Inclusive Language

Engaging Stakeholders as Experts in the Trial and Evaluation of Disability Language Guidance

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Executive Summary

To support inclusive and equitable study, universities often categorise students as 'disabled' for them to access specific 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 precursor studies, 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) (Lister *et al.*, 2019; Lister, Coughlan and Owen, 2020b, 2020a). Survey results from one of the precursor studies 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. Building on these findings, the project team worked with a wide range of stakeholders to collaboratively develop drafts of guidance for student-facing staff, and researchers and policy-makers to use when talking to students about disability. We also developed draft guidance for students to explain the type of language commonly used by universities around disability (available on https://weblab.open.ac.uk/incstem/language/).

This project aimed to collaborative with a wide range of stakeholders, in STEM and more broadly throughout the OU, to refine and improve the draft guidance, disseminate it with relevant OU groups, and evaluate its effectiveness. We did this using a participatory design methodology in collaboration with a network of staff and student stakeholders, and via a final survey.

This report details the participatory design approach used, explores the input staff gave and how this led to the co-creation of research-informed guidance on language use. Through this, we draw conclusions on how to develop understanding of inclusive language across an educational institution. This guidance will support stakeholders to understand and use inclusive, supportive language to discuss disability-related study needs, with a view to moving towards inclusive, student-led language approaches.

Aims and scope of your project

This student-centred eSTEeM project aimed to address an issue that was identified by disabled students in a precursor study; the importance of language and terminology when discussing disability and study needs with students (Lister *et al.*, 2019; Lister, Coughlan and Owen, 2020b, 2020a). Many students with conditions or study needs that are classified by HESA, the HE sector and beyond as 'disabilities' (i.e., mental health conditions, dyslexia, etc.) have stated they do not identify with the term 'disabled student', or other disability-related terminology. This can mean that they do not disclose their needs to the Open University, or they do not seek the support and reasonable adjustments they need. Student success, in terms of completion, progression and attainment, can be affected as a result of this.

Work took place in a precursor study to identify the terminology and language that students prefer, and, as part of the HEFCE-Funded *Inclusive STEM* project (McPherson *et al.*, 2019; Pearson *et al.*, 2019), draft guidance was produced for different stakeholders, using STEM students as the focus. The following draft outputs were created:

1. Guidance for student-facing staff (including ALs and Student Support teams) on the impact of language on student identity, on specific terminology, and on how to mirror students' language in conversations
2. Guidance for students on how to engage with current disability-related terminology, and on how to influence others' language and advocate for their preferred language
3. Guidance for researchers and policy-makers on how to replicate the precursor study or investigate language preferences in their own context

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The objectives of this project were:

- To seek critical input from staff and student stakeholders into the drafts of the guidance created, via a series of participatory design workshops
- To trial the guidance with students and staff
- To evaluate the guidance and the extent of dissemination

Activities

Having created a first draft of guidance in the precursor study, the first step in this project 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.

The guidance documents for students and student-facing staff were co-refined through a series of participatory design workshops held with student-facing practitioners and an eSTEeM conference workshop with staff and students. The guidance for researchers and policy makers on replicating the methodology was co-refined through a national STEM education conference (Horizons in Hull, 2018) and call for input from academics in other institutions.

The participatory design workshops started by introducing the findings from the precursor studies, introducing the draft guidance, and then led on to 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 discussion in which they shared their overall opinions on the guidance and ideas for how it could be operationalized.

Seven workshops were held in total. Five workshops were held for OU student-facing staff: one in Manchester, one in Belfast, one in Edinburgh, one in Cardiff and one in Milton Keynes. One workshop was held in the eSTEeM conference which was attended by students and wider OU staff stakeholders. An initial workshop was held in the Horizons in STEM conference (2018) for wider HE stakeholders. Additionally, extensive asynchronous participatory design activity took place with students, OUSA representatives and other stakeholders via email and student-led social media activity. Feedback from this activity was actioned alongside feedback from workshops.

Workshops were extremely well received. Over 180 stakeholders 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 staff 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.

Actioning feedback on the guidance

The project team met 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 (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 staff and students for consultation, resulting in further minor edits.

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Outputs

The final 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/).

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

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

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 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

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- How student can ask university staff to use the language they prefer
- How students can access study support

Figure 2. Part of the guidance for students

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

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

Evaluation

The guidance continues to be promoted by student-facing practitioners and by the Disabled Students Group and student social media moderators. After one year of promotion and use, further input was sought from staff and student stakeholders (by email, due to the pandemic) on:

- The extent to which the guidance had been shared and was being used
- How useful the guidance had been
- Whether any further changes were needed

The extent to which the guidance had been shared

The guidance was shared online with Disability Support Team, across Student Access and Support, in all nation offices, the Staff Tutor and SEM Resources and Development Site. It was also shared with student groups (including the Disabled Students Group, the Wales Student Volunteer Panel and via OU student social media spaces. There was discussion about uploading it to the OUSA website, but this was unresolved.) Additionally, copies were also printed and placed around the Disability Support Team offices as promotional pieces.

How useful the guidance had been?

The guidance was well received. Comments received by email (reported verbatim) included:

- "Reassuring that the key message and guidance are at the core of delivery within DSTs IAG [information, advice and guidance] conversations daily
- Reminder the guidance is available as a document but felt experienced staff would not refer to on a regular basis
- Staff were able to exemplify where guidance has been used in recent conversations as standard
- Acknowledge some students do not consider themselves to have a disability but an additional requirement (SpLD)
- Felt some of the guidance is covered in the MH training package specifically around mirroring language, consider how the student is referencing the condition/impact, adopting similar tone and language

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- Agreed guidance should not inhibit ability to interact with students but aid as a reference tool
- Considered framework would be ideal for new starters (across many roles not just student facing)
- Discussion points around other content: article / online material / day to day content where standard paragraphs contain reference specifically to a disability"

Whether any further changes were needed

One person commented:
"I'll be honest they didn't have much to say on them beyond appreciating having received them, and being glad that such guidance was available so they didn't have to feel uncertain or worried about using the wrong terminology or inadvertently offending someone. So from a reassurance perspective, they found it useful."

No concrete changes were identified, but comments were given that included areas to consider in future. These comments (reported verbatim) included:
- "Possibly open to interpretation – those that refer to the document literally and those that refer to it as guidance – possible impact in variance
- Possible evident link with IAG framework and importantly quality monitoring tool to ensure staff are positively demonstrating guidance within service delivery / thinking / planning
- Consider impact towards students who do not wish to declare because of disability reference/title – impact"

Survey questions

Additionally, survey questions were added to the biennial Measuring Accessibility Practices and Perceptions (MAPP) surveys (Lister *et al.*, 2020) for student support staff and ALs. The results are shown in tables 1, below.

30. I have seen guidance on inclusive language and how to talk to students about disability.

		Agree	Disagree	N/A or blank	Neither agree nor disagree	Total
ALs	Count	121	85	4	64	274
	% within Data group	44.20%	31.00%	1.50%	23.40%	100.00%
Student support	Count	53	38	8	17	116
	% within Data group	45.70%	32.80%	6.80%	14.70%	100.00%
Total	Count	174	123	12	81	390
	% within Data group	44.60%	31.50%	3.10%	20.80%	100.00%

Table 1: Staff who report having seen the guidance

If staff stated they had seen the guidance, they were asked whether it was useful to them.

Of the 121 ALs, 79.3% (N=96) said it was useful for them. No one said it was not useful, but 20.6% declined to comment (N=25.)

Of the 53 student support staff, 79.2% (N=42) said it was useful for them. 3.8% (N=2) said it was not useful, and 17% declined to comment (N=9.)

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Conclusion

This report has presented an account of how, building on precursor studies and adopting a participatory approach, an issue was identified, researched, and steps were taken to address it in practice through co-created and co-refined guidance.

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. Stakeholders raised a variety of issues that enhanced the guidance and would not have been identified from the research alone. This collaboration and participation strengthened 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; and 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 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.

Figures and tables

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

- Figure 2. Part of the guidance for students

- Figure 3. Part of the guidance for researchers and policy makers on the project methodology
- Table 1: Staff who report having seen the guidance

References

Lister, K. *et al.* (2019) 'Towards Inclusive Language: Exploring student-led approaches to talking about disability-related study needs', in *Proceedings of the 12th annual International Conference of Education, Research and Innovation (ICERI 2019). 12th annual International Conference of Education, Research and Innovation (ICERI 2019)*, Seville, Spain: IATED, pp. 1444–1453. Available at: http://oro.open.ac.uk/68408/ (Accessed: 12 July 2020).

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