

Project Team

Nick Anim - Project Researcher, The Bartlett

Elise Crayton - Psychology and Language Sciences, Faculty of Brain Sciences (FBS)

Jason Davies - UCL Arena

Manjula Patrick - Principal Investigator and FBS Disability Equity Lead

Nicola Ridgway - Ear Institute, FBS

Acknowledgements

We would like to thank all the staff and students who took part in the study and, despite having some reservations about how much change their voices and opinions could or would instigate within the Faculty and UCL, entrusted us with their candour and hopes.

Contents

Project Team.....	2
FOREWORD by Nicole Brown	5
Executive Summary	8
Awareness raising and training	8
The tyranny of protocol.....	9
Signposting.....	9
Fear of overreaction and stigmatisation	9
Personal and career development.....	10
Solutions and recommendations	10
Background	12
Aims.....	14
Methodology.....	15
Research Methods	16
Data Collection	16
Ethics and Confidentiality: Do no harm	17
Limitations	18
Findings.....	19
Staff.....	19
Experiences	19
Equity: Disability awareness and reasonable adjustments	22
Belonging.....	25
Ableism and Discrimination.....	26
Recommendations.....	27
Students.....	29
Experiences	29
Equity: Disability awareness and reasonable adjustments	33
Belonging.....	36
Ableism and Discrimination.....	37
Recommendations.....	37
Conclusion	40
Recommendations.....	42

References.....	44
APPENDIX.....	45
A1: Research sub-questions (staff)	45
A2: Research sub-questions (students)	47
B1: Participant information sheet	50

FOREWORD by Nicole Brown

When I began my advocacy and activist work on ableism in academia in 2017/2018 and spearheaded the fully accessible and inclusive hybrid conference Ableism in Academia in March 2018, I was convinced that with the help of others I had gained sufficient momentum to raise awareness about the lived experience of disability, chronic illness and/or neurodivergence in higher education to bring about long-lasting change. Admittedly, I am now in two minds following this report from Manjula Patrick and Nick Anim.

On the one hand, it is fantastic to see that others are keeping that initial momentum going by building on what we all learned from those initial events of the conference and all launch webinars for the associated books (Brown, 2021; Brown and Leigh, 2020). On the other hand, it is disheartening, and indeed shocking to read in this report that practically nothing has changed in those five years. The fact that staff and students of UCL are still struggling to make their voices heard, to gain a sense of belonging and to access support to simply navigate what should be an ordinary, everyday experience that is higher education is shameful.

As a university of global standing, under the leadership of and endorsed by Professor Michael Arthur, then Provost and President of UCL ([click to access Prof Arthur's talk from the day](#)), we began that all-important journey towards equality, inclusion, and diversity as the leaders in the UK higher education sector, with other universities keen to contribute to and associate with our work. The evidence from this report now suggests that we may have forfeited our head start. Generally, I am an optimistic person, though, and so I do think that there is scope to gain back that edge.

Manjula and Nick's recommendations are well-grounded in substantial evidence based upon robust qualitative analysis, and are very realistic, pragmatic, and practical: more relevant training and signposting, more flexibility around processes and procedures, more inclusive environment that would foster higher rates of disclosures, more opportunities for career development, and more spaces and opportunities to network and connect. Most of these recommendations reiterate what I also call for in publications and presentations.

My question therefore is not to Manjula and Nick, but to university leadership teams and the higher education sector, as a whole: what else is needed for these individuals to be heard, for their needs to be met, and their asks to be answered? As a sector, we pride ourselves in

offering opportunities for all, we emphasise widening participation strategies, we focus on decolonising curricula, we concentrate on supporting BME students, we regularly complete Athena SWAN applications, and yet, we routinely overlook and ignore a significant population group. I wonder what is so complicated about creating a network for neurodivergent students, for example, to ensure that they can build a peer support system, or why reasonable adjustment processes need to be so dehumanised that individuals shy away from engaging with them altogether.

The consequence of our collective non-response to the plight of disabled, chronically ill and/or neurodivergent staff and students is devastating, as we basically become complicit in reinforcing discriminatory practices and social injustices by excluding brilliant minds, merely because of their ways of working not fitting within a one-size-fits-all model. Disability-awareness and -confidence cannot merely be box-ticking exercise, instead, they must be embedded at all levels under all circumstances. Manjula and Nick propose a design with inclusion, which draws on the principles of the Universal Design for Learning, a philosophy that means all events and learning provision will be made as accessible and inclusive as possible so that nobody needs to formally ask for reasonable adjustments anymore. This Universal Design for Learning was also the basis for the above-mentioned conference back in March 2018, where there was even a water bowl available for dogs, in case someone would bring along a guide-dog (Brown et al., 2018). Rather than burdening those with disabilities, chronic illnesses and/or neurodivergences with additional labour that is required for them to ensure that they can access education and research, we take those pressures off. We invite them into a welcoming space where nobody is required to disclose their needs, and where they can engage with the learning experiences in the same way non-disabled staff and students would. For all of us in higher education the COVID-19 pandemic has presented significant challenges relating to health and wellbeing, but for many individuals, as is also reported here, the online or hybrid ways of working were in some ways opportunities to level the gaps in accessibility and inclusion. Indeed, many staff and students were suddenly able to engage with higher education as they had not been able to before. Let us now not lose focus or forfeit our own learning during the pandemic by insisting on "going back to normal" (Brown et al., 2020). Instead, let us look to integrating and normalising what was originally a pandemic-response or an adjustment. Naturally, we may make mistakes, in the process of developing such an inclusive environment, but the potential of mistakes must not become an excuse for continuing the bad practices of the past.

And this report by Manjula Patrick and Nick Anim helps us with that, so let us all listen and internalise what they say, even if – or rather because – some of the report makes us uncomfortable and is difficult to stomach.

Dr Nicole Brown
Associate Professor, IOE Head of Research Ethics and Integrity

Executive Summary

Within the broader context of Equity, Diversity, and Inclusion (EDI) at UCL's Faculty of Brain Sciences (FBS), this is the first piece of research carried out to explore the question "What are the experiences of disabled staff and students?"

Against the backdrop of the recent Covid-19 pandemic and the associated disruption to the conventional campus experience, the research was conducted through a series of online focus group sessions that aimed to examine how disabilities, visible and invisible, shape working and social experiences at the university, for both staff and students.

In total, five focus group sessions were conducted, two for staff, and three for students. The number of attendees involved were eight staff, and twelve students. For both staff and students, the research question was disaggregated into the following five sections: (1) Staff/students experience, (2) Equity (3) Belonging (4) Ableism and discrimination, and (5) Recommendations. The related sub-questions are in Appendix A1 and A2.

KEY FINDINGS

Due to the nature of voluntary engagement of this research method, the report is presented as a representation of some, not all, experiences. However, given that participants presented a very broad spectrum of physical, mental and neurodivergent disabilities, we can say with a high degree of confidence that the experiences shared, offer a significant starting point for the FBS to better understand and hence improve the environment for all disability groups.

Awareness raising and training

Whilst there was recognition and appreciation of some good individual efforts in the FBS, as well as praise for the disability and dyslexia service and Occupational Health services, most participants expressed being very or fairly concerned that there is insufficient awareness and training on many different aspects of disability and the necessary processes to foster an equitable and inclusive environment for disabled people both within the FBS and UCL in general.

The tyranny of protocol

Many negative experiences expressed by staff were also linked to issues of inflexibility in implementing top-down protocols 'by the letter'. Such approaches cannot, by definition and application, accommodate the variety of individual needs. In that context, for most disabled staff participants, expressions of dissatisfaction were often about their line-manager's strict adherence or interpretation of blanket Human Resources (HR) edicts and processes that failed to take into account the specific requirements of a particular category of disability, or indeed related concerns raised by the individual member of staff.

For most student participants, the 'tyranny of protocol' is apparent in experiences such as long-winded processes of trying to get support, for example, to do with extensions to deadlines, and being "referred from pillar to post" without any clear signposts. That often reflects the fact that Extenuating Circumstances processes and protocols take time to work through, even though the speed of informing students of decisions is often crucial.

For students with AD(H)D, the relative lack of understanding of the condition within UCL mental health services in general, and more specifically the FBS support structures, adds yet another layer of complications. In most cases, similar to staff experiences, the support available was a broad approach that did not address the specific needs of the individual.

Signposting

In many instances, although lecturers and line managers were sympathetic to requests from disabled students and staff, they often did not know how to initiate or implement the necessary remedial procedures. Additionally, support infrastructures such as websites often fall short in providing adequate information; even basic information such as signposting to Occupational Health services. One notable effect of such shortcomings is to discourage people from talking about their situation and needs. Overall, many of the participants in the study thought issues of signposting are rather chaotic within the FBS.

Fear of overreaction and stigmatisation

The decision by any person to reveal or share information about their particular disability is often mediated by the environment within which they are located and operate. For some disabled members of staff, that decision is based on experiences either within society at large, or previous places of employment. In many cases, the constant fears of overreaction and stigmatisation prevent people from sharing information about their disability, even at the point of

applying for particular academic courses or employment positions. Relatedly, many of the staff expressed a surprise that UCL does not appear to be a disability confident employer. As a result, some people are choosing not to share information about their disability.

Fears of overreaction and stigmatisation for students with disabilities are felt across all levels, from undergraduate to doctoral studies. Many students with non-visible disabilities described experiences of fellow students and lecturers being 'freaked out' when they shared information about their disability, leading many to conclude that it is perhaps better not to tell others. Despite periodic events and campaigns, there remains a general lack of awareness and understanding, particularly about neurodivergent conditions such as AD(H)D.

Personal and career development

Across both academic and professional services staff, participants expressed a frustration at what they described as very limited chances of progression. Perhaps most disturbingly, some participants highlighted incidents of being used to access groups or communities related to their particular disability for research purposes, without thinking much about how to encourage or help the personal and career development of the staff members themselves. Such experiences have left many staff despondent and feeling they cannot progress at UCL.

Questions of personal development for student participants in the study were more difficult to gauge due to the disruption of the Covid-19 pandemic and remote learning. Whilst some neurodivergent participants felt they benefitted greatly from the switch to online learning, others felt their personal development was stifled because many courses took on more students than normal, and therefore lecturers could not give sufficient attention to their specific needs. In that respect, many students have felt very challenged and overwhelmed by the lack of recognition and attention.

Solutions and recommendations

Both staff and student participants in the study were, in the first instance, very grateful for the opportunity to engage and share their experiences and opinions in this study. All participants expressed a wish for the study to just be the beginning of a process that will periodically invite them to share their experiences, not only online but where people could meet and have some sort of bonding session. Beyond that, there were three main recommendations put forward by the participants, which we believe can be set in motion immediately. First, there should be a concerted and consistent effort within the FBS, and more broadly UCL, to raise awareness and

provide information about various disabilities, visible and non-visible. This can be achieved, for example, by having more posters around the FBS and the university, and making issues of disability more prominent in online communications. Doing so would make more disabled people feel they are included, they belong, and can talk openly about their disability or neurodivergence. Second, participants expressed the need for a network or forum to openly discuss their challenges with other people who face similar challenges and barriers. Third, participants recommended mandatory training for all professional services, academic and research staff about disability issues, with action planning and accountability linked to the training. Relatedly, all HR staff should be aware of the Equality Act (2010) and what it entails regarding disability equity in order to provide pertinent guidance that moves away from the deficit model of disability.

Background

Although there is an increasing recognition of the broad spectrum of disabilities in society at large, disabled people continue to be underrepresented in most sectors. In the Higher Education sector, a lot of research has focused on student experiences with impairment and disabling environments. In 2019/20, 332,000 students, 17.3% of all home students in the UK's Higher Education sector identified as having a disability. That figure represents an increase of 106,000 or 47% since 2014/15. Much of the increase has been attributed to those declaring neurodivergent conditions such as dyslexia, dyspraxia and Attention Deficit Hyperactivity Disorder AD(H)D. The next most common declaration, with an increase of more than 180% since 2014/15, has been in relation to mental health conditions such as panic disorders, anxiety disorders, and depression.¹ Despite these noteworthy increases, disabled students in Higher Education Institutions continue to have somewhat worse outcomes than their non-disabled counterparts. Even after other factors such as prior attainment, gender, age, and ethnicity have been considered, disabled students are more likely to drop out of courses, and those that complete their degree tend to have lower degree results. Furthermore, the prospects for employment are also worse for disabled students.²

Against that backdrop of much research focusing on various aspects of students' experience, there appears to be relatively fewer studies and literature about the experiences of disabled staff in Higher Education. That said, according to the Department for Work and Pensions, 22% of working age people in the UK reported having a disability in 2019 to 2020.³ Comparatively, in the same period, 5.5% of staff working in Higher Education Institutions identified as disabled.⁴

Among both the professional services staff and academic staff, the most commonly declared impairment types were a long-standing illness or health condition (24.5% and 23.0% respectively), or a specific learning difficulty (20.6% and 24.3% respectively). More than one in eight professional services disabled staff (17.0%) and academic disabled staff (12.6%) declared

¹ Hubble and Bolton, 2021.

² *ibid*

³ DWP, 2021.

⁴ AdvanceHE, 2021.

having a mental health condition.⁵ Overall, the proportion of staff who declared having a disability was higher in lower contract levels of both academic and professional services staff.

Despite the increasing awareness of issues related to disability in recent years, staff and students with disabilities are likely to face more barriers along their journey in Higher Education Institutions than those without disabilities. Institutions such as UCL must therefore reflect on how they can better understand and best meet the varied needs of their disabled staff and students to improve their university experience. At UCL, staff and students with disabilities and neurodivergence have reported frequent discrimination and a lack of equitable opportunities to thrive.

Where and when society's dominant cultural norms concerning impairment – such as regarding disabilities/neurodivergence as burdens – are reflected in institutions, for example, in terms of who occupies the top positions of leadership and how they behave, or by providing reasonable adjustments that are guided by notions of equality rather than equity, then doing enough is incompatible with aspirations for greater inclusion and belonging. Enough is not enough!

⁵ Ibid.

Aims

This project is part of the FBS's overall EDI strategy to explore, understand, and improve the experiences of staff and students from minoritised groups. Based on some evidence indicating that disability can have a negative impact on staff and student experiences at UCL due to, for example, frequent discrimination and lack of equitable opportunities, this study was undertaken to initiate a process that not only gives recognition and voice to the different concerns of staff and students with a broad spectrum of physical, mental and neurodivergent impairments, but instigates solutions based on their recommendations. The aims of the study were, specifically, to explore the following:

1. Positive and negative experiences of disabled/neurodivergent staff and students within FBS.
2. Staff and students' perceptions and motivations of personal, academic and career development and success, as well as any barriers in achieving this.
3. Staff and students' perceptions of belonging and the degree to which this is felt within Divisions and Institutes across FBS, as well as the wider UCL.
4. Whether staff and students have experienced incidents of discrimination in FBS/UCL, and if so, how these were addressed.
5. Identify recommendations/suggestions to improve experiences of disabled staff and students in FBS.

Methodology

In the absence of any previous research on the topic, this study set out to explore the following question: “What are the experiences of disabled staff and students at the FBS?” That primary research question was disaggregated into semi-structured sub-questions presented in five categories:

(1) Experience

Participants were asked if and how their disability had impacted their experience at UCL, and whether there were any significant differences as a result of Covid-19 restrictions.

(2) Equity: Disability awareness and reasonable adjustments.

This section sought to explore the staff/students experience from the perspective of accessibility and attitudes towards disability at UCL. We also questioned the awareness of support available in the context of reasonable adjustments and invited ideas about possible solutions that could be implemented, both immediately and in the longer-term.

(3) Belonging

In this section, we tried to find out if participants felt that UCL in general, and the faculty or their Division offered a welcoming and inclusive environment. Relatedly, we asked if there are any physical spaces where staff/students do not feel particularly welcome.

(4) Ableism and Discrimination

Participants were asked how and to what extent the environment created by the Division or Institute had impacted, positively or negatively, their disability and wellbeing. We also tried to find out if there are any specific environments that are better or worse.

(5) Recommendations

Reflecting on their time at UCL to date, as well as knowledge or experiences with other organisations, participants were asked to offer any suggestions they might have for improving staff/students experience at UCL in general or, more specifically, the faculty.

The full set of sub-questions can be found in Appendices A1 and A2

Research Methods

The study was conducted through five online focus group sessions. Potential participants – any FBS staff and students who self-identify as disabled/neurodivergent – were made aware of the study by email invitations within the FBS, an announcement on the FBS website, as well as via relevant communications such as Institute or Division newsletters. The notifications included the promise of a £20 gift token, to be sent within four weeks of participation. Although there were almost fifty expressions of interest following the call outs, the total number who eventually participated were twenty, comprising eight staff, and twelve students – ranging from undergraduates to final year PhD students.

The demographics of participants spanned across a broad spectrum of physical, mental and neurodivergent disability identities. Each of the sessions lasted for two hours, with a minimum of two ten-minute breaks; an option for an additional break was proposed in all sessions but rarely taken. To encourage full engagement, the maximum number of participants for each session was four. For purposes of anonymity and to create a ‘safe and brave space’ for open and frank sharing of experiences and reflections, the sessions were not audio or video recorded.

Data Collection

The focus group sessions were held in early November and December 2021. Although they were not audio or video recorded, we employed the services of an independent live captioning company who provided transcripts for each session. The transcripts were saved in a secure online folder, which was only accessible by two members of the research team. Following each focus group session, participants were sent the session questions to add any further thoughts and reflections they may have, or indeed comments they felt were too sensitive to share in the group session. The returned questionnaires were then added to the secure folder.

The analyses of the transcripts and returned questionnaires began in February 2022. The coding of participants' responses into prominent themes was guided/informed by the sub-questions (see Appendix A1 and A2) under the five categories of exploration (see Methodology section above).

Ethics and Confidentiality: Do no harm

Before the start of the focus group sessions, all registrants were sent an information sheet (see Appendix B1) confirming that the study had been approved by UCL's research ethics committee. The information sheet also contained other details such as the names of all the project team members, the eligibility criteria for participation, aims of the project, assurances about confidentiality and the limits therein, a consent withdrawal clause, data protection guarantees, contact details for a variety of UCL's support services, and other points relating to the overarching ethics and confidentiality consideration to 'do no harm'.

It follows, then, that all stages of planning and implementation of this study were guided by UCL's research ethics principles and protocols. The project team were aware of ethics requirements across many disciplines. In particular, the project researcher, who also facilitated the focus group sessions, had over five years' experience of UCL's research ethics requirements from tutoring different groups of Masters students at The Bartlett Development Planning Unit in preparation for their annual field trips to carry out research in various 'developing' countries. Additionally, he had extensive experience of conducting community-based workshops, research and focus group sessions – both in-person and online – covering sensitive and emotive topics concerning a broad spectrum of minoritised groups. That experience occasionally required recognising and managing early signs of distress, and conflict resolution within and between many different groups.

Considering the sensitive nature of this study, the project researcher's experiences therefore helped ensure the well-being of the participants, at all times respecting their boundaries and recognising the emotional labour required to recall and reflect on some sometimes difficult and emotive experiences that had clearly left quite a lasting effect. Overall, his lived experience as part of a minoritised group, and his extensive familiarity with carrying out research with, within and for marginalised groups, guaranteed a high degree of ethics considerations and conduct throughout the study and much beyond – including into the analyses and presentation of this report.

For the purposes of interpreting the research findings, beyond acknowledging that a significant proportion, nine out of twelve student participants in the study, self-identified with one or more neurodivergent disability identities, no further demographic details can be divulged here, to respect confidentiality and ensure the anonymity of all participants.

Limitations

We identified two key limitations of the study. First, due to funding constraints and the nature of voluntary engagement with such studies, we could only offer five online focus group sessions. That means we were not able to hear all voices from the target groups. Second, from the very first focus groups session, it became clear that two hours would be insufficient to cover all the sub-questions that we set out to explore, and at a comfortable pace that allowed all the participants to not only share their personal experiences, but also respond to some answers and reflections they had heard from fellow participants in the session. As previously said, to address the time limitations during the sessions, all participants were sent the full set of questions after each session and asked to provide responses to the sections we could not complete, as well as add any additional thoughts they may have had to the questions already covered. To be clear, we decided not to send the questions in advance of the sessions in order to elicit 'unsanitised' responses.

Whilst recognising the above limitations, we are quite confident that the findings are representative enough to inform the beginning of a meaningful and effective strategy that will improve the experiences of disabled staff and students within the FBS, and hopefully inspire similar studies across all UCL faculties.

Findings

The analyses of the transcripts and post-session questionnaires revealed several key and often shared experiences of disabled staff and students at the FBS and UCL in general. The participants were extremely clear, thoughtful, detailed, and frank in providing insights into, and recollections of, their formal and informal experiences. Some responses were quite disturbing and frustrating, with particular regard to inflexible 'standard operating procedures' not only within the FBS, but necessarily involving departments such as HR. The findings are presented in a format accordant with the five main categories explored.

Although the study has revealed significant structural commonalities such as insufficient awareness of the processes related to improving accessibility for both staff and students, there are distinct experiences that warrant the presentation of the findings separately. Again, the full set of sub-questions for each category can be found in Appendix A1 and A2. All participant names are replaced with pseudonyms to ensure anonymity.

Staff

The workplace experiences of most disabled staff are, broadly speaking, mediated by various relations with colleagues and line-managers, as well as top-down procedures that often involve, for example, departments such as HR and Occupational Health services. Within and outside those interpersonal and structural relations, the physical environment – and facilities therein that reflect varying degrees of disability awareness – is also crucial to influencing any sense of belonging, or conversely othering, for disabled staff.

Experiences

Three out of eight staff in the study reported having a very or fairly positive experience as a disabled person at the FBS and UCL. As 'Jules' noted, "In terms of workplaces, this has been the most encouraging in terms of disability." That sentiment was echoed by 'Paula', who complimented the team she works with, saying that they have been quite helpful in trying to create an inclusive working environment by making sure she had everything necessary to accommodate her disability. According to 'Paula', "My experience has been quite good because the team I'm working with, they are well-versed [in disability-related matters]. They asked me 'what do I need?', and I said that what I need to start with [is] access to work because in that case the cost is shared. They said don't worry, we will get whatever you need."

Despite the willingness of the team to help, however, 'Paula' also pointed out that her request took a long time, over two months, because "everything in UCL takes so long, [even] to get new computers. It shouldn't be [like that]. It took me five weeks to get my contract of employment." Relatedly, 'Jules' expressed severe frustration with the slow pace of procedures, stating that "one thing I am most disappointed about is that although I declared a disability at the time of applying for my job, they did not contact me about it, I had to chase them up. That's the thing I'm most disappointed with, because they didn't explain their reasons why, and the fact what happened happened."

'Xavier' shared a similar experience after starting the job. He revealed that "I disclosed my disability, and nobody reached out to me when I started the job. I didn't even get a package of language and literature and what UCL offers, and I know that eventually I will get sick, and I live knowing I will have to figure out all of the ways to navigate UCL once I do that. It takes a lot of mental energy to figure out what UCL offers etc. I thought that by disclosing my disability I would get help to get some information about when that would happen and what I should do. Because no one has contacted me I have that dread in the back of my mind that I don't want to have to click through websites and reach different documents to try and figure out what to do. Why am I disclosing something when no one is reaching out to me to see how they can help me?"

Most of the staff participants communicated having similar experiences, which shows that the corollary of awareness and knowledge deficits often means that things that should be relatively straightforward can often take a frustratingly long time.

Beyond the limited positive experiences within a few teams, there was some praise – from six out of eight staff participants – for the Occupational Health services, who were deemed generally very empathetic. As 'Anna' explained, in relation to increasing tensions with her line-manager and HR about her inability to physically come to work daily, she was referred to Occupational Health, who took a holistic approach to assessing her predicament. Reflecting on that experience, 'Anna' said, "At the end of the day, what you need is empathy not sympathy, and some support to carry on because there are many ways to do your job, and those are the things that need support. I went to Occupational Health, and they looked into all my things and suggested a few things in a detailed letter." She was very much reassured when the person who handled her assessment told her that UCL, as a big organisation, has a duty of care to look

after her. From her interactions, she reflected that, “of all the things, I would say that Occupational Health in UCL is fantastic.”

The commendations for Occupational Health services sometimes mask but also often, and paradoxically, bring to light an array of negative experiences for many disabled staff. In that context, much of the discontent expressed by staff participants were in relation to issues of awareness and what we might call ‘the tyranny of protocol’ or ‘the protocol trap’ in line-managers’ attempts to adhere to ‘standard operating procedures’ set by HR. For example, ‘Xavier’ revealed he has had a very “chaotic journey” of experiences so far because although many of his team members have been quite “nice and understanding”, including his line manager who has tried to make a lot of adjustments for him, it has become apparent that, “a lot of people do not know how to implement certain things”. This led ‘Xavier’ to understand and conclude that, “they had no clue how to deal with a disabled person, so all they could think was ‘access to work’. They were wanting to, but they did not know who was in charge or who would be paying for certain things. They didn’t know the structure. In general, I would say it’s very chaotic, but I’m grateful.”

The ‘tyranny of protocol’ in relation to HR is a recurrent issue that has shaped negative experiences for many of the staff participants in the study. For instance, despite an acknowledgement and agreement between Occupational Health and some physically impaired staff that they should work from home and only come in for team meetings, line managers were periodically urged by HR to demand that staff must come in every day. Those demands often cause or exacerbate mental health conditions such as anxiety and depression, which sometimes have a cascading knock-on effect on the overall well-being of staff. As ‘Ali’ explained, “you don’t need protocol knocking on your doorstep, to your email, saying the same thing every year or so, knowing that your condition is permanent. And that is now starting to happen again as we come out of the pandemic and lockdown.”

For ‘Ali’ and four other staff participants in the study, the disruption brought on by the Covid-19 pandemic served as a vindication of and for many of the requests they had been making for some time to be given more flexibility in terms of working from home. As ‘Jules’ pointed out, “I think for me the good thing is that with the pandemic, everything changed to be more online. Working by MS Teams has been very comfortable for me. Coming back into the office recently has been incredibly hard”. That reflection was also echoed by ‘Jas’ who said, “I can still

participate and do my work with my colleagues, and still join team meetings or other important group meetings. So that is something where I personally feel much more included, because if that was not the case, then I could not participate in the way I do at the moment.” That feeling was also shared by ‘Alfie’, who said, “for me personally, I think the pandemic was a good thing. It sounds the wrong way around, but for me I think if people would not have been used to working from home, I think I would have lost my job because if I can’t physically be in the workplace, then I can’t participate fully. There are so many levels where I think, yes, people are doing the best they can, but for me personally, I cannot fit in normally. And what’s more, the pandemic opened up participating in a panel like this. Before the pandemic, it would’ve been in person, so I could not have participated. I think it’s good that I now feel included.”

Whilst, as has been widely acknowledged, the Covid-19 pandemic exposed and, in many cases, exacerbated stark inequalities in society at large, quite ironically the disruption somewhat levelled the field for many disabled members of staff. Most staff participants in the study suggested an overall positive effect on their well-being due to remote working. ‘Ali’ perhaps summed it up best in saying “I’m physically and mentally happier, do you know what I mean? And funnily enough, my manager is also happy about that.”

Equity: Disability awareness and reasonable adjustments

Broadly speaking, the experiences of people with disabilities at work are influenced by environmental and contextual factors. Very often, though, the biggest barriers people with disabilities encounter are other people. Disability awareness as a proactive idea necessarily involves educating people to enhance knowledge and acceptance of disability. In that regard, it is not enough just to know that disability discrimination is unlawful. The Equality Act 2010 places a legal obligation on employers to make reasonable adjustments to ensure that employees with disabilities, or physical or mental health conditions, are not disadvantaged when doing their work. We must note here, however, that employers are not obliged to make any reasonable adjustments unless they know, or ought reasonably to know, that an employee has a disability and is likely to be placed at a substantial disadvantage because of it. In such cases, employers should take reasonable steps by putting systems in place to encourage and support the sharing of relevant information during recruitment processes, and once employment has begun. Further, whilst employers cannot provide specific adjustments if people do not share information about disability, the Equality Act legislates anticipatory action. That means inclusive systems should already be in place as a matter of normal practice.

Responding to questions about their experiences in terms of disability awareness, all the staff participants in our study suggested that there needs to be much greater and better awareness about disability issues and associated protocols within the FBS. As 'Nimo', who has a non-visible disability explained, "For people like me who have not spoken about it much, I think having more awareness in general is really helpful. I do not know the relevant channels to go down and it almost feels like I am telling this secret. But actually, there are people with very obvious disabilities, and it should not have to be this hush hush thing. That could be because I have had very negative experiences before." Similarly, 'Jules' pointed out that "[disability] awareness is essential to making the working and studying environments more inclusive for everyone."

Linking greater awareness to improved inclusivity, 'Nimo' offered a poignant assessment in saying that "it always feels like they are saying 'these are the rules, and we are agreed that you [as a disabled person] are an exception'. But I do not want to be an exception, yet that is the way it is. There has to be better awareness. And I hope this gets fed back to the organisation or the senior management team to do something about it, and not just file it in a nice little, 'not to be approached' cloud platform." For 'Nimo', a further issue of frustration is colleagues and managers always expressing sympathy due to the lack of general awareness. 'Nimo' said, "I think the issue of disability and visibility is so important. People are always saying 'sorry, or I'm sorry to hear that' when they find out about my disability. If there was greater awareness, they wouldn't be saying that". Echoing that point about incessant sympathy, 'Anna' revealed "it has been very hard for me this year. I have spent a lot of time in hospitals. The people that I spoke to said I had to be very open, and I had a lot of sympathy and empathy, but also people generally feeling sorry."

Although expressions of sympathy are, at surface level, well-intentioned and therefore seem innocuous, most staff participants suggested that they tend to reinforce underlying anxieties about overreaction, which is correlated with stereotyping, stigmatisation, and discrimination, particularly with issues of mental health disability. The consequence of having those fears is a constant deliberation about whether to share information about non-visible disabilities. As 'Nimo' pointed out, "I was very apprehensive about disclosing my non-visible physical disability. I would be much much more apprehensive about disclosing my mental health disability, and that is even in the Division of [redacted for anonymity]. The problem is that once you put it out there, you can't take it back, and it frames people's attitude towards you. Like, once you say I

have a mental health issue, then everything is attached to you with mental health, and even when you are making a serious point in a meeting for example, it could be dismissed. That is the general point.” As ‘Nimo’ further highlighted, “If you are a woman in a man's world, there is that added effect that you do not disclose mental health issues because you want to be seen as performing at the same level as a man and you've got the model that men do not talk about mental health issues, then what do you do as a woman in that field, right?”

The fear of overreaction is one that extends beyond the immediate team or department. ‘Paula’, whose team you may recall are “well-versed [in disability-related matters]”, had to forego an important career-enhancing conference because the conference organisers “panicked and overreacted” when she shared information about her non-visible disability. As ‘Paula’ noted, “Most departments and organisations very much overreact when they hear that someone has my condition because they need to consider the possible effects of it, or something like that so... There's lots of these things I imagine most people who have some disability expect Occupational Health might take an overreaction to. I purposefully have not officially declared that I have it simply because I'm expecting an overreaction”.

There is a particular quandary to consider here in terms of the fears of overreaction or stigmatisation being significant barriers to sharing information about non-visible disabilities. As mentioned earlier, employers are only expected to make reasonable adjustments where they are aware – or should reasonably be aware – that an employee has a disability. Again, we must remember here that the Equality Act legislates for anticipatory action. That being said, in many cases where staff have officially shared information about their disability, it has not necessarily resulted in the automatic provision of reasonable adjustments. As ‘Ali’ noted, “the whole question of disclosure is really interesting. It has been quite challenging for me. I had a lot of battling I had to do and that's been my experience all the way through, having to battle to get the diagnosis and to get recognised and to get the adaptations and adjustments, all of that has not been easy.”

In considerations about reasonable adjustments, once again, the pandemic proved to be a catalyst to resolve many struggles and demands by some disabled staff participants. As ‘Anna’ noted, “Working at home now, it seems really ironic because pre-pandemic I had to really fight to be able to work from home, even though I was in a lot of pain. And then during the pandemic, it suddenly became fine for people to work at home, so it was kind of like I had fought for this for

[many] years and then the pandemic happened, and it is not an issue anymore. But before that, it was incredibly hard, so the pandemic has been easier for me because I have not had to fight to do that.”

Like ‘Anna’, some of the staff participants reported feeling emotionally burdened when trying to get support for reasonable adjustments put in place. In some instances, staff have had to pursue various relevant departments themselves to organise and ensure the provision of reasonable adjustments. Consequently, many disabled members of staff face considerable extra labour with respect to organising their own resources and support. As ‘Alfie’ pointed out, “You should not have to seek out your own support, it should be there for you. It should just be there, treating everybody equally in that sense without it feeling, well, it always feels a bit secretive to me.”

That reflection was also shared by ‘Jas’ who responded to questions about barriers to accessibility by saying, “I think it is management that have been the difficulty for me. All of the bad experiences have been to do with management. I've been adhering to protocols even when they don't fit my way and experiences because my manager always wants to implement protocol by the letter. Tick boxes and protocol, those are the main barriers.” “My manager has tightened up doing anything outside the box. My manager themselves are being pushed to ask me to come back so it is not them. It is HR writing off my situation in terms of them asking me to do something. HR is also one of the main barriers.”

Belonging

This study was and remains very much driven by visions of fostering greater inclusion, which hinges on the sense of belonging that any particular person or group of people feel in a given environment. For staff participants with visible or unseen physical, mental, or neurodivergent impairments, insufficient awareness about issues of disability translates to a lack of empathy, which consequently brings up questions of belonging. For example, ‘Jules’ noted that “the general lack of awareness and understanding about my [unseen] condition meant that I did not feel cared for, and I still do not feel cared for. And I have this really difficult time, but I got through it with the support from elsewhere and not from my manager. Belonging is very much what we are talking about here. With all of the best intentions on equality, diversity and so on, there is still an enormous issue at UCL, which is the White abled middle-class male, if you look at the management team.”

'Anna' also noted, in relation to the physical space, that "it would be impossible for anyone in a wheelchair to access my office. We have an open plan office, but the doors are inaccessible because you have to use a card to open the door but then you have to pull the door towards you and then once inside the door, there is a ramp that you have to go up, it will be impossible for anybody in a wheelchair to access it, just impossible."

Ableism and Discrimination

Most participants agreed that they felt an underlying sense of discrimination due to the general lack of awareness about various issues connected with disability. Further, as 'Jas' pointed out, although particular teams might feel quite inclusive, "you always feel and know that everything is made for abled people, and what they do is try to do just enough so the department can tick boxes to show that they have done enough. But most times, enough is not enough when you are talking about being inclusive for disabled people. we should be very open about disability as an extension of normal existence."

Our questions on ableism and discrimination also enquired about equitable opportunities to develop and progress. Some reflections from all the staff participants included:

"My progression has been limited by my condition and I have had to do the extra work when I am well to compensate for when I am not well, there is no allowance for me at all."

"Unlike academia, professional services do not have much progression and I think that is something that UCL is looking at separately. They are going through [it] and how you can, in professional services create progression. I do what I do very well, but I am not expecting promotion or anything else."

"There are a lot of suggestions for organisations to be a disability confident employer with different levels of accreditation. So UCL should aspire to be a leader and then a lot of opportunities will open up naturally for disabled people to feel being cared for, and development opportunities opening up. Liaising with charities that work with disabled people of many hues, for example Disability Rights UK, RNIB, RNID and many others, will help to open up avenues to support better outcomes for people with disability"

"I feel in the [number of] years I've worked at UCL, that they are taking the piss a bit in that they use [disabled people] at the centre to access the community without thinking how to develop

the [disabled] people in the department. We are there to help them get research participants, but in terms of our own growth in the department it seemed quite limited.

“This is the way it is at UCL. We can't do anything about it basically. That kind of thing. There are no real opportunities for growth, and it is very much pointed out that this is how academia works. Basically, tough.”

“There has not really been much growth. I used to work as a research assistant and now I've moved to the professional services side of things, and actually now I have a much more supportive team. I used to have a more supportive manager and it's only with that manager that started to think about what my growth is. But I also think that is to do with the fact that she is a minority as well, and she understands what it's like to be held back or to be fighting for equity. In terms of my identity, my ethnicity, I don't fit into my department because everybody is White. In terms of my disability, more so. I don't fit in because there's a distinction between those who are disabled and senior members of staff and that's why I don't feel I fit in or I feel like long term I cannot stay there because I will never grow and I will never progress in that department.”

Recommendations

For most of the staff participants, solutions to their grievances and demands hinge on two interrelated issues: awareness, and ‘the tyranny of protocol’ or ‘the protocol trap’. All participants recommended better training and support as important approaches to addressing many of the issues.

“People should be given regular training. The biggest problem with stuff at UCL is it is all online training and very much ticking a box and taking something and that is it. But I feel like people need to be given in-person training that is delivered by a disabled person themselves. I think it makes so much more difference than these tick boxes and you click this or play to watch a video, and then go on to the next thing. I feel they don't work.”

“The reason I came on this platform is that I want to be vocal and make things move. We can do a lot of lip service, but it is not right. But I want all academics and researchers to be given mandatory training of how to deal with disabled people. Absolutely, and it should be done on an annual basis, and they should also go every year and relearn what is needed and make sure that disclosure is a norm and not an exception.”

There are already some positive examples that departments can learn from: “It [UCL] is very hierarchical. It's a massive organisation so it's going to be difficult and all the different things going on. In my own very small department, and its only 20 people, we have a reasonable adjustment coordinator as I said before and they are about access to work and stuff like that so they are someone I would feel comfortable going to speak to about and they tried to keep on top of everything that is going on and stuff like that.”

“I would just suggest, UCL staff, we should have this kind of forum not only online but where people could meet and have some sort of bonding session, that would be great.”

“Athena Swan is a financial incentive and that's why the University do it, if it wasn't financially incentivised, they would not do it. We need that for equity and disability. If you really want to get them to do something it has to be financially incentivised.”

“At UCL we have the enable network, but in some ways that is too broad. People wouldn't email the enable network and say I have this issue, it doesn't have the same impact, it's more a localised level.”

“If you make the platform very easy for people to disclose, there will be many people who will be disclosing instead of sitting and finding it difficult to carry on day-to-day activities.”

“A department or team being diverse doesn't make it inclusive. Also, just because you can get a wheelchair into a building doesn't automatically mean that you can still participate.”

“Just thinking about what you are saying about HR, if they had specialist people who were experienced in disability and disability legislation, disabled staff could go to, that might be something like disability support advisors for students but something like that.”

“Each HR person should know in and out the Equality Act and what it entails. I am gobsmacked that UCL has not faced any litigation. Because if you go to tribunal, it will be a big trouble for UCL, forget about the reputation. It is time now to act, this is what I will say, mandatory training, HR should be on top of anything and if you go to access to work, there is a time lag of at least six weeks.”

Students

Like their staff counterparts, the experiences of disabled students in Higher Education institutions like UCL are influenced by environmental and contextual factors, which, of course, include interpersonal relationships with their peers and academic staff within faculties such as FBS, and support structures such as the disability and dyslexia service. Within and beyond those factors, the experiences of disabled students are not just shaped by teaching and learning considerations, but also by their living and social interactions, as well as navigating transitions into and out of Higher Education. Accordingly, there are, arguably, more factors that should inform assessments of disabled student experiences. Indeed, relatedly, there is a relative paucity of research on disabled staff experiences in Higher Education compared with the abundance of literature about student experiences. Whilst this study focuses specifically on experiences within the FBS, it is our hope that it might inspire a broader and more holistic evaluation of the student journey at UCL.

To recall, we held three focus group sessions with a total of twelve student participants. Also, although the students represented a broad spectrum of overt and unseen disability identities, it is noteworthy here that nine out of twelve participants self-identified with one or more neurodivergent disability identity groups. This is an important factor to keep in mind when reading or interrogating the range of responses and reflections presented.

Experiences

Due to the relatively transient nature of student journeys in Higher Education institutions such as UCL, the experiences of participants in our study have wholly or mostly been shaped within and by recent disruptions brought on by the Covid-19 pandemic. In that sense, many of the responses and reflections presented here should be construed as representing perhaps more personal accounts of those journeys than being significantly influenced by different interpersonal and peer-network relations which, under normal circumstances, would be expected to have a much greater impact on students' analyses of their experiences. That being said, as has been said and backed-up by numerous studies across various sectors, the pandemic has functioned like an X-ray on society at large, exposing and exacerbating a wide variety of stark and persistent structural inequalities.

In Higher Education institutions like UCL, those inequalities have often been hidden in plain sight by an assortment of processes marshalled by rather inflexible protocols. At the onset of

the pandemic, as different faculties and departments scrambled to provide students with alternative ways to study and engage away from the built environment of the campus, various ideas about flexible reasonable adjustments and tailored support, which had long been sought by many students with disabilities and learning difficulties but often denied by the intransigence of protocols, suddenly became viable and available.

Against that backdrop, the shift to online learning during the pandemic has been widely presented as beneficial to many disabled students insofar as enhancing access to teaching in ways that are deemed more flexible and adaptable. However, some disabled students in this study, particularly those with neurodivergent impairments, have reported feeling let down by insufficient reasonable adjustments and support for their specific needs. This highlights the importance of recognising the diversity within the disabled student cohort. It also shows that many individual needs must be acknowledged and accommodated in processes that pursue a blanket approach under the aegis of HR protocol. In that context, it is our hope that the responses and reflections herewith presented will offer some instructive points of enlightenment for both the FBS and UCL in general on how to better foster a more equitable and inclusive learning environment going forward.

Asked if their disability has had an impact on their experience at UCL, all twelve students in our study reported that it has. Like the responses of staff participants in the study, many of the reflections shared were about negative experiences related to a general lack of awareness and support about matters of disability, and the 'tyranny of protocol'.

'Lourdes', an undergraduate student revealed that before the lockdown, "there was a point where I did ask the uni admin, could I access some of the material in a different way because I was really struggling with the lecture. I was having to almost adapt the slides that I was given but it was a really long-winded way... I had to almost make my own word document from it in order to make notes. Because I did not have that diagnosis, I believe that if I had it, they would have probably accommodated, but because I didn't, they didn't. That meant I did not get that same level of support. Basically, I wasted a lot of time."

This highlights an important issue related to neurodivergence in particular, where late diagnosis is very common. Further, we have to accept that some students (and staff) will never feel safe to share information.

Similarly, 'Rocco', on a one-year postgraduate course, said that "of course, my disability has had an impact on my experience at UCL. All the time". Like many others in the study, 'Rocco' felt anxious about sharing details of his impairment, saying "I do not want the others to know that I have this reading and listening problem " .

The shift to remote learning due to the pandemic had a profound effect on all the students in the study. Asked if there were any differences compared to previous years, they all reported a mixture of some good, but many bad experiences, which are presented below.

'David': "I think Covid did impact me quite a lot because, sitting at home, it's a lot easier to become distracted by things that I shouldn't be distracted by. Whereas, if I was in the lab, when I'm doing lab work, I don't feel distracted by anything, but when I'm sitting and writing, that's when I can become easily distracted. When all I have to do is just write because of lockdown, I lost a lot of productivity there."

'Rocco': "Before the pandemic, seminars, used to be held in person. Personally, I have always found it quite difficult, I used to put my hand up at the end of the seminar sessions because the pace of the seminar was always very uncomfortable. It's very, very fast.

'Mercy': "I have depression and anxiety, and I've been diagnosed with both of these. I think particularly with depression, it had more of an impact on my experience when the pandemic started. I basically went into a depressed episode when it started, and I'm still trying to manage that. This has been very different from my previous experience at UCL when I was doing my Masters. It wasn't during the pandemic obviously. I felt able to manage the anxiety and depression I work with day-to-day during that time. I wouldn't have considered myself to have had a disability then"

Stelle: "I feel that my course took on more people because they can do it online and I thought it was insulting because there can only be a limited number of slots on the course. I get less personally. For someone who suffers with online learning it's almost taking the piss. I also thought the students should be told what the consequences are for their learning schedules by taking on more people for a course. That is something that kind of annoyed me that I think could be changed."

'Estere': "I found this year overwhelming, incredibly challenging and intense. I probably need a lot more support than I got, in my work, maybe university wise. There was a point where I thought I would fail. It has been challenging the whole way through."

'Maddox': "But there is a lot of anecdotes within the [redacted] community. There are a lot of people where their [redacted] became more visible during the pandemic and I have noticed that my [redacted] is very present nowadays."

'Pax': "Coming back to do the Masters four years later has been interesting because I tried to do it without any help but studying online changed everything. My ability to prioritise the value of what I should be doing and what was important to me meant that everything would get spread out really thin. I have been feeling overwhelmed. That is exactly how I have found this year, so intense, to the point that I had to question myself. I have been wanting to quit the course because I have been feeling myself struggle so much, to the point of where I had to question, can I do this? Is it causing me too much stress?"

'Zahara': "I think, honestly, that I have been very fortunate that we have been online. I think a lot of people who are neurodivergent or physically disabled feel that they would be the same. I just feel really fortunate to be able to access the content online."

'Shiloh': "This last year, during the pandemic, has been great for accessibility but for learning, it has been a disadvantage. There is no socialising during breaks or after the teaching lecture so I really feel like I have missed out a lot in terms of my student experience and learning through those conversations which I probably would have gained a lot more out of. So, I think it is interesting to hear 'Zahara' say that they have felt quite a lot of benefits. I think that I feel a bit disadvantaged. Being on Zoom does not help very much because I do feel that we rely on visual cues. And it does not help very much because we might have an opportunity to establish a rapport with someone with a little bit of small chat, getting to know the environment, and the person. That is not possible on Zoom, which does increase the stress."

'Vivienne': "It has put a lot of stress on me, personally. There is also a bit of anxiety about many things. You know, the accessibility being taken away, potentially, in the future, if they want to go back to full-time or face-to-face."

Equity: Disability awareness and reasonable adjustments

For disabled students in our study, the revelation that UCL can, and indeed should, offer online resources and flexibility was not news to them. The flexibility of online learning and support is something that many of them had been advocating for for quite some time before the pandemic. Hence, as what was widely portrayed as the 'new normal' ushered in by the pandemic increasingly reverts to the status quo ante, the 'old normal', feelings of anxiety are starting to increase in connection with issues of equity related to the 'tyranny of protocols' and what that means for, for example, disability awareness, reasonable adjustments, stigmatisation and people's general attitudes towards disability within FBS and UCL in general. Again, the students were forthright with their reflections, which, taken together, reveal a few inconsistencies about the awareness and support available. This should raise some concerns. A sample of responses to our questions about disability awareness, support, and barriers to accessibility are presented below.

'Knox': "I've always worried that the stigma is out there. If I disclose, it might bite me in the ass. I had an experience this year that reinforced that. That's why it was so difficult to manage because I guess I felt I was safe to say these things but struggling with my [lecturers] it became clear it wasn't an inclusive or safe space. They were doing the best they could. They were just completely freaked out by it [my impairment] and it made me realise I was carrying this characteristic of myself with me that a lot of people won't get that, and maybe it's better to not tell people still. That is so hard because there's been so many campaigns on normalising mental health and having mental health difficulties."

'Zahara': "I think we have a long way to go, and I wish I had a community that would celebrate the differences I experience, but I don't feel that at the moment. I have that for depression and anxiety. I got a lot of responses when I've told people and they say oh, no."

'Rocco': "It is something that I have noticed in general, the real lack of understanding about the kind of support that people with AD(H)D need. I think it does not outwardly present that there is anything different or anything that I would need that would be different to someone else. I feel like people do not really understand it that well and I seem fine, so no one really considers."

The lack of awareness and therefore understanding by many people about certain forms of impairment, particularly related to neurodivergence, translates to inconsistencies in accessibility that impact students' experience. For example, 'David' revealed that "when I talked about

extensions to my personal tutor, they were not aware of the different processes. One week extension or two; it has got to be one or the other, you cannot apply for both. One cancels the other option.”

Similarly, ‘Maddox’ had some difficulties applying for extensions, saying “It is a long-winded process in a way, because I have to chase the documents and it is really hard to get the GP to support with things. Just having that diagnosis does not necessarily mean anything and I had other stuff going on so to try and back it up, explaining that. I think it is difficult having different processes, in terms of extensions and it being limited to one week, to be honest. One week, is better than nothing and it is great that they can supply that. But for me, one week would not have been adequate for what I had needed. It is quite stressful when you know that you have assignments that you are struggling with.”

Unlike ‘Maddox’ and ‘David’, ‘Shiloh’ had a positive experience in seeking extensions, revealing “I think it has been good to have the support there, in terms of, I get extensions for projects and things like that. I know that I personally, can really struggle with time management and get very overwhelmed when there is a big project and there and I will ignore it for a long time because I know it is there and overwhelming. I will say, when I did get to the appointment, eventually, I found the disability team really great, when I had my assessment. When they created my statement of reasonable adjustment, I found the person that I spoke to super empathetic and understanding. That was regardless of a diagnosis or not. The individual that I had spoken to, at least, was really great and helpful.”

The switch to online learning exposed deficits in the support structures available to some students in several ways. As ‘Vivienne’ said, “I don't think there's too much support available, at least to my knowledge. Then with AD(H)D, UCL refer you on to look at help from DSA (Disabled Students' Allowance). I don't think there's much support they offer other than possibly reasonable adjustments, and they say you can have up to six free counselling sessions, but they won't be related to AD(H)D, they will be general sessions”

Like ‘Vivienne’, ‘Lourdes’ expressed some disappointment about the lack of support, saying that “I think the onus is definitely on the student. For a lot of us, it is a lot of hard work to even reach out and send an email to the disability team. Even though I have the diagnosis, I really struggle and relate to a lot of AD(H)D-related issues. Last year, when I was going through the process of getting the appointment with the disability services, the process of having to fill out all of the

forms and then to send them back, was just really tricky and even though I had the appointment and got the support, I did not go until this year. It had been a whole year that this document had sat there.”

Again, to highlight the inconsistencies, a few students had positive experiences with the reasonable adjustments and support they received when they managed to access the right services. For example, ‘Zahara’ told us that, “For me, personally, when I applied for the course, I ticked the box that said that I was a student with a disability. I think because of that, when my email was set up, they sent me an email and I think, without that, I may not have reached out to them.” That positive outcome from sharing details was also experienced by ‘Rocco’, who revealed that “You do a self-referral online which is helpful. I did not have to really discuss it prior to referring myself, I did not have to get back in touch with the disability team. I found it a really helpful resource to have. There are questions about whether it could be longer.”

Another factor adding to inconsistencies is the study programme pursued by students. As ‘Estere’, one of a few PhD students in our study revealed, “In all honesty, I feel like I am struggling, and I am continuing to struggle my way through things and other things feel like they take priority. What I have been told is that since I am not doing a [taught] program but a research program, I am not a bachelors or Masters student, but a PhD student, these reasonable adjustments cannot be forced on professors because it is between me and them whether they can give me it. That is because a PhD is a personal relationship, so the reasonable adjustments might not be kept. So basically, it is a lottery whether they follow the reasonable adjustment or not. They are known for being a bit bully-ish, they are known for not always speaking very nicely to the students. When I have checked in with previous students, they have said that they have experienced the exact same thing, that they had heard the same things and were treated in the same manner. I know that this is just temporary, that this will come to an end, but unfortunately there will be future students that will work with the same professors and supervisors. So, there is a bit of a question mark on how they [the faculty] prevent this from happening again.”

Those anxieties were shared by ‘Mercy’, another PhD student, who revealed that “I just don't understand the summary of reasonable adjustment. It doesn't seem to apply to PhD students, so it hasn't been helpful. There seems to be very little specific support for PhD students, because PhD students are diverse and difficult to get involved in one place or whatever. But it's

been a lonely and strange experience doing a PhD from home, at least I have struggled with it immensely. I personally haven't reached out to anyone in my department. I have kept it to the disability team because it makes it easier in terms of applying to the DSA and if they thought it was wise to tell someone then they can do it but I don't think I'd really want to do it myself. During my Masters, I always sought out help from UCL, but I do feel a slight inability to tell my supervisors for my thesis project."

The point about not reaching out to anyone in the FBS or specific department reflects ever-present underlying anxieties about overreaction and stigmatisation, which are the by-products of a general lack of awareness and knowledge about different disabilities. These anxieties cut across all programmes, from undergraduate level to Masters and PhD. As another of our PhD student participants revealed, "I kind of feel like it's my own problems to sort out and I'd rather my supervisor didn't know. I have never even thought of reaching out, and I wouldn't want UCL to know in any formal capacity. At the back of my mind, I still think what if you think less of me? What if some decision down the line, it could influence negatively on me because they think maybe I can't do certain things? So, I didn't want to tell my supervisor about my diagnoses, it didn't seem like it. I'm self-conscious of the diagnosis of depression because of what you're saying, I was worried it would make me seem like I was soft, or I needed something, I needed extra help, or I was weak or couldn't maybe finish the deadlines."

Belonging

The above testimonials on issues of equity related to disability awareness, reasonable adjustments, stigmatisation and people's attitudes towards disability within FBS and UCL in general, all contribute to an underlying sense of a lack of inclusion and belonging felt by many students with disabilities. Such feelings have recently also been amplified by the pandemic and the accompanying remote learning regime. As 'Shiloh' revealed, "because my experience has been purely online it has been very hard to meet people, I just go to labs where I work alone".

Efforts by some departments and UCL in general to foster a sense of belonging through, for example, newsletters have had limited effect due to their frequency. As 'Maddox' suggested, "They're always sending out these newsletters, far too frequently and I don't read them. I think they have some kind of inclusivity in there somewhere, but I wouldn't know. I think they try but it is just too much going on." Also, based on fears of overreaction and stigmatisation, some students have not engaged with the Students Union at this crucial time of enforced isolation. As

'Stelle' said, I think about getting involved with the Students Union, but I get anxious about getting involved with them because I think maybe if I want to learn a new skill, there will be lots of people who are already good at the skill and will be laughing at how awful I am. I'm not very good at not being good at things. I don't try many new things. To my own detriment really."

Ableism and Discrimination

That revelation by 'Stelle', very much exemplifies the fear of discrimination that many disabled students constantly have to negotiate due to the general lack of awareness about various disabilities across the university. This has had some impact on some students' well-being, particularly during the pandemic. As 'Rocco' noted, "I don't know how much my well-being has been impacted in general by the pandemic, and I don't want to dump it all on UCL. To be fair, they have hosted some interesting sessions. There has been a Pilates online. They tried, but I think studying has been detrimental to my well-being in the way it has been structured for me."

Recommendations

'Lourdes': "I think a group for neurodivergent students would be amazing. I'm now in my ninth year at UCL, and I have never had the knowledge of there being anyone else with AD(H)D here – I think because I very much keep this information to myself and wouldn't be surprised if others did. Finding people who shared similar experiences to me was amazing and something I wish I could have found as an undergraduate."

'David': "it would be good to form or have a group or network of students with similar challenges. I think it is a wonderful idea and wonder how best to make this happen. The most obvious route would be via a society – though I don't think I would have taken much notice of such a society as an undergraduate. I think to be effective and reach the people who need it, there needs to be some sort of endorsement from UCL. October in the UK is mental health awareness month, which could be used to highlight such a group, and this also happens to be convenient timing to catch the new intake of students. I'd be very happy to be involved in a neurodivergent support group/network!"

'Mercy': "We definitely need more outreach, potentially, from people from the disability team. More communication saying this is what is available for you. And this is what you will be entitled to. I think that would be helpful. We had someone from the library team come. She was doing a session on how to access stuff; accessing journals is so complicated. I am not going to bother. I cannot wrap my head around how complicated the online system is to access. Great you can

access it, but you cannot, it is so ridiculously difficult. For me, on my course, something that really helped me feel included was when one of the PhD students set up a mental health peer support group.”

‘Stelle’: “One way to join it up, at the start of the course, I don’t know how this would work, someone come in to say I am from, for example, the well-being service, if things feel intense or you are struggling, get in touch with us, and it is personalised. Seeds planted; this is what we are here for. Something like that at the start, I wonder if I would have been more proactive or reached out to them earlier.”

‘Vivienne’: “The responsibility and onus are always on the student or staff member who might be having, actively struggling to be the one who has to do all the research and find out who they need to contact and just making that a little bit easier would be helpful.”

‘Pax’: “I know that at some universities you can access diagnosis for autism and AD(H)D as well. My brother went to university somewhere and they offered a service that was not free, but instead of having to pay £1000 for an assessment they offer cheap assessments for students seeking assessment for autism or AD(H)D. I don’t believe, there is anything similar at UCL. That is something I would personally really have benefited from.”

‘Zahara’: “there seems to be a discrepancy at the moment between the specific learning disabilities and neurodiversity. I know they are under the same umbrella but there does not seem to be as much provision.”

‘Estere’: “I have not engaged in meeting other people. I feel the loss of that. An experience of meeting new people in general and making new friends, the social aspect, that has been lost. I believe there are things that could have been done earlier on to facilitate that. For example, opening a lunch, virtual room.”

Shiloh’: “We need a peer support group you can come to for people experiencing mental health disability. It was really nice and also made me feel quite welcome and included. It can be very isolating when you experience these things. Sometimes you feel maybe you should not be there. I know I feel like that. Having some peer support, space for it, it normalises it. It goes back to ADHD specific support. I don’t know if there is some way there could be someone who

helps with organisation. A lot of learning difficulties, organisation is a big thing. Depending on the learning difficulty, I got told by so many people, plan and do it.”

‘Vivienne’: “When it came to requesting a tutor to help me with my disability-related issues I actually could not do that, because you have to apply for the disabled students’ allowance to access that. I spoke about issues with my mental health, disability, I think it would be good practice and helpful if they would follow up meetings with action points and links, website links, information. So I am posting to the relevant team. It might sound small but when you receive it, it is there for you. It might feel a lot more accessible than leave it to me if I have time, when I have time, when I feel able to do it.”

Conclusion

From an intersectional perspective, our analyses of widely available studies showed that disabled staff and students are likely to face more barriers along their Higher Education journey than those without disabilities. Institutions such as UCL and the faculties and departments therein must thus reflect on how we can better address the varied needs of our disabled staff and students to improve their university experience. Against that backdrop, we set out in this study, to explore the experiences of disabled staff and students in the FBS in order to better understand and, ultimately, help contribute to addressing a variety of durable inequalities that have long proven to be barriers for inclusion, and fulfilment of individuals' potential to thrive within the faculty and beyond.

Overwhelmingly, all participants were very grateful for the opportunity to be involved in the study, with most revealing this to be the first time that, in any educational institution, they have been able to discuss their experiences, to have their voices heard. As one participant so poignantly summed up, "I have never had this experience come up before. I think it made me reflect more on notions of community around these sorts of things. They are not necessarily factored into the experience. We always think university experiences will be towards the subjects students study and staff manage and deliver. But it has been extremely good to be around people with similar characteristics. It gave me many things to think about and I'm glad I participated. It was very nice. Thank you."

That this was the first known study of its kind in the FBS, serves as a telling (read terrible) indictment of standard Equity, Diversity, and Inclusion (EDI) structures, procedures and practices not just in the FBS but, by a logical extension of probabilities, also across many other UCL faculties. To engage meaningfully with the needs of disabled groups, and indeed other marginalised identity groups in the university, the aphorism "nothing about us without us is for us"⁶ comes to mind here. That is to say, without hearing, and perhaps more importantly listening to, the voices of disabled and other marginalised groups, the standard operating procedures of most EDI approaches are perceived by those groups as being inherently compromised by an inexorable regime of diversity targets that are invariably achieved through, for example, tick-boxing exercises that achieve little to no meaningful structural change. In that

⁶ Charlton, 1998.

context, as one participant said, “the university feels more like a business than a community a lot of the time. I wish it was more community”.

On that point about community, many participants felt that disabled people are far too often treated as one homogenous group or community. In that respect, ‘disabled identity’ is in many ways complicated by the heterogeneous political and personal characteristics and grouping of disabled people. This highlights the ongoing struggles of various disabled identity groups for distinct recognition because ‘it is often assumed that by having an impairment or the label “disabled” thrust upon you, you become part of a specific community with a distinct culture; this is far from the case.’⁷ This indicates the pervasive lack of awareness about the diversity of needs and experiences across different disability identities and intersectionalities.

Consequently, blanket approaches to disability-related issues and needs, often follow standard operating procedures and unyielding protocols that make them, at best, limited in effectiveness or, at worst, not fit for many purposes. And in that regard, as noted in a recent report for the Faculty of Engineering Sciences, “meaningful solutions will only be achieved by engaging with this diversity within disability/neurodivergence and including intersecting marginalised identities.”⁸

In matters of awareness, procedures, stigmatisation, and barriers to inclusion and a sense of belonging, which shape the experiences in FBS and UCL, we found that disability is often viewed through the medical model lens and, in some cases, due to the ‘tyranny of protocols’ some disabled students and staff become hesitant about sharing information about their condition. This, of course, reflects a wider societal problem whereby ableism, based on the corporeal standard of ‘individual’ excellence, creates barriers for disabled people.⁹

It is our hope this study and report give some valuable insights into how disabled staff and students at the FBS understand and formulate their own experiences of the barriers that they encounter within the Faculty and UCL in general. And on that note of hope, we offer below some recommendations for what it might begin to take to improve inclusion.

⁷ Brewster et al., 2017.

⁸ Patrick and Diaz, 2022

⁹ Brown and Leigh, 2020.

Recommendations

Drawing on participants' reflections and suggestions, we recommend the following:

- (1) The FBS should setup a framework for disability support; a substantive post at faculty level working in partnership with the Disability Equity Lead to provide expert strategic leadership and guidance to the FBS leadership, identify and lead key projects, establish a network of support that reaches into all departments and institutes to provide guidance and advocate for disabled staff and students. As part of this new structure, all divisions and departments within the FBS should have a disabilities and reasonable adjustment coordinator or lead. *Note: The current Disability Equity lead and group do not have adequate resource allocation to undertake the commitment required to effect the degree of change urgently needed in FBS.*
- (2) All departments and divisions within the FBS must go beyond the formal responsibilities, standard operating procedures, and inflexible protocols of accessibility and support, to provide all staff and students with clear guidelines. Obligatory annual training to improve disability literacy is needed to ensure a fair and inclusive environment throughout the Faculty. The training should be delivered in flexible learning formats by/with disabled people, and in association with a framework of accountability such as action planning at department/Faculty level, proactive contributions to EDI assessed in annual appraisals for all staff and reported to the faculty – not just online tick-box exercises.
- (3) There should be a concerted and consistent effort within the FBS, and more broadly UCL, to raise awareness and provide information about various disabilities, seen and unseen, from the social model perspective. In other words, an understanding of disability that steps away from the medical (deficit) model, viewing disability as homogenous. We must celebrate and give platform to the unique contributions of disabled people in our community.
This can be achieved through regular disability equity dedicated communications around the faculty and the university and making issues of disability more prominent in online communications. Relatedly, as put forward by the participants, the FBS “should adopt a broad approach that assumes everyone has a disability they are not sharing”. More awareness in the departments would facilitate that in many ways. The distinction has been pointed out, someone new versus someone who has known for a while, can have a journey of emotional adjustments as well as practical ones related to adjustments. There is a level of experience we should focus on as well. It is quite a labyrinth if you are newly diagnosed. It is something to raise awareness”.
- (4) The FBS should set up and support a network or forum for disabled staff and students to openly discuss their challenges with others who have similar lived experiences and barriers. This network should have a pledge of support from FBS leadership and an accountability framework that enables the voices of the FBS disabled community to be heard and acted on. Relatedly, an online disability platform that is dedicated to inclusive practice, could serve as a pedagogical resource bank for all Divisions and departments.
- (5) Role models play a key role in students' sense of belonging. They help to create safety for others to share information about disability. FBS must actively recruit and progress disabled people – this may be enhanced by having greater representation in recruitment and promotion panels.

- (6) There should be a bespoke mentoring scheme for actively providing tailored opportunities for disabled staff across all roles, investing in developing specific training opportunities for disabled staff but also for those who will be mentoring them.
- (7) Design with inclusion – when inclusion (including accessibility) is designed into new activities (programmes of study, staff initiatives), events and even routine meetings as a core and obligatory priority, the labours of requesting and arranging assessments are reduced for everyone.
- (8) Our student data highlights very poor experiences but investigating quantitative data was beyond the scope of this project, so we cannot correlate these experiences with student outcomes. The recent report by Patrick and Diaz¹⁰ from the Faculty of Engineering Sciences (FES) considered both qualitative and quantitative data and identified very serious awarding gaps for disabled and neurodivergent students. It is important that the FBS conducts a follow-up study to investigate awarding gaps using the FES framework.
- (9) A number of staff highlighted poor experiences related to HR. FBS leadership should feedback these issues to HR, and update the FBS Disability Equity group on HR's response and actions for dissemination to the participants in this study.

We must note that no single one or handful of these recommendations will be adequate to address the various inequities highlighted. To be meaningful and effective, all solutions must be inclusive of both the diversity in types of disabilities and neurodivergence and all their subgroups with intersecting identities.

¹⁰ Patrick and Diaz, 2022

References

- AdvanceHE, 2021. Equality in higher education: statistical report 2021. First published 28/10/2021. Accessed on 22/02/2022, via: <https://www.advance-he.ac.uk/knowledge-hub/equality-higher-education-statistical-report-2021>
- Brewster, S., Duncan, N., Emira, M. and Clifford, A., 2017. Personal sacrifice and corporate cultures: Career progression for disabled staff in higher education. *Disability & Society*, 32(7), pp.1027-1042.
- Brown, N. and Leigh, J., 2020. *Ableism in Academia: Theorising experiences of disabilities and chronic illnesses in higher education* (p. 241). UCL Press. Accessed on 24/02/22, via: <https://library.oapen.org/bitstream/handle/20.500.12657/51775/9781787354975.pdf?sequence=1>
- Brown, N. (ed.) (2021). *Lived Experiences of Ableism in Academia: Strategies for Inclusion in Higher Education*. Bristol: Policy Press. DOI: [10.2307/j.ctv1nh3m5m](https://doi.org/10.2307/j.ctv1nh3m5m).
- Brown, N., Nicholson, J., Campbell, F. K., Patel, M., Knight, R. & Moore, S. (2020). COVID-19 Post-Lockdown: Perspectives, Implications and Strategies for Disabled Staff. *ALTER – European Journal of Disability Research, Revue Européenne de Recherche sur le Handicap*, 15(3), 262-269. DOI: [10.1016/j.alter.2020.12.005](https://doi.org/10.1016/j.alter.2020.12.005).
- Brown, N., Thompson, P. & Leigh, J. S. (2018). Making academia more accessible. *Journal of Perspectives in Applied Academic Practice*, 6(2), 82-90. DOI: [10.14297/jpaap.v6i2.348](https://doi.org/10.14297/jpaap.v6i2.348).
- Charlton, J.I., 1998. *Nothing about us without us*. University of California Press.
- DWP, 2020. Family Resources Survey: financial year 2019 to 2020. Department for Work and Pensions. Published 25 March 2021. Accessed on 23/02/22, via: <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2019-to-2020/family-resources-survey-financial-year-2019-to-2020#disability-1>
- Patrick, M. and Diaz, V., 2022. Improving Experiences of Disabled and Neurodivergent students in the Faculty of Engineering Sciences. UCL Engineering online report. First published 28/01/22. Accessed on 24/02/22, via: https://www.ucl.ac.uk/engineering/sites/engineering/files/improving_experiences_of_disabled_and_neurodivergent_students_in_the_faculty_of_engineering_sciences_10-12-21.pdf
- Hubble, S. and Bolton, P., 2021. Support for disabled students in higher education in England. Accessed on 27/12/2021, via: <https://dera.ioe.ac.uk/37390/13/CBP-8716%20%28redacted%29.pdf>

Appendix

A1: Research sub-questions (staff)

Questions 1: Experience

How has your experience as a disabled person been at UCL so far?

Were there differences in 2020 (due to COVID-19 restrictions) compared to previous years?

Have these been positive or negative experiences?

Can you provide examples of this impact? How does this make you feel?

Questions 2: Equity (Disability awareness, reasonable adjustments)

Can you tell me about your overall experience in terms of accessibility and people's attitude towards disability here at FBS/UCL?

Do you know of any support available?

Have you had any good experiences?

To what extent have you experienced any barriers to accessibility?

To what extent have people's attitudes been negative?

Question 2a: Equity (Disability awareness, reasonable adjustments)

Can you tell us about solutions you think could be put in place to address issues with awareness/reasonable adjustments? (You might, for example, want to consider solutions experienced or knowledge of in other organisations).

Questions 2b: Equity (Disability awareness, reasonable adjustments)

Have you shared information about your disability with anyone at UCL?

If yes, who have you told, and how did it go?

If no, why not?

What would encourage you to share information about your disability.

Questions 2c: Equity (Disability awareness, reasonable adjustments)

Have you ever approached staff in your department about reasonable adjustments and/or pastoral issues?

If so, what role were they in?

If yes, how did it go?

If no, would you feel comfortable doing so? Why/why not?

Questions 3: Belonging

Do you feel like there is an inclusive environment in your Dept/ UCL - do you 'fit in'?

If so, where do you think you 'fit in'?

In what way do you fit in or not?

3a. Where do you spend most of your working time and social time at UCL and why?

Do you feel there are any physical spaces where you do not feel welcome?

3b. Do you think your Dept/UCL fosters a sense of belonging for all staff, and why?

What makes you feel this way?

If no, what could help create a sense of belonging?

Questions 4: Ableism/Discrimination

How has your wellbeing been during your time at UCL?

Has the environment created by the department had an impact on your wellbeing?

To what extent does the environment created by your department have an impact on your disability (positive or negative)?

Are there any specific environments that are better or worse?

4a. Would you say your opportunities to develop and progress have been or are equitable? Why?

Can you provide examples?

Which barriers are Department-specific, and which UCL?

Questions 5: Recommendations

Reflecting on your time at UCL to date, what, if any, suggestions do you have for improving disabled staff's experience in FBS/ UCL?

Can you give some local (faculty/dept) and UCL level suggestions if possible?

A2: Research sub-questions (students)

In total, five focus group sessions were conducted involving ten staff, and twelve students. For both staff and student, the research question was disaggregated into the following five sections and sub-questions:

Questions 1: Experience

- a) Do you feel that your disability has had an impact on your experience at UCL? If so, how?
- b) Were there differences in 2020 (due to COVID-19 restrictions) compared to previous years?
- c) Have these been positive or negative experiences?
- d) Can you provide examples of this impact?
- e) How does this make you feel?

Questions 2: Equity (Disability awareness and reasonable adjustments)

- a) Can you tell us about your overall experience in terms of accessibility and people's attitude towards disability here at UCL?
- b) Do you know about the support available?
- c) Have you had any good/positive experiences?
- d) To what extent have you experienced any barriers to accessibility?
- e) To what extent have people's attitudes been negative?

Questions 2a: Equity (Disability awareness and reasonable adjustments)

- a) Can you tell us about solutions you think could be put in place to address issues with awareness/reasonable adjustments?

Questions 2b: Equity (Disability awareness and reasonable adjustments)

- a) Have you shared information about your disability with anyone at UCL?
- b) If yes, who have you told, and how did it go?
- c) If no, why not?
- d) What would encourage you to share information about your disability.

Questions 2c: Equity (Disability awareness and reasonable adjustments)

- a) Have ever approached anyone in your department about reasonable adjustments and/or pastoral issues?
- b) How did that go?

Questions 3: Belonging

- a) Do you feel like there is an inclusive environment in your Dept/ UCL - do you 'fit in'?
- b) If so, where do you think you 'fit in'?
- c) In what way(s) do you fit in or not?

Questions 3a: Belonging

- a) Where do you spend most of your learning time and social time at UCL and why?
- b) Do you feel there are any physical spaces where you do not feel welcome?

Questions 3b: Belonging

- a) Do you think your Students Union/department/UCL fosters a sense of belonging for all staff/students and why?

- b) What makes you feel this way?
- c) If no, what could help create a sense of belonging?

Questions 4: Ableism/Discrimination

- a) How has your wellbeing been during your time at UCL?
- b) Has the environment created by the department had an impact on your wellbeing?
- c) To what extent does the environment created by your department have an impact on your disability (positive or negative)?
- d) Are there any specific environments that are better or worse?

Question 5: Recommendations

- a) Reflecting on your time at UCL to date, what, if any, suggestions do you have for improving disabled students/staff experience at UCL?

B1: PARTICIPANT INFORMATION SHEET FOR Disabled/Neurodivergent STAFF AND STUDENT FOCUS GROUP - FACULTY OF BRAIN SCIENCES

UCL Research Ethics Committee Approval ID Number: 19411/001

Title of Study: Faculty of Brain Sciences Equity Focus Groups Project

Department: Faculty of Brain Sciences (FBS)

Contact Details of the Principal Investigator: Manjula Patrick, Disability Equity Lead
fbs.edi@ucl.ac.uk

The FBS Disability Equity Team are running a series of Focus Groups (FG) to collect data on experiences of disabled/neurodivergent staff and students.

The Project Team are Manjula Patrick (Principal Investigator and FBS Disability Equity Lead) Jason Davies (UCL Arena), Elise Crayton (Psychology and Language Science) Nicola Ridgway (Ear Institute), and Nick Anim (Project Researcher, The Bartlett). The diverse core team has representation of disability, ethnicity and gender, and expertise in project management, pedagogy, behaviour change and translational research as well as lived experience of disability.

You have expressed interest in being part of this research and before you decide whether or not you would like to take part, it is important for you to understand why the research is being done and what participation will involve.

This is a qualitative investigation into the experiences of Disabled/Neurodivergent, staff and students in FBS, and participation is purely voluntary. Please take time to read the following information carefully and discuss it with others if you wish before consenting to take part.

Ask us (fbs.edi@ucl.ac.uk) if there is anything that is not clear or if you would like more information. Thank you for reading this document.

1. What is the project's purpose?

Data collected from the Focus Groups will inform FBS' EDI action planning and will allow us to improve our understanding of the experiences of Disabled/Neurodivergent, staff and students, so we can begin to address the disparities.

We are aware that within UCL and our Faculty, Disabled/Neurodivergent, staff have different experiences (both positive and negative) in terms of access to opportunities to develop and progress their careers or prosper and achieve as students.

Although there is data from surveys, a limited amount of research has been undertaken directly with Disabled/Neurodivergent, staff and students in FBS or UCL. This project plans to collect in depth information about the experiences of Disabled/Neurodivergent, staff and students, the

findings of which will inform FBS's EDI action planning of future initiatives that are more equitable.

Specifically, the research project aims to:

1. Explore positive and negative aspects of experience for Disabled/Neurodivergent, staff and students.
2. Explore perceptions and motivations of success, as well as any barriers in achieving them.
3. Explore perceptions of belonging and the degree to which this is felt within departments, as well as the wider institution and Students' Union UCL
4. Explore whether there have been experiences or discrimination on campus, and if so, how these have been addressed.
5. Put forward recommendations/suggestions to improve the experiences of Disabled/Neurodivergent, staff and students at UCL

2. Am I eligible to take part?

In order to participate in this research you must meet inclusion criteria; self-identify as a Disabled/Neurodivergent, member of staff or student in the Faculty of Brain Sciences.

The project aims to recruit 5 participants per Focus Group. Focus Groups for staff and students will take place separately. If you identify as Disabled/Neurodivergent,, we will arrange access to the Focus group session. Note: Focus Groups may be conducted in person or remotely, and comply with Covid-19 guidance.

3. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and asked to sign a consent form to participate. You can withdraw from the project at any time without penalties and without giving a reason.

Your data will be anonymised 7 days after your focus group session. If you withdraw from the project, within this 7-day period, your personal data will be removed, and you will be asked what you would like done with your data from the focus group session. If you decide to withdraw after this 7-day period, you will still be entitled to the benefits of participating.

4. What will happen to me if I take part?

Focus groups will be:

- Be a single, 90 minute focus group, either remotely (MS Teams) or in-person (Covid-19 guidance will be followed). You will be offered a choice in whether you wish to participate in person or remotely.
- Follow a structured format using a set of predetermined questions
- Take place on the following dates (insert dates – TBC).
- Take place on UCL campus or remotely.
- Be facilitated by an independent researcher (from UCL but external to FBS)
- Travel expenses will not be reimbursed, however, you will receive a £20.00 voucher via email within four weeks of the focus group to thank you for your participation (this will be an e-voucher).
- Focus groups will have transcripts generated by a live captioning service, no recordings will be made. Transcripts will be anonymised and you will not be identified in any ensuing reports or publications.
- A consent form will be sent to you to sign prior to the focus group session.
- Focus groups will include sensitive questions regarding disability/neurodivergence. You can leave the focus group at any time and/or decline to answer questions without penalty.

5. Will I be recorded and how will the recorded media be used?

You will not be recorded. A live captioning service will be used as a reasonable adjustment, this service will generate an anonymised transcript. The transcript will be checked for accuracy and anonymity by the project researcher who conducts your focus group session. All transcriptions will be anonymised, and you will not be identified in any ensuing reports or publications. No one outside of the project team will have access to the transcripts.

6. What are the possible disadvantages and risks of taking part?

The project is centred on understanding your experiences at UCL and the research involves sensitive discussions around the topic of disability/neurodivergence. You will be asked to draw on your own personal experiences in focus groups when answering or discussing questions. Drawing on your personal experiences may trigger negative emotions. If you show signs of upset at any point, the focus group will be stopped and you will be asked whether you wish to proceed or not. You can decline to answer any question and/or stop or withdraw entirely from the focus group at any time

7. What are the possible benefits of taking part?

The following benefits have been identified for taking part in the project:

- Financial incentives: £20.00 voucher for participation in a focus group
- By sharing your experiences, you will inform the delivery of initiatives to improve Disabled/Neurodivergent staff and student experiences in FBS and improve inclusion.

8. What if something goes wrong?

If you wish to raise a complaint at any point during the project, these should be directed to Anna Cox (FBS Vice Dean for Equality Diversity and Inclusion), anna.cox@ucl.ac.uk . If you feel your complaint has not been handled to your satisfaction, you can escalate your complaint to the Chair of the UCL Research Ethics Committee, ethics@ucl.ac.uk.

9. Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential.

We are collecting information about which department you are from to help us identify patterns across the faculty, and target local support. We will not share any details that enable your department to identify you.

The live captioning service will generate a pseudo-anonymised transcript, the project researcher conducting the focus group will check for accuracy and anonymise further if needed. The live captioning service used will be UCL approved supplier, and transfer of data will be secure and meet UCL and GDPR/data protection requirements. You will not be identified in any ensuing reports or publications resulting from the research.

10. Limits to confidentiality

1. Please note that assurances on confidentiality will be strictly adhered to unless evidence of wrongdoing or potential harm is uncovered. The researcher has a duty of care to report to the relevant authorities possible harm/danger to the participant or others.

- Confidentiality will be respected subject to legal constraints and professional guidelines.
- Confidentiality will be respected unless there are compelling and legitimate reasons for this to be breached. If this was the case we would inform you of any decisions that might limit your confidentiality.

- Participants will be informed that focus group discussions should remain confidential, but there is some risk that confidentiality may not be honoured by all participants.

11. What will happen to the results of the research project?

The findings of the research will be presented in a report. The project team aims to make this report available to University stakeholders and participants by April 2023. You will not be identifiable in any report or publication ensuing from the research. Data collected during the course of the research will be used to inform the delivery of initiatives to redress Disability/Neurodivergence inequities in FBS.

Anonymised/pseudonymised transcripts will be retained for 10 years, only accessible to the project team, and will not be used outside this project.

12. Data Protection Privacy Notice

Notice:

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, click [here](#)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and 'Research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the [ICO website](#).

13. Contact for further information

For further information regarding the research project, please contact the Faculty of Brain Sciences Disability Equity Lead Manjula Patrick by emailing fb.s.edi@ucl.ac.uk

If you agree to participate in the project, you will be given a copy of the information sheet and a signed consent form to keep for your records. Thank you for reading this information sheet and for considering to take part in this research study.

Support Services at UCL

This is a list of support services for staff and students that you may find helpful. After your session, we will provide this list again. You can also speak to the project researcher after your session if you would like more guidance about any of these services.

Staff

- Being Well at UCL – wellbeing resources and support - <https://www.ucl.ac.uk/human-resources/health-wellbeing/being-well-ucl>
- Employee Assistance Programme (EAP) – 24/7 free access to a confidential professional counsellor - <https://www.ucl.ac.uk/human-resources/health-wellbeing/workplace-health/employee-assistance-programme-eap>
- SilverCloud – free access to online CBT programmes - <https://www.ucl.ac.uk/human-resources/health-wellbeing/being-well-ucl/healthy-mind/online-psychoeducational-and-cognitive-behavioural>
- Support for disabled staff and their managers - information and guidance on disabilities and accessibility - <https://www.ucl.ac.uk/accessibility/support-disabled-staff-and-their-managers>

Students

- Student Support and Wellbeing Team – provide support and resources for wellbeing, disability and mental health - <https://www.ucl.ac.uk/students/student-support-and-wellbeing>

Seek an adviser: <https://www.ucl.ac.uk/students/support-and-wellbeing/seeing-adviser>

- UCL Cares – guidance for students on looking after your body, mind and those around you - <https://www.ucl.ac.uk/students/support-and-wellbeing/resources/uclcares>
- UCL Crime Prevention and Personal Safety Officer – support for victims of crimes, or for those looking for tips to stay safe. <https://www.ucl.ac.uk/students/news/2020/jan/crime-prevention-and-personal-safety-advice-ucl>

- Student Psychological and Counselling Services – short-term counselling, psychiatric support and group workshops - <https://www.ucl.ac.uk/students/support-and-wellbeing/student-psychological-and-counselling-services>
- Support for disabled students – resources and guidance on accessing support or advisers - <https://www.ucl.ac.uk/students/support-and-wellbeing/support-disabled-students>

Staff and Students

- Dignity Advisors - UCL has a network of trained Dignity Advisors who provide an informal, confidential information service to staff and students on issues relating to bullying, harassment, sexual misconduct and equality. <https://www.ucl.ac.uk/equality-diversity-inclusion/dignity-ucl/dignity-advisors>