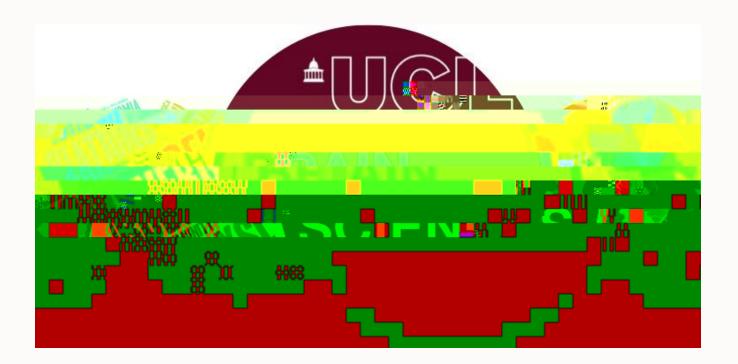
### **ENOUGH IS NOT ENOUGH!**

### A Report on The Experiences of Disabled and Neurodivergent Staff and Students at The Faculty of Brain Sciences

By Manjula Patrick and Nick Anim



UCL Research Ethics Committee Approval ID Number: 19411/001

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# **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

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.

### **Executive Summary**

#### the experiences

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 diffeess 1y-3(e)-3(ss )-3(n)-3()8

### The tyranny of protocol

Many negative experiences expressed by staff were also linked to issues of inflexibility in implementing top-

application, accommodate the variety of individual needs. In that context, for most disabled staff participants, expressions of dissatisfaction were often about their line-

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 of protocol is apparent in experiences such as longwinded processes of trying to get support, for example, to do with extensions to deadlines, and ut 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

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

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 theETQq,sersoa

## 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

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.<sup>1</sup> 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.<sup>2</sup>

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.<sup>3</sup> Comparatively, in the same period, 5.5% of staff working in Higher Education Institutions identified as disabled.<sup>4</sup>

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

<sup>&</sup>lt;sup>1</sup> Hubble and Bolton, 2021.

<sup>&</sup>lt;sup>2</sup> ibid

<sup>&</sup>lt;sup>3</sup> DWP, 2021.

<sup>&</sup>lt;sup>4</sup> AdvanceHE, 2021.

### Aims

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,

# Methodology

In the absence of any previous research on the topic, this

Reflecting on their time at UCL to date, as well as knowledge or experiences with other

The analyses of the transcripts and returned questionnaires began in February 2022. The mes was guided/informed by the subquestions (see Appendix A1 and A2) under the five categories of exploration (see Methodolo

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

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

the overarching ethics and

It follows, then, that all stages of planning and implementation of this study were guided by

requirements across many disciplines. In particular, the project researcher, who also facilitated

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

# 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 provid

computers.

ility at the time of

applying for my jobTQt00300579@06e.l480003≫3i(t)8i.cË@gd6( )8(o60.004 ch(r )-3(gsETQt003b)6(e)6S0

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

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

It sounds the wrong way around, but for me I think if people would not have been used to

doing the be

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-

mean? And funnily enough, my manager is also ha

### 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

a non-

t 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

awareness is essential to making the working and studying environments more inclusive for

Linking g

visible

#### ion, yet that is the

way it is. There has to be better awareness. And I hope this gets fed back to the organisation or

managers always expressing sympathy due to the lack of general awareness.

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

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

-versed [in disability-

important career

[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

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

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

#### accessibilit

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 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

### 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 ques

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 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.

are no real opportunities for growth, and it is very much pointed out that this is how academia works. Basically, t

moved to the professional services side of things, and actually now I have a much more y 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

### Recommendations

For most of the staff participants, solutions to their grievances and demands hinge on two tyranny participants recommended better training and support as important approaches to addressing many of the issues.

ine

training and very much ticking a box and taking something and that is it. But I feel like 560h(ing)-5()8()-3

### **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 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.

felt anxious abo

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.

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

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.

particularly with depression, it had more of an impact on my experience when the pandemic started. I b

### 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.

increase in connection with issues of equity related to the of protocols and what that means for, for example, disability awareness, reasonable adjustments, stigmatisation and

to

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

-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

s 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 was is 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

The switch to online learning exposed deficits in the support structures available to some students in several least to my knowledge. Then with AD(H)D, UCL refer you on to look at help from DSA (Disabled ibly reasonable adjustments, and they say you can have up to six free counselling sessions, but

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

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

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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

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

#### **Ableism and Discrimination**

ny disabled

students constantly have to negotiate due to the general lack of awareness about various -being,

w 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-

#### Recommendations

year at UCL, and I have never had the knowledge of there being anyone else with AD(H)D here

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

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

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 helps with organisation. A lot of learning difficulties, organisation is a big thing. Depending on the learning

# 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

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 ave 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

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

<sup>6</sup> 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 invariantly achieved through, for example, tick-boxing exercises that achieve little to no meaningful structural change. In that

<sup>&</sup>lt;sup>6</sup> Charlton, 1998.

## Recommendations

commend 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

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AdvanceHE, 2021. Equality in higher education: statistical report 2021. First published

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 -

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

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 disabil?proving

- 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?

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

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

### 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?

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 <u>data-protection@ucl.ac.uk</u>

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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

The lawful basis that will be used to process your personal 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 <u>data-</u>protection@ucl.ac.uk