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Towards Inclusive Language: Exploring student-led approaches to talking about disability-related study needs

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Abstract

To support inclusive and equitable study, universities often categorise students as 'disabled' in order for them to access support for their studies, and require them to engage with terms such as 'disclosing a disability' and 'reasonable adjustments'. This pathologises them by requiring them to identify as 'different' even if they do not consider themselves to be. Indeed, many students report that they feel uncomfortable with this; they do not identify as 'disabled', and this can discourage students from informing the university about their 'disability' and can create barriers to accessing support.

There is little understanding of how members of these diverse populations identify themselves or their preferences for discussing 'disability-related' support. In this paper, we report on a study where we sought to understand students' language styles and preferences when it comes to discussing disability and study requirements, and contrast these with the language used throughout our institution (and UK higher education institutions in general). The aim of the project was to investigate the language that students feel comfortable using when talking about their 'disabilities' and to identify gaps between the language students use to describe their own disabilities and the language used in UK higher education. We initially utilised a mixed-methods approach to investigate students' perspectives of language. This combined a qualitative approach using discourse and positioning analysis techniques to investigate the language students use, and a quantitative approach to analyse these results at scale. Survey results showed that terminology addressing students as 'disabled' was uncomfortable for many (particularly those with mental health conditions or specific learning difficulties); 'additional study needs' was preferred. However, we found divergence in these preferences across contexts, rather than consistent preference for any recognised language model. We also identified clusters with significantly different perspectives on language within the population.

The project team then worked with a wide range of stakeholders to collaboratively develop guidance for student-facing staff, and researchers and policy-makers to use when talking to students about disability. We also developed guidance for students to explain the type of language commonly used by universities around disability. In this paper, we explain the process we followed to turn the findings of the first stage of the research into guidance. We explore the issues staff raised and how these led to the creation of suitable research-informed guidance on language use. Through this, we draw conclusions on how to develop suitable understanding of inclusive language across an educational institution. These include the sensitivities both staff and students may feel regarding terminology such as 'needs assessments' and 'adjustments', the importance of mirroring language in a one-to-one setting and the need to provide clear examples as well as abstract terms. This guidance will support staff to use, investigate and influence language used to discuss disability-related study needs, with a view to moving towards inclusive, student-led language approaches.

Keywords: disability, language, accessibility, inclusion, student voice.

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1 Introduction

To provide students with suitable study support, and to enable inclusive and equitable study, universities often categorise certain student students as 'disabled'. As part of this, they require students to identify as 'a disabled student', to 'disclose a disability' and to request 'reasonable adjustments' in order for them to access support for their studies. Although this is clearly meant to support students, many students report that they feel uncomfortable with this terminology, that they do not identify as 'disabled', and that discomfort with this language can actively discourage them from informing the university about their 'disability', thus creating a barrier to accessing support.

There is little understanding of how 'disabled' students identify themselves or their preferences for language and terminology for discussing 'disability-related' support in higher education. However, research in the wider context of disability argues that language and terminology play a fundamental role in communicating, often unconsciously, the speaker's beliefs and values about [1, 2]. For example, a 'medical model' of speech focuses on a disability as a deficit or fault, something needing to be fixed or remedied [3], and can be 'deeply dehumanising' [4]. However, it is argued that a 'social model' of language, which focuses on removing societal barriers, can empower people and promote societal change, rather than focusing on the person's impairment [3].

In a higher education context, it is known that issues with language can affect how likely a student is to disclose a disability to the institution [5, 6] or to seek support, accommodations or adjustments [7, 5]. We also know that requiring them to identify themselves using terms with which they do not feel comfortable affects their experience of higher education [8, 9], and that challenges in communication and administrative procedures can have a range of negative impacts on students [10]. Alongside this, Gibson et al., (2016), show how labelling students can pathologise them, setting them aside as distinct to the rest of the student population [11]. They argue that institutions need to be proactive in their engagement with the students as key stakeholders in the process, where they currently often excluded.

It is clear, therefore, that there is a need to consider the language that institutions use to describe disability. However, there is a danger in research of this nature that universities can adopt a top-down approach to language, in which non-disabled people dictate terms used to describe disabled people. 'Linguistic hegemony' is a phenomenon in which language set by those in power can subtly empower dominant forces in society while disempowering minorities [12]. To counteract this, it is essential that 'disabled' students participate as stakeholders throughout this process, that their right to shape the language used to describe and identify them be recognised, in line with the 'nothing about us without us' movement in disability rights [13]. This participation must be meaningful and consistent; not an 'empty ritual of participation', without 'having the real power needed to affect the outcome of the process' [14]. Our research recognises that not only does language need consideration, but also the processes through which we construct or decide on this language; it is therefore an attempt to follow this agenda and engage students in the creation of the language used to describe and engage with them.

In this paper, we provide an account of the work that has taken place in our institution to address the issues identified above and move towards more inclusive language for students. Involved in this were a series of research and scholarship projects, some of which are described in more detail in other publications [15, 16, 17]. However, although research and scholarship were important aspects of this process, when taken alone they present only certain parts of the project. Much of the change was enabled through ad-hoc activity such as events, outreach activities, creation and promotion of guidance and other collaborative work to embed change in practice; these aspects of the project are not detailed elsewhere, yet without these the picture of the project appears incomplete. We therefore publish an account of this work in its entirety, in order to

provide a full picture and a roadmap that other institutions may use to embed similar change in their own institutions.

2 Approach

The approach detailed in this section covers the initial activity in which language was identified as an issue for students, through the research phrase, into the drafting and testing of guidance to apply research findings to practice.

2.1 Participatory research event

In 2016, a participatory event with students was carried out in order to develop new participation and collaborations in research with the OU's large population of disabled students. The intent was that this could have both internal benefits (identifying issues and means for research), and the potential to lead to new projects and research. It was during this event that language was first identified as an issue for students.

The first stage of this event was a Facebook post that asked group members about the things that make it hard to live and study independently, and what they would like to see changed. Following this, as a means for wider discussion, a Facebook group was created and members of the Open University Disabled Students Group were invited to attend. The event lasted five days and consisted of a different discussion starter every day (n = 34). Finally, a face-to-face workshop was held using the same themes (n = 15).

To facilitate a participatory approach to developing a research agenda, the team were mindful not to treat these activities as discussions, not as data collection or as research on students. We made it clear that conversations would not be captured or shared verbatim, and neither would personal stories and details be captured or shared. In addition, the discussions were conducted in student-owned spaces, in forms guided by the input of Open University Students Association (OUSA) and Disabled Students Group (DSG) members.

One of the key themes arising was language; many students were uncomfortable identifying with the word 'disabled'. An idea arose for a project to explore how disabled people feel about the language used to describe disability, and what language they use themselves when they interact with different people or situations.

2.2 Cross-disciplinary collaboration

It was identified that language is an area that cuts across a range of disciplines and that the project would benefit from cross-disciplinary knowledge sharing. Therefore, a group was established consisting of staff with academic interests in different areas, including linguistics, disability studies, health and wellbeing, education and educational technology. Working with students in the Disabled Students Group, and staff in the Health Discourse Special Interest Group, a methodology was co-constructed to investigate students' language preferences regarding disability in higher education.

Once drafted, the methodology received input from a wide range of stakeholders, including staff in Student Support, Disability Support, Accessibility and Technology Enhanced Learning. The project was championed by a professor in Linguistics; supportive of the cross-disciplinary and collaborative nature of the project, he supported the team to gain the necessary funding for the project to take place. The project was approved by the University's Research Ethics Panel and the Student Research Project Panel.

2.3 Student focus Groups

The next task was to establish the general landscape of language used by disabled students to discuss their disability, their experience of studying and their study needs. This was explored through focus group sessions (n = 12) consisting of 1-3 participants.

Focus groups sessions were carried out either face to face or remotely, through videoconferencing, telephone or email exchanges, according to the participants' preferences. Students were reimbursed for their travel and were thanked for their participation with a £20 voucher. The focus group sessions had two objectives. The first was to identify what language students used in a 'natural' setting, producing data that could be analysed to identify language norms and models. This was achieved through a conversation task in which students talked about their study journey to date.

Disability was not mentioned in the task, so as not to prime students or influence their language, but students invariably mentioned the impact of disability on their studies. The second objective was to explore students' reactions to the language used in university communications related to disability and study support. This was achieved through a task in which students chose one of three examples to critique.

Focus groups were recorded and transcribed, and transcripts were analysed using discourse variation analysis in NVivo. It was identified that students used three different models of language:

- A deficit or medical model, focusing on the disability itself and the issues it causes
- A support model, focusing on 'barriers and obstacles to study' and the institution supporting the student
- An empowerment model, focusing on student 'needs', autonomy and 'independence', with the institution enabling and empowering the student

2.4 Survey

Following the small-scale data arising from the focus groups, the next stage was to investigate language preferences with a larger cohort of participants. It was decided that a survey was the most appropriate method for this stage of the project. The survey instrument was designed by the project team with substantial input from a variety of stakeholders, including the Disabled Students Group. The survey had two aims. The first was to establish which of the language models identified from the focus group data participants preferred for institutional communications. The first section of the survey therefore presented participants with examples of institutional communications both in their original form and reworded using language used by students in the focus groups. Participants were invited to select which wording they preferred; they also had the option to keep the communication in the original wording or to suggest something else entirely.

The second aim was to establish what wording students preferred in order to identify themselves as disabled. The second part of the survey therefore asked participants how comfortable they felt (using a 5-point scale) with specific phrases identifying them as disabled. The phrases were taken from the data arising from the focus groups.

Regarding language models, the survey results showed no single model was consistently preferable for all communications. Instead, the findings revealed students' language preferences depended on the context of the communication. For example, regarding the disability disclosure question students are asked upon registration, students displayed a clear preference for medical model language, whereas when asked about the disability profile that states what adjustments and accommodations a student requires, students preferred other language models. This implies that a single language model is not a suitable approach to take for institutional communications; just as disabled students are not a single homogenous group, communications regarding disability should not be expected to fit into a single category or be addressed using a single approach. These findings stand in stark contrast to the usual discourse in disability studies that advocates for a single preferred model.

Regarding wording to identify a person as disabled, the term 'disabled student' proved the least popular. This presents a clear contrast to the official position of our institution, and most institutions in the UK, which

adopts this wording as standard. A common alternative to this phrase is 'student with disabilities', in line with the people-first movement supported by the United Nations [18]; however, this was also not popular. Instead, students preferred terms such as 'additional study needs', 'your circumstances' or 'conditions that affect your study' that did not directly reference disability. An additional point of note is that there were variations in responses according to gender and disability type. Generally, with men and people with mobility-related disabilities stated they were more comfortable with terms including the word 'disability', while women and people with specific learning difficulties or mental health conditions were less comfortable with these phrases.

2.5 Application to practice

In order to identify how the findings could be applied to practice, it was necessary to identify the stakeholders who could support, promote and operationalise new practice. The project team consulted with the Disabled Students Group and staff in various roles, and it was decided that the main stakeholder groups were:

- Student-facing staff (e.g. student support and teaching staff)
- Researchers and policy-makers
- Students

Student-facing staff could support the project by ensuring they use inclusive language when speaking to students about disability and by modelling and promoting good practice with other staff. Researchers and policy-makers were identified as a stakeholder group since they may want to replicate the project in other institutions. Finally, it was felt that students could benefit from learning more about the language commonly used in disability support, what is meant by the terms, and how students can advocate for terms they prefer.

The next stage was a series of discussions with different stakeholders, both in different units within the university and also in other institutions, to seek advice on the most appropriate and effective ways to disseminate the findings from the study and impact on practice. It was broadly felt that written guidance was the most useful output, so it was decided that a set of guidance for each stakeholder group should be developed. This guidance should be succinct, practical and should be easily usable in a working context. In order to ensure this, it was decided that guidance should be drafted by a project team and collaboratively refined with wider sets of stakeholders.

2.6 Collaboration with IncSTEM to create draft guidance

Meanwhile, a larger project was taking place with the aim of identifying ways to embed and sustain inclusive practices in the STEM disciplines (IncSTEM) [19, 20]. IncSTEM worked to identify existing and ongoing work to support inclusive practice, with the aim of transferring or scaling it up. IncSTEM supported the work on inclusive language, agreed that the creation of three sets of guidance was a suitable focus for one of its work packages, and confirmed that the skills to do this were present in the IncSTEM project team. A small group of staff were assigned to this; this formed a new project team comprising staff from Science and Engineering, as well a member of the original project team from Educational Technology.

The new project team initially met to discuss the research in detail and identify the core messages from the research that were most suitable to share with the three stakeholder groups. For the student support staff, the finding that a single model of language was not preferable to students was particularly challenging, as this was a complex issue to convey in guidance that should be succinct and practical. After consultation with colleagues in Student Support, it was felt that these findings needed to be simplified and communicated in conjunction with the concept of 'mirroring' [21], where staff listen for particular styles of speech or terminology a student might use and work to use the same phrases themselves in conversation with the student. This practice fitted with the findings of the study, as students would be likely to use their preferred

language to communicate, and staff mirroring this back to them would support an inclusive conversation environment.

For researchers and policy makers, it was felt that an appropriate message would be a combination of the methodology we followed and thoughts on how this could be adapted for other institutions. It was decided this should be communicated using a step by step approach.

For the student guidance, it was identified that a key message should be around what universities mean by the terminology we use, and how students can understand and influence it. Although our goal is to improve the language we use, there may still be cases, such as applying for a government-funded Disabled Students Allowance, where students are required to use terminology such as 'disabled'. Guidance to explain these terms and how they are used would be beneficial. Another key message should support students to feel empowered to influence language or advocate for their preferred language and terminology in one-to-one conversations. The project team checked these key messages with the Disabled Students Group to ensure these were the most appropriate messages to communicate. The Disabled Students Group confirmed this and offered to support the promotion of the guidance when it was finished. With this confirmation, the project team were able to create a first draft of the three sets of guidance.

2.7 Co-refining the draft guidance

Having created a first draft of guidance, the next step was to collaboratively refine (co-refine) the guidance with stakeholders. The aim was to ensure the guidance was informed by practitioners and students, and to give them a shared sense of ownership over the final guidance. For the guidance on replicating the methodology in other settings, this was done through a national STEM education conference and call for input from academics in other institutions. For the guidance for staff and students, this was done through a series of internal workshops held with student-facing practitioners and a conference workshop with staff and students.

Each workshop introduced the findings from the focus groups and surveys, introduced the draft guidance, and included an activity where practitioners identified the positive aspects of the guidance for their role, and annotated the guidance with comments on what they would change or anything they felt was missing. This was followed by a plenary in which they shared their overall opinions on the guidance and ideas for how it could be operationalized.

Workshops were extremely well received by the staff. Over 150 staff took part; they recognized that language was a perennial issue in their contexts and commented that they had been aware of the issue for some time and valued having their opinion sought as experts in their area (example comment: 'This is an area I have been wondering/worried about in my conversations with students for a while'). In every workshop staff contributed to the guidance and appreciated the opportunity to air concerns. Additionally, there was consensus across the different workshops held; staff identified similar issues and suggestions and were positive about the need for the guidance (example comment: 'This is brilliant – would be great to use in induction of staff who are student facing'.)

The students who participated in the conference workshop were also extremely engaged and supportive of the project and the guidance (example comment: 'this is excellent'.) They provided constructive input on the guidance, as well as highlighting the need for the guidance to be checked with a wider pool of students in the next iteration. Students also commented that they appreciated being involved in the project, that inputting to the guidance helped develop their skills and gave them greater awareness of, and sense of inclusion in, the wider university context.

2.8 Actioning feedback on the guidance

The project team then met again to review and consolidate the suggestions and create a second draft of the guidance.

One key theme concerned an area in the staff-facing guidance in which the team had attempted to detail high-level findings from the study, particularly the demographics around language preferences. Many staff commented this was not useful to them, that it made the guidance confusing and switched the focus to research findings, rather than guidance on practice (example comments: 'Don't like this, very general and could lead to issues' and 'Difficult to condense to make applicable to all scenarios'). This was a valuable lesson on the practicalities of how to use research to inform and improve wider practice.

Another finding was the need to provide clear examples as well as abstract terms. This was particularly the case on a section in which the project team encouraged staff to ask students in conversation about their language preferences. Staff commented they wanted to know how to frame these questions and see examples of good practice (example comment: 'need examples of questions')

A third theme was around Disabled Students Allowance. This had not formed part of the study, but staff identified that it was a key area in which language was especially confusing and daunting to students (example comment: 'This needs to be explained in a way that encourages students to do it. This is not PIP – this is there to help you, not undermine your disability.') This highlighted to the project team the need, when translating research findings in to practice, to broaden the scope beyond the initial (fairly narrow) research context and look at wider issues for target groups.

The issues raised by workshop participants (both staff and students) were extremely valuable in honing and refining the guidance. They enabled a second draft to be created that addressed the needs identified by the target audience, while raising awareness of the issue of language. This second draft was sent to a wider pool of students for consultation. Finally, the project team worked with the Disabled Students group to identify a plan to promote the guidance with students; the students will play an active part in dissemination, with named students acting as champions.

3 Outputs

The guidance was created with the support of a graphic designer, funded through the IncSTEM project. All guidance can be accessed at the IncSTEM website (<http://weblab.open.ac.uk/incstem/>). Currently, the guidance is being promoted by student-facing practitioners who attended the workshops, and by the Disabled Students Group. Student social media moderators have agreed to act as champions for promote the guidance more widely. After one year of promotion and use, the project team will work with staff and students to evaluate how it has been used and how useful it is perceived to be, along with identifying any additional changes that need to be made. After two years of promotion and use, a survey will be run with various staff groups to identify the impact on practice.

3.1 Student-facing staff guidance

The guidance for student-facing staff (including student support staff and teaching practitioners) covered the following topics:

- Why universities use the word 'disability
- The importance of language and terminology and the potential for poorly chosen wording to create communication barriers
- Listening and mirroring, including practical tips on how to do this
- Feeling confident to ask a student about preferred terminology if staff are not sure
- Practical tips on how to start a conversation with a student about disability
- Links to related resources

Talking to students about disability and study needs



Why universities talk about disability

It's against UK law for universities to treat 'disabled' students unfavourably. All universities have a duty to make 'reasonable adjustments' to ensure 'disabled' students are not discriminated against. We therefore need to talk to students about disability and the adjustments that need to be made to allow them to study effectively.



Language is important

You'll be aware that communication with a student is key to effective support; the language you use can build understanding or create barriers. This is particularly the case in communicating about disability and study needs; for example, using the term 'disabled' might not fit with the way a student with dyslexia sees themselves, and this could make them feel uncomfortable or less likely to tell you about their needs. The following tips can help you avoid creating barriers by using language a student feels comfortable with.



Listening and mirroring

Listen to the words a student uses to refer to their disability or study difficulties and use the same words when you respond. This can help the student feel comfortable and encourage them to provide more information, which will make it easier to support them. For example:

- if a student says they have extra study requirements because of their dyslexia, you should use 'study requirements' and 'dyslexia' rather than terms such as 'disability'.
- if a student refers to a medical condition by name, such as epilepsy, try to use the name of the condition, or the word 'condition' in response.
- if a student uses the word 'disability' or 'disabled', mirror this term back to them in your response.

Figure 1: Part of the guidance for student-facing staff

3.2 Student guidance

The guidance for students covered the following topics:

- What universities mean by the word 'disability' and what types of disabilities are included
- Additional Study Requirements students may have, including examples of these and how students can discuss them with staff
- Information about Reasonable Adjustments (accommodations) the university can make, students; legal right to these and examples of typical adjustments
- Information about Disabled Students Allowance (DSA), what this means in a practical sense and who may be eligible to apply
- Information about what is involved in a DSA Needs Assessment Meeting
- How student can ask university staff to use the language they prefer
- How students can access study support

Communicating with the university about your study needs

Your university may encourage you to 'disclose a disability' in order to access support for your specific study needs. Around one in five students disclose a disability at some point in their studies.



Why do universities use the word 'disability'?

Universities use the word 'disability' to cover a lot of things that you might not think of as a disability, such as dyslexia, depression and anxiety. They do this to make sure your study rights are legally protected under the Equality Act, which uses the term 'disability'.

Universities often classify study needs using the following categories:

- **Mental health conditions** (e.g. depression, anxiety, PTSD or other conditions, with or without a formal diagnosis)
- **Specific Learning Difficulties** (e.g. dyslexia, dyscalculia or dyspraxia)
- **Fatigue and pain conditions** (e.g. fibromyalgia, arthritis, ME or MS)
- **Long term health conditions, sometimes referred to as 'unseen disabilities'** (e.g. diabetes, epilepsy, cancer)
- **Mobility impairment** (e.g. using a wheelchair, crutches or other support to move around)

Figure 2: Part of the guidance for students

3.3 Guidance on methodology for researchers and policy makers

The guidance on the methodology broke our project down into five steps. For each step, we wrote a section on 'What we did', detailing our methodology; 'What you could do', identifying how it could be applied to different types of organisation or institution, and 'Things to consider' detailing components of the methodology, such as impartiality, informed consent, etc. Below are the steps we identified:

- Step 1: Listen to the language that people interacting with your organisation use about themselves
- Step 2: Get their input on the language that your organisation uses
- Step 3: Analyse
- Step 4 (optional): Consult more widely
- Step 5: Make changes to the language you use as necessary



Figure 3: Part of the guidance for researchers and policy makers on the project methodology.

4 Discussion and Conclusions

This paper has presented a narrative of how, through participatory research and collaboration with students, an issue was identified, researched, and steps were taken to address it in practice. This kind of whole life-cycle account is not frequently seen in literature, which tends to focus on findings and implications rather than the steps taken to change practice.

This project identified the importance of language to 'disabled' students, and the findings reveal complexity and variety in the way that they perceive themselves, their disability, their study needs and the role of their institution and of themselves as students. Our findings call into question the idea of disabled people as a single homogenous group.

A key factor throughout this project has been the participatory approach. This has been of incalculable value to the project and has been an extremely positive experience for the project team. Engaged as experts in identifying a student-driven research agenda, students contributed tangible issues to be investigated that led to a funded research project. Engaged as stakeholders in the research design, students and staff stakeholders added valuable suggestions that strengthened the methodology.

When inputting to the guidance, participants raised a variety of issues that enhanced the guidance and would not have been identified from the research alone. This consistent thread of collaboration and participation strengthened every aspect of the research and was extremely valuable in supporting the application to practice.

Engagement throughout the project has also been a positive experience for the student and staff stakeholders. Both students and staff commented on how pleased they were to be involved and consulted; students commented that they felt it added to their skills and their sense of being part of the university community, and staff commented that they appreciated having their experience in student support valued by the researchers. Both groups have demonstrated a sense of ownership over the outputs, promoting it to peers and colleagues. This sense of ownership is likely to be a direct result of their participation in the project.

Using a participatory approach to turn research findings into guidance for practice, and engaging stakeholders as experts in different stages of this journey, has been both valuable and enlightening. It has modelled inclusive practice while seeking to investigate and promote it. This highlights the need for researchers to listen to and collaborate with students and practitioners when translating research into practice, as tangible benefits to research design and application to practice can be gained, as well as modelling positive ways for researchers, students and practitioners to work together and learn from each other.

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