsory internships or placements. The

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[29] Another issue is that if a student is studying less than 25% they are ineligible for DSA, and thus their support becomes the responsibility solely of the research organisation (Student Finance England for Practitioners, 2023, p.28; UKRI, 2021b)

expectation of most funding bodies is that under normal circumstances students will complete their studies and submit their thesis within their funded period. However, studies have also found that some students receive only three years of funding for their degree in a manner which relies on an unfunded 'writing-up year' (Tazzyman et al, 2021).

Grant end dates were mentioned as problematic in numerous conversations with university and doctoral training programme staff. They were perceived to be rigid in all but a very few cases. This was particularly problematic in cases where students experienced fluctuating conditions. For example in the case of a student with Chronic Fatigue Syndrome/ME. The availability of extensions is very important for disabled students, not just due to their disabilities themselves but also because disability support is often delayed.

Many staff participants interviewed for this project were of the view that flexibility within the modes of study or attendance should be a key adjustment, citing that a large proportion of students with disabilities are unable to finish within the funded period. There was again a mismatch between UKRI regulations and their institutional regulations, where institutional regulations are sometimes more inclusive and progressive, when attempting to keep in sight completion. It was suggested that guidance is gradually improving, however in the meantime there was concern that putting in place a reasonable adjustment has sometimes meant having to 'gamify' the permitted (UKRI regulated) suspensions.

The 2022 UKRI commissioned literature review into EDI barriers to postgraduate research also identified the duration of PhD funding as a barrier to postgraduate studies as financial security is a significant factor for successful participation in doctoral education (Office for Students, 2018; Linder, 2020; University and College Union, 2022). The report concluded that *"[t]he current expectation for PhD students to complete within three or three and a half years contrasts with the needs of the PhD population, who have suggested that funding and the minimum completion length be extended to at least four years"* (Sotiropoulou, 2022, p.21).

It is also important that students are supported during extensions. UKRI guidance specifies that student support should be extended to offset for instance paternity leave and absences covered by a medical certificate. The 2023 assessment of UKRI terms and conditions of training grants from an EDI perspective recommends that this should also apply to extensions due to disability, including extensions due to delays in implementing reasonable adjustments.

Part-time funding

The UKRI terms and conditions require grant holders to offer the option of studying on both a part-time and full-time basis. However, students who work part time are normally paid part time on a pro rata basis. Unfortunately most students who need to reduce their hours because of disability (rather than because of taking on other work) would not be able to survive on a part-time stipend (University and College Union, 2022). In practice this means that doctoral study often becomes financially inaccessible to those who need to study part time. When asked how their institution or research centre could become more accessible going forward several students raised this:

> *"I think if a disabled student needs to reduce hours down to part-time due to health concerns that the pay should not also be halved. It means that I am not able to afford to be part time even though I should be, as my stipend (which is already not much) would be halved and I would have to get another job, which is not possible due to my health and defeats the purpose of going part time!"*

When we asked our focus groups about the option of reducing their hours with preserved funding, many participants indicated that they would take this option, but they had not considered it possible in the current system:

> *"I wouldn't even have thought of, kind of, asking to go down to four days a week, because I wouldn't--it just seems like you either do it full time and you struggle massively, or you go part time, which isn't financially possible. But there doesn't seem to be other flexible options."*

However, pockets of good practice mentioned by survey participants showed that it could be done:

> *"[My doctoral training programme] have made the amazing choice to fund my stipend full-time even though I had to switch to working 50% after I became more disabled. Living in [name of city], I would not be able to afford food and rent on a part-time stipend (I'm not considered disabled*

> *enough for PIP and my fatigue is too bad to work and do PhD, so I have no way of supplementing my income). If they had not supported me by doing this, I would have had to drop out as I don't have the means to supplement my income from savings for several years."*

Cultural causes behind the fast pace

Participants in both the survey and focus group mentioned the culture of overwork in academia, as discussed in Chapter 4, as one reason for the above mentioned policies. Even in those cases where leave, extensions or part time studies were permitted in theory, many reported attitudinal barriers which made them difficult to access in practice, and asked for these to be addressed. One survey participant recommends:

> *"Being more encouraging to lower workload/take time off - I am allowed time off, but I have to be very assertive about taking it (or have a strong reason like a trip abroad or physical sickness) or take it in secret, otherwise more responsibilities are bestowed upon me."*

Doctoral training programme staff interviewed noted that there is sometimes a perception that part time study is incompatible with research achievements. There was a fear that other research projects may get ahead of the student in publishing the same findings, unless the student was working at a certain pace. The possibility for part-time study is not ubiquitous; it may be easier to do heavy computational projects part time than fieldwork in Peru for instance. However, we found examples indicating that the root of this scepticism is at least partly that attitudes toward disability differ from attitudes toward other situations which may result in pace changes, such as pregnancy. One focus group participant commented:

> *"I requested going down to four days a week instead of five. [...] they said there was no kind of reason to do that, because I'd been doing it [working full time] this far. And yet again, once I said I was pregnant, they said I could do whichever reduced hours I wanted, because it would look really good on their next Athena Swan application."*

Knowing that they could not live up to the pressure to produce material at the rate of an abled person, two students in our focus group who had the option of going down to part time studies had chosen to do so officially as a way of managing expectations. In practice, however, they were still studying full time:

> *"...going part time was almost a tactical move, because I wasn't going to finish on time, full time. And so, in a sense, I'm officially part time, but I'm working full time. In my own time, I'm doing a lot of work on the PhD."*

However in addition to being financially unviable for most, an issue with this informal solution is that the student only receives disability support for half of the time they are working:

> *"[...] I know that a lot of other like, non-disabled PhD students do this to give themselves more time. The problem is as a disabled student, if you do that they half your support. So while I have gone part time, the support that I'm receiving now is a lot less."*

A culture of overwork can be enforced or combatted by research institutions, doctoral training partnerships and funders.

Funding providers

Participants in our focus group pointed out that even if the decision goes through a research organisation, funding providers are the ones to ultimately set the policies here:

> *"[M]y university (and I gather many) are very hesitant to give like, waivers, or an extension beyond the four years, because basically for every student they have that is more than four years is on a full time PhD, their funders get very grumpy with the university. And that's more compelling to the university than supporting students with, you know disabled students with additional needs."*

56% of our sample were UKRI funded, 19% were institutionally funded, 11% were charity funded, 8% were self funded, 6% were industry funded, while the rest were funded by other sources. Of those who were UKRI funded 54% were funded by BBSRC, 22% by MRC, 17% by EPSRC and the rest by other UKRI Research Councils.

Our survey asked if respondents' funding bodies were understanding when their disability impacts their attendance or performance. If we exclude those who responded that they do not feel the question is applicable to them, we are left with a sample of whom 20% agreed that their funder was understanding, 19% disagreed and 43% did not know. However, this was largely dependent on which funder the student had. Only 13% of UKRI funded students agreed that their funder was understanding while 30% of other students did. A focus group participant commented:

> *"Oh, yeah, there's sort of like--inflexibility for me, overall, in that while I've got the privilege of being kind of like, funded by a Research Council, I know that my funding is capped at three years, regardless of what's happening. Whereas school funded, I think they have a six month extension that is possible. And while obviously, I'm only first year, but it does hang over my head because I know that I don't work perhaps at the most consistent of paces."*

When asked whether their funder was flexible, accommodating, and valued their wellbeing, the largest group, 33% of respondents, stated that they did not know, 30% agreed and 24% disagreed. This was again affected by the funding body:

27% of those who were funded by UKRI agreed that their funder was flexible, accommodating, and valued their wellbeing, while 36% of those who were non-UKRI funded agreed.

While there is clearly an issue with funding bodies' approach to disability overall these statistics indicate that the issue is especially pronounced for UKRI. As discussed in Chapter 3 it was widely held by doctoral training programme and wider university staff members interviewed for this report that Research Councils were inflexible around disability support. This included a lack of understanding around the importance of flexibility in regards to funding and extensions.

The difference in support received from UKRI versus other funders may play some role in explaining why UKRI students are less likely to declare a disability: 8% of UKRI funded students declared a disability in 2019/20 (UKRI, 2021a, p.15) compared to 11% of PGR students overall in 2019/20 (HESA, 2023b, Figure 5). The lower declaration rate among UKRI students is especially surprising considering that UKRI funds proportionally more home students than other funders (Westphal & Ilieva, 2022) and home students are much more likely to declare a disability (see Appendix A).

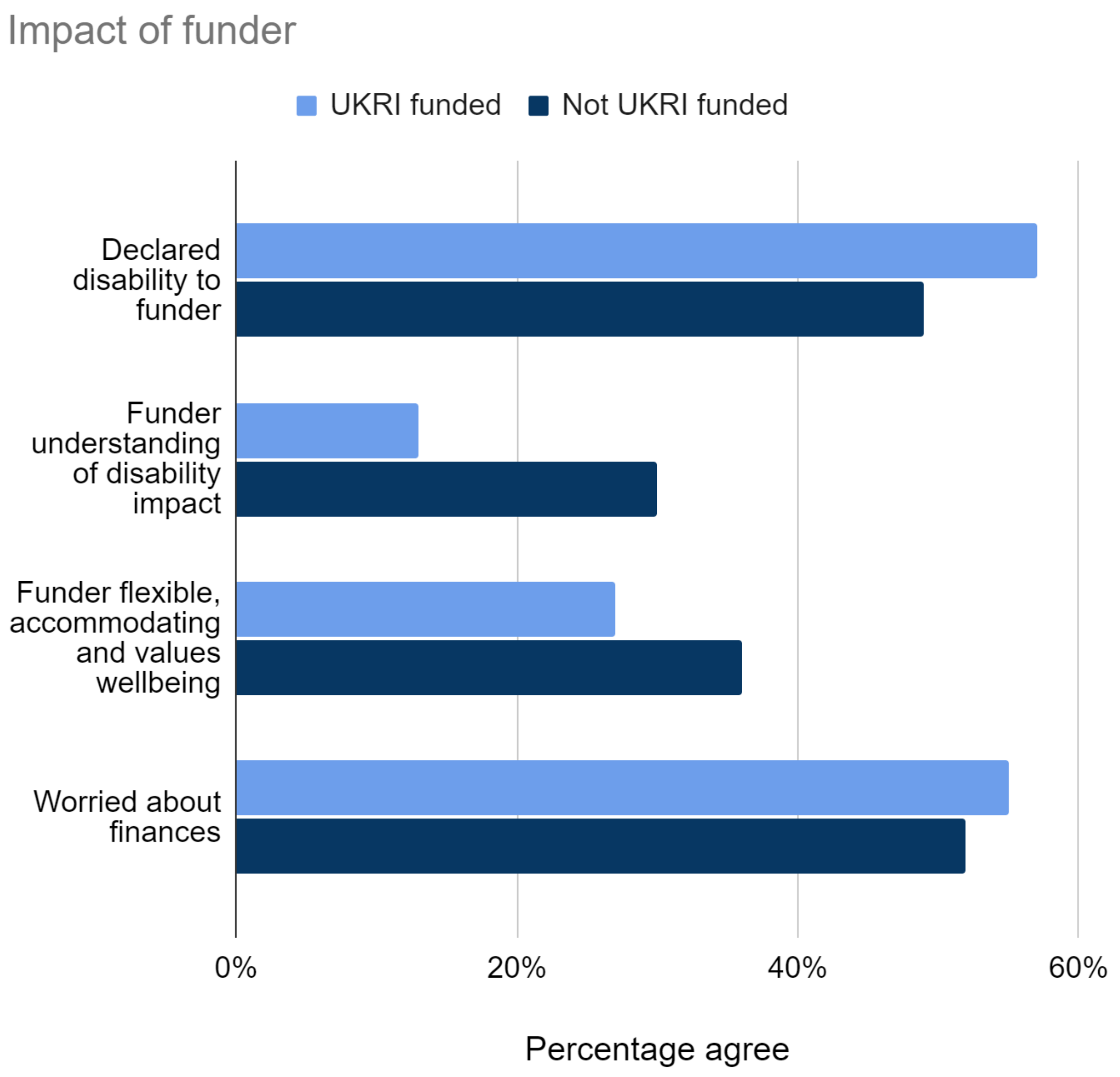


Figure 12. Funder comparison

When we asked participants to write freely about how well they feel their funding body supports, and is adaptive to, disabled PhD students, many student responses revealed a recurring theme of having little contact with the funding body. This could explain why 33% of participants responded that they did not know whether their funder was flexible, accommodating and valued their wellbeing. Several participants reported that there was little information out there about how the funding body might support students with disabilities. Among those receiving funding from a funding body, only 53% had declared their disability to that funding body.

Those who had some contact with their funding body evaluated how supportive and adaptive it was based on factors such as:

- How easily available information about support was
- How much administrative work the funding body required the student to go through in order for the student to receive support
- Whether the funding body's staff members were knowledgeable and positive around disability support
- What type of DSA disability support the funding body was willing to fund (if they were responsible for DSA)
- Whether training, symposia, summer schools, networking events and similar events were made accessible upon request
- Whether the requirements attached to funding were adjusted for disability
- Whether the funding body offered sick leave, extensions and part time options
- Whether there were delays for the funding body in providing support or making adjustments

There were both positive and negative evaluations on these measures:

> *"I think my funding body nominally supports disabled PhD students, but doesn't actually understand a) how to go about supporting disabled students and b) that the research culture they create is unaccommodating of disabled PhD students."*
>
> *"They are accommodating, quick, well prepared. They are kind when dealing with student issues. They told me "suspending you status doesn't make you less of an x scholar. It happens all the time. Take the time away you need your scholarship will be here when you come back". They have allowed me to speak on how my disability shaped my academic path. I have fellow scholars who are disabled as friends. There is community in my funding body for this."*

Conclusion

Having looked at current policies around the pace of studies, it is perhaps unsurprising that, when they were asked about how their institution or centre could become more accessible, a large group of students requested being allowed to go part time, take sick leave or get extensions without financial implications.

It was regularly observed in the conversations with staff relating to this project that there was a lack of alignment between funder's Terms & Conditions and common employment practice in terms of sickness pay, phased return and other standard approaches commonplace in university employment practices. When students are forced to work at an unsustainable pace it limits disabled students not just from paid work but from taking full advantage of other career development opportunities such as teaching or participating in outreach activities.

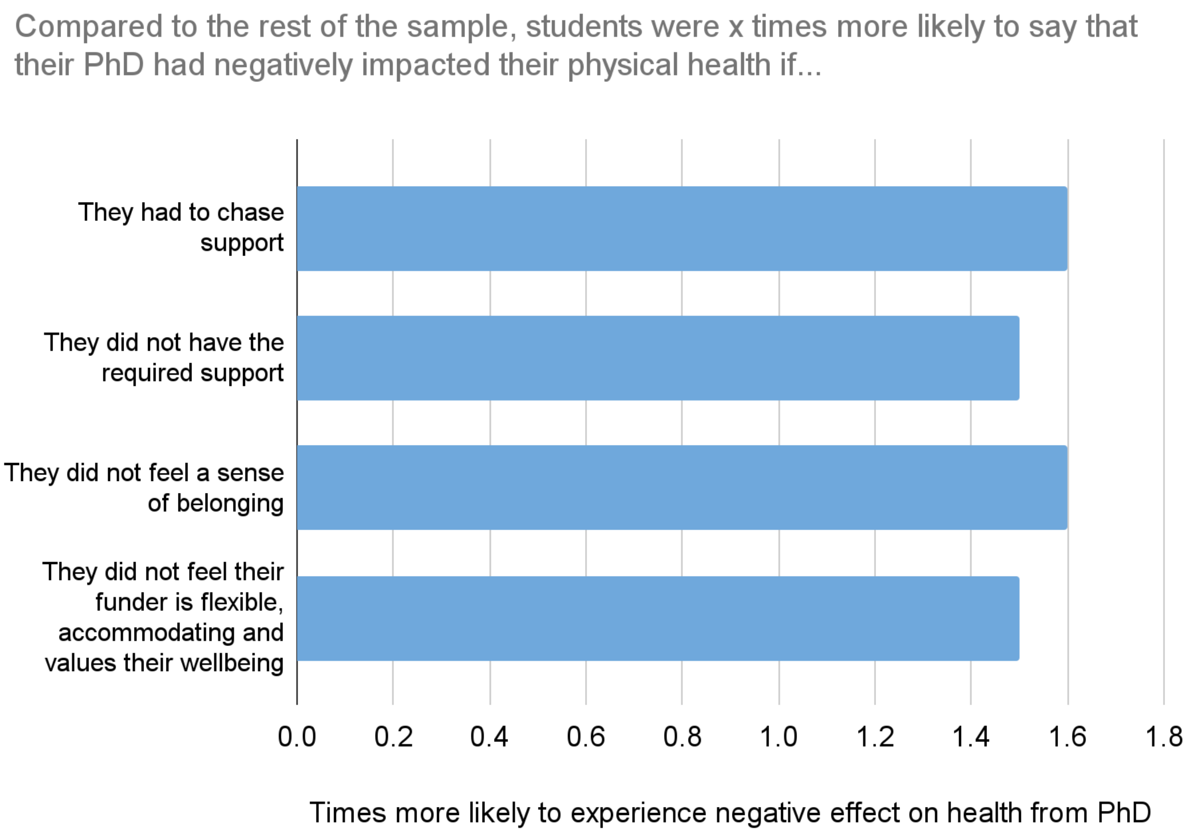
Being unable to change their pace of study to match their capacity also has consequences for disabled students' health. 67% of respondents to our survey stated that conducting their doctoral studies had impacted on their physical health, and 86% stated that it had impacted on their mental health and wellbeing. Students who did not feel that their funder was flexible, accommodating, and valued their wellbeing were 1.5 times more likely to say that undertaking the PhD had negatively impacted on their physical health. One survey participant explains:

> *"[T]he fear of [losing] a stipend which is my only source of income has prevented me from taking a step back when needed, and therefore has negatively impacted my work and wellbeing."*

We do not know how many students choose not to apply for or embark on doctoral study due to financial constraints, however we do know that disabled students are more likely to drop out of their PhD programme (Lopes & Wakeling, 2022). We have every reason to believe that this is caused in part by funding policies which mean that doctoral students are unable to work at a pace that is healthy for them.

We urge funding bodies to consider how their sick leave and extension policies can be brought in line with the Equality Act and seriously consider full time stipends for students who only have capacity to study part time.

UKRI has recently invested £8 million pounds to widen participation of Black, Asian and minority ethnic students in postgraduate research (UKRI, 2023b). A similar initiative for disabled PGR students would be welcome. In September of 2023 UKRI stated that it will be prioritising reviewing their support for disabled students, in particular looking at their terms and conditions as well as funding (UKRI, 2023e).



Compared to the rest of the sample, students were x times more likely to say that their PhD had negatively impacted their physical health if...

Figure 13. Predictors of physical health

Recommendations

1. Funders should allow 28 weeks of paid sick leave, not requiring medical evidence in the first 14 days for any PhD students and not in the first 28 days for PhD students who have registered as disabled.

2. UKRI should change their terms and conditions to highlight the need for research organisations to ensure that there is support for students who need to take a break from their studentship due to health and safety reasons related to their disability. This in keeping with the recommendation of the 2023 Assessment of UKRI terms and conditions of training grants from an EDI perspective.

3. Funders should automatically extend funding to offset disability related absences in the same way that UKRI does for paternity leave.

4. Funders should allow funding extensions on disability grounds, creating an accessible application process for this purpose.

5. Research institutions should not charge students extension fees when an extension is requested on disability grounds.

6. Funders should allow PhD students to study for less than 50% FTE and to make a phased return to work over a longer time period than 4 weeks, in principle. UKRI should:
    a. "*expand the terms and conditions to recognise that people may need flexibility […] and want to change their commitments or a change in employment status etc.*" (Pugh, 2023, p.23) and "*work with research organisations to understand whether a PGR could study for less than 50% of the FTE at points in time and the implications of this for the registration period, research relevance and if there are particular barriers for some research disciplines*" in keeping with the recommendation of the 2023 Assessment of UKRI terms and conditions of training grants from an EDI perspective, currently under review. (Pugh, 2023, p.23)
    b. Clarify in which situations part time studies are not just permissible but required as a reasonable adjustment.
    c. "*take steps to ensure that where part-time study is feasible, in relation to the research area and objectives of research funding, part-time students have access to the same funding support as full time students.*" in keeping with the recommendation of the 2023 Assessment of UKRI terms and conditions of training grants from an EDI perspective, currently under review. (Pugh, 2023, p.22)

7. Funders should change the minimum funding length to 4 years to minimise the need for unfunded writing up periods.

8. Funders should offer an option to study part time with full time funding for students whose needs assessment shows that they are unable to healthily work or study full time. The 2023 Assessment of UKRI terms and conditions of training grants from an EDI perspective states that UKRI should "*liaise as appropriate with HMRC and DWP on the feasibility of any change in financial support for part-time students*" (Pugh, 2023, p.22).

9. Funders should review stipend amounts and whether any additional support can be provided to students who are likely to struggle financially. The 2023 assessment of UKRI terms and conditions of training grants from an EDI perspective recommends that UKRI both review the level of stipends (taking EDI and part-time studies into account) and introduce grants that are targeted at disabled students.

10. Funders should ensure that their support for disabled students, from DSA to reasonable adjustments at networking events, to part time study options, are clearly signalled and that all student facing staff within the funding body are aware of what is available or who to turn to if a student asks about disability support.

11. Funders should review whether attitudinal and administrative barriers within their organisation are keeping disabled students from accessing the disability support provided by the funder.

Conclusion

This project set out to collect data on the experience of disabled PhD students in STEM with the aim of providing recommendations to research organisations and funders regarding how they can provide equal opportunities for their disabled students.

Despite the obligation to remove the disadvantages caused by inaccessibility, we found that only 33% of disabled PhD students felt they had received the support they needed to be on an equal footing with their non-disabled peers. However, this can be addressed. Our research provides 7 steps to improving the experience of disabled PhD students:

1. Address gaps in the provision of individualised support and clarify which bodies are responsible
2. Reduce the administrative burden associated with attaining support
3. Resource decentralised bodies
4. Encourage a culture of support
5. Build on the positive aspects of the supervisor-supervisee relationship while addressing possible difficulties
6. Make the physical and sensory environment more accessible
7. Allow students to study at a pace that suits different bodies and minds

Our report consistently shows the importance of allocation of responsibility, communication and collaboration within and between the bodies responsible for accessibility for doctoral students. We also find clear evidence that the human element, staff members having the time and incentive to act compassionately, has a disproportionate impact on whether disabled students feel supported.

This report lays the groundwork for further investigation into how to ensure equitable opportunities for disabled PhD students. There were several areas which we hope will be addressed in further depth through future research. Firstly, intersectionality is a crucial part of the disabled PhD student experience. This is particularly important, as highlighted in Appendix A, as it relates to international students, but also racially marginalised students. Due to our sample size we were unable to draw as many conclusions on this topic as we would have liked and we encourage future research to specifically target these groups, as we believe outcomes can be substantially improved by doing so.

Secondly, there are a number of areas of accessibility which are particularly relevant to disabled PhD students which we have touched on in Appendix B. Whole reports could be written about the accessibility of the PhD experience specifically as it relates to interviews/admission processes, conferences/careers, assessments, placements, teaching positions, fieldwork and lab work of different kinds. We encourage funders and advisory or policy-making bodies to develop best practice guides for accessibility in these areas.

Undertaking a PhD has the potential of transforming one's life, and disabled students have much to contribute to the world of research. However to do so they must be afforded the support required to even the playing field. Throughout this work we found numerous examples that whether accommodations were put in place was largely down to whether disability was prioritised to the same degree as other protected characteristics. Senior leaders must take responsibility and listen to the data and lived experience expertise to create lasting change.

Survey demographics

All 192 participants in our online survey were STEM PhD students, with 56% being UKRI funded. 54% of the UKRI funded students were funded by BBSRC. We especially reached out to students in the life sciences - 29% of all participants studied biological and sports sciences, 28% studied subjects allied to medicine, while the rest studied other STEM subjects.

25% of participants studied at Oxford while the rest were distributed among 45 other universities. Only 9% of our sample studied part time, a smaller proportion than within the disabled student population as a whole (HESA, 2023b)

The vast majority of our survey respondents (96%) had some form of diagnosis of a disability, including long term health conditions and neurodiversity. Almost one in four (23%) lacked a diagnosis for at least one of their conditions. We know that it takes time for many to receive their diagnoses, so the fact that so many of our participants have at least one diagnosis likely reflects a self selection bias regarding who feels “disabled enough” to be entitled to fill in the survey.

The most common disabilities in our sample were long term mental health conditions (49% of participants), specific learning differences (43%), chronic health conditions (40%) and autism (29%). If we include neurological impairment and mental health conditions in the definition of neurodivergence, 92% of our sample is neurodivergent. 68% of our survey respondents report having multiple disabilities. It is difficult to compare our disability breakdown to the national average as previous record keeping has treated differing disabilities as mutually exclusive, however autism is more prevalent in our sample than in the Disabled Students UK 2021 sample, which is dominated by undergraduate (UG) students. Long term health conditions (mental or otherwise) on the other hand are somewhat less prevalent in our current sample.

Only 18% of our participants identified as men, an underrepresentation that we repeatedly find in surveys of disabled students, which is not reflected in the wider disabled student population demographics. 8% of our sample identified as non-binary and 74% as women. 6% of the sample shared that they did not identify with the gender they were assigned at birth.

Only 15% of our sample are international students, which unfortunately does somewhat reflect declared population demographics: low declaration rates among international (EU and non-EU) students mean that international students make up 45% of PGR students without a declared disability but only 18% of PGR students with a declared disability (see Appendix A) (HESA, 2023b).

86% of our sample is white. While this is an overrepresentation compared to the PGR population as a whole, we cannot know if it is reflective of declared disabled PGR population demographics due to the lack of intersectional data in the sector.

Acknowledgements

First and foremost, we would like to thank the disabled PhD students and staff members who contributed with their knowledge and time as they filled in our survey, took part in our focus groups or volunteered to be interviewed. We very much value your effort and insight.

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Disabled Students UK

Founded in 2020, Disabled Students UK (DSUK) has quickly become the largest disabled student-led organisation in the UK. The organisation empowers students to share their insight into accessibility with the goal of driving policy change.

DSUK has built a reputation as an evidence-based organisation. Their 2020 report, which warned the sector about the impact of the pandemic on disabled students, was mentioned in parliament. Their 2022 report Going Back is Not a Choice which presents key accessibility lessons from the pandemic has been hailed as “a potential game changer in its review of UK HE inclusive provision”. DSUK has a collaborative approach to change and offers consulting and training to universities and students’ unions, disseminating disabled students’ insight.

They have worked with institutions such as the University College London and organisations such as the National Union of Students, presenting for the All-Party Parliamentary Group for Disability and Westminster Higher Education Forum. Their vision is a truly accessible higher education experience, ensuring disabled people equal access to education and the associated societal and self-development opportunities.

Pete Quinn Consulting

Pete founded this Consultancy in 2017 following a career spanning 15 years in student support, as a specialist in Equity, Diversity and Inclusion (EDI), disability and well-being at the Universities of Oxford and York.

Pete Quinn Consulting have undertaken projects on inclusive teaching and learning, disability and neurodiversity support and physical and digital inclusion with Universities throughout the UK. Recently this included work with the University of Bristol Neurodiverse Staff Network (University of Bristol, 2022) and Subtitling (The University of Edinburgh, 2019) and Accessible VLE projects with the University of Edinburgh. These have been alongside international consultancy projects with Polytechnics and Universities in Singapore and in Hong Kong via the Education University of Hong Kong where Pete has been a guest lecturer. Beyond Higher Education Pete Quinn Consulting works with organisations in a range of sectors including Culture, Arts and Heritage, Engineering, Retail, Health and Legal and is also an active contributor to Student Minds, York Menfulness and the Jo Cox legacy events including Run for Jo and the Jo Cox Way.

The Oxford Interdisciplinary Bioscience Doctoral Training Partnership

The Oxford Interdisciplinary Bioscience DTP is an inclusive and innovative four-year graduate training programme, funded by the Biotechnology and Biological Sciences Research Council (BBSRC). It aims to equip a new generation of researchers with the skills, insight and knowledge needed to tackle the most important challenges in bioscience research. The DTP comprises ten partner organisations: The University of Oxford, The Pirbright Institute, Oxford Brookes University, Diamond Light Source, ISIS Neutron and Muon Source, STFC Central Laser Facility, The Rosalind Franklin Institute, the Research Complex at Harwell, the INEOS Oxford Institute and the Novo Nordisk Research Centre Oxford. The DTP aims to work in partnership with BBSRC and with other doctoral programmes to inspire, enable and support both staff and students to achieve their full potential. We aim to create a scientific community that is innovative, inclusive and collaborative, in which everyone feels valued, respected, and supported.

Appendices

- **Appendix A** – Disability Declaration and International Students
- **Appendix B** – Areas of Accessibility
- **Appendix C** – Application and Admissions

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